Rearing Up America

The Journal of a Father's Reflection on Special Needs

Robert Glenn

www.RearingUpAmerica.com

Creative Team Publishing
San Diego

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Foreword

This story is very much a coming-out-of-the-closet experience. I'm guessing there are too many American families who are simply trying to endure the circumstances of raising children with severe special needs. Talking about severe difficulties seems to bore others after a while, and people seem to start keeping their distance. It becomes easier to say you're okay and move on to safer topics like the weather. But that doesn't change your day-to-day reality, does it?

You may find yourself isolated and wondering where to turn. We were there! Our daughter was born with an extremely rare genetic brain malformation and sharing the day-to-day events of our family life over a seven year period wasn't easy for me.

Writing our story took three and a half years and turned out to be a healing process for myself and my family. You may find our story compelling; however, for me it is only a tool which I pray will open up new communication for many families. The underlining theme for *Rearing Up America* is *choices.* The choices we make in difficult situations lead us down certain paths. Individual choices become habits and habits are the hardest behaviors to change. The word *habit* embodies the concept of being ingrained and refers to a foundational characteristic. Believe me, habits can be changed and the survival of your family may depend upon those changes.

When you have completed reading our story I hope you will be ready to make new choices of your own. This is a personal journal, our journey, and it is designed to help you, so approach it with intentionality.

God was our rock and strength through seven years of day-to-day severe seizure activity and behavior problems. We simply stopped counting the seizures when they reached sixty, seventy, and eighty-plus seizures per day. I know there are families struggling with the health of their children and parents may feel ill equipped for the job at hand. But there is always hope. You must believe that there is always hope!

There is also truth to be realized for situations which evolve totally out of your control. For your own health, you must find a way to be able to release any feelings of guilt you harbor. Guilt will only tear you down and prevent you from maximizing the potential of your family to do more than endure. Guilt is a lie which needs to be released!

In the book I explore a number of relational issues, including those of husband and wife, parent and child, as well as the importance of being a medical and legal advocate for your children, and the importance of taking care of yourself. You can't maximize the success of your family if you are falling apart. The daily choices you make are important. They will form habits and ultimately identify character.

Dedication

Rearing Up America is dedicated to my family:

- To my loving wife, Lee, who together with me has shared all that life has presented to us for twenty-seven years.
- To our son, James, whom we love immensely. We are so thankful to have him in our lives.
- To the memories of both sets of our parents whom we miss greatly. We have appreciated all of their loving support over the years.
- And to our daughter, Joy, who embodies the innocence and joy of youth. We have learned and continue to learn so much from her due to her unique genetic anomaly.

Introduction

America has always been proudly promoted as a melting pot of cultures and as the open society that accepts everyone to its shores. We should be proud of our heritage and of the great accomplishments and responsibilities this promotion has placed upon us as a nation. But this heritage has never been a bed of roses. Family members have fought and died for our country and those who remain have learned to carry on and build the country for which they can be proud.

Our nation's core is comprised of our family units. These are the dads and moms who lead and transform our country generation by generation. Rearing children is the most important single act these people may accomplish. While raising children may include activities like baseball, football, dance lessons, after school activities, or one's first experience of falling in love, there is a lot more to it.

Too many families struggle with more basic issues like keeping food on the table, a roof over their heads, or managing the health of their families. We have seen the telethons and the campaigns to raise funds for the homeless, cancer research, multiple sclerosis (M.S.), and a number of other health problems which rightfully cause concern for a society.

The motivation is high. The responses are many. They often sound like, "Let's help! Let's conquer these diseases and negative situations!" Really? Is this all it is about? As wonderful and needy as these causes are, I think the focus should be even more to the moment. What about everyday life? Families and the individuals who live out the recurring reality of their situation need more than the promise of a future cure. Daily help and support are vital.

For many parents it's not a question of what college my child may someday attend. For many it's a question of surviving in the here and now. Our daughter was born with a severe brain malformation and struggles in many areas of daily life. Just in the last month she fell twice. Each fall produced a gash less than one inch from her eye. She could have easily lost her sight in either of these incidents. This is our reality, and it is the reality for many others with special needs children.

This story is about the struggles and challenges my family is working through. It's a journal that provides insight into not only what we have faced, but the larger causes of rearing up children.

So why should you read it? Because I believe there is much more to life than what we are able to see with our eyes. Our story is merely a tool to explore more of our humanity, relationships, purposes, and goals. Who doesn't know someone who is struggling in some area of their life? Family units are the fiber of American culture. Families need to strengthen their bonds of affection through better communication and closer cooperation.

This is my journal as a father, written to other moms and dads who may be walking in shoes similar to mine. It is written for you and I believe it touches the core of our nation. We aren't meant to live in isolation nor should we feel unable to open up to others for support. God uses *us* as His hands and feet to make a difference. We need to be comfortable with change if we are to accomplish any worthwhile and meaningful goal. Rearing up kids in this country is that goal.

As you read through the book, please take advantage of the journaling pages I have provided for you. Begin to explore new thoughts and perhaps dig a little deeper into your own realties to better prepare for your tomorrows. Hope is a wonderful ally. When combined with faith, it is unstoppable.

Let the communication and cooperation begin here. Read, think, pray, and share new thoughts, hopes, and concerns with someone else. It may change you. It changed me.

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Chapter One
Parents: On Your Marks, Get Set, Go?

Lissencephaly (pronounced Les-sen-SEF-a-lee) is a rare birth anomaly and one that most people have yet to hear about. The word literally translates as “smooth brain.” The condition is severe even in its mildest form, and a number of the children who are born with this condition won’t live to be discharged from the hospital. A majority of those who are discharged may have a life expectancy of only ten to twenty years. Some of those same individuals will only realize a cognitive level of that of a child three to five months old.

In the event of death an individual won’t have Lissencephaly listed as the cause; rather, the condition leaves the body more susceptible to causes of death which might normally not be life threatening, for example, an illness such as pneumonia, or a choking episode. Or an individual may even stop breathing because the brain might stop communicating with the muscles connected to the lungs.

Genetic anomalies aren't something parents feel they signed up for when planning a family. When anomalies occur, parents are in a new reality which is totally unique. Their situation, although similar in nature to other families', will be theirs alone.

I feel there may be many families who are trying to make sense of a difficult situation just as we did. This book is my journal of our family's experience with a rare genetic disorder and how it has changed our lives.

I've included our thought processes and attempts to overcome adversity. In some instances it still may be years before we know whether our choices were the most beneficial ones or not. We love our daughter, Joy, as dearly as we do our son, James. Meeting the needs of both of our children has been a monumental effort. The results you read here are collections of parental successes and failures because life has been filled with both.

One purpose for the core journal content is to present a detailed record of our daughter's medical history so that her caregivers will know her better now and in the future. Also it's written for you, if you are a parent with a child who has a special need. If our journey helps even one family, it will be worth every minute spent in this pursuit.

We recently located a web site in which a very small group of families exchanges thoughts and information, each of which has a child with Lissencephaly. We are now among them and are communicating via email. Mainly due to the rare nature of this condition, we are all part of a special international community. All the families are exploring the realities of their child's diagnosis and the dramatic changes which may develop with little or no warning.

No one who experiences a unique medical condition can foresee the raw emotions and the feelings of isolation which may accompany and sometimes dominate daily life. Talking and sharing experiences is helpful and therapeutic; however for us, finding a person to confide in wasn't easy. It still isn't.

What about family and friends? They're okay for sharing some things with, but the intensity and consuming nature of care can be overwhelming to us. The experiences may unknowingly reduce the ability to open up to others.

I would like to share a portion of one email with you which I received from one of our international families during 2009. "I do not like to be unable to control this! I have studied and learned as much as I can about epilepsy. I believed that with knowledge I will be able to find a way to have control.

"But I was wrong. It has been over four years…I don't even know anymore…it feels as if this has been going on for an eternity and only in the last year I have started feeling helpless.

"I am physically and mentally exhausted...I am going through such a bad time. I have to admit…I think I am depressed. I feel so alone. Nobody is there to help.

"I am so tired, so very tired. And it finally hit me last month that I could not cope any longer. I have cried and cried, and I could just not get out of bed…

"I am better now…I am out of bed.

"I still do not want to talk to friends or family. They don't really understand what it is like to deal with this: the behavior, the tantrums, the seizures. They have no idea of the pain I feel, because they are not going through it.

"So I have decided to confide in you all, tonight."

This email was from a single mom. My heart broke as I read this letter. She is in a place of great pain, yet even this letter is a wonderful first step she is taking toward a long and difficult healing process.

Even when there are two parents working together, it can be difficult to share raw emotions with anyone outside of the immediate family unit. Feelings of failure, lack of control, inability to cope, and perceptions of weakness may contribute to parents maintaining a silent posture. By not breaking the appearance of control, when none really even exists, they may feel a small bit of control and normalcy.

We felt a lack of control for many years, partially due to the fact no one in our medical community knew why our daughter experienced the severe difficulties she did. After almost thirteen years we finally learned her true diagnosis. The day-to-day realities didn't improve with our new knowledge; however, we were then more connected to a community who understood us. The knowledge we have acquired since then has subsequently brought us some comfort and peace of mind.

Most childhood illnesses resolve themselves in a reasonable or understandable amount of time, but some don't.

When one starts to talk about conditions of genetic origin, you are talking about a lifetime of learning and coping. You learn as you go. Those who cope will survive, and those who are unable to cope will fail or barely thrive.

There are sections in this book in which I may sound like I am giving advice, but that's not my intent nor is it my responsibility. I am simply telling our story. I'm writing to you as one parent to another, using the journal format to convey concepts such as patience, self-control, open-mindedness, freedom to ask questions, advocacy for your child, courage, and faith.

I'm not a doctor or lawyer, and cannot and will not offer medical or legal advice. Nothing you read here should be taken as advice of any kind. While I bring up a number of issues which might prompt you to seek professional advice in these and other areas that pertain to your situation, that is solely your prerogative and choice.

I felt for a long time that no one could be going through anything as challenging and difficult as what our family was facing, but now I know I was wrong. You can always find someone who is going through a harder time than yourself if you look for them. That truth doesn't make it easier to live through those times, but there is hope in knowing others are feeling similar emotions and realities, and they are making it through. Perhaps if they can, my family and I can.

Each situation is unique. Either one has a positive mental outlook, and a support group for their circumstances, or one doesn't. Everyone should take some reflective time to think about short term and long term resolutions which could improve their future outlook, then evaluate what kind of a support group might be needed to better achieve those goals and, if it looks feasible, seek it out.

Make a list of people around you whom you trust and can call on if needed. Call them and determine their willingness and availability. Where you feel there are certain areas of support those people can't provide then brainstorm new ideas about how you might fill in those gaps. Emotional pain and depression can create an impenetrable wall which can block a creative thought process. Recognize the blockage and move beyond it. Your friends may be able to help you do this.

Never give up hoping in tomorrow and seeking a source of strength to help you along your difficult path. No one can maximize success over incredible circumstances by standing totally alone. We are simply not made to be alone; we need each other.

As a single man, I was happy, but there was a continuous underlying feeling that I wasn't complete. I desired to have a wife and family. Finally after a lot of patience and prayer that desire became a reality, and it quickly became hard to remember what my day-to-day routine schedule as a single man had been.

Marriage was and is great, but life is filled with good and bad experiences. As a couple we dealt with the daily challenges together. This earth isn't a Garden of Eden any more, and we won't be returning to one, either, as far as I know.

As we have moved around the country, from one state to another over the years, we have found there is a good chance that our local medical community has never had a patient with this anomaly before. Information we receive will most likely be generic comments from a doctor which have been located on the internet. It's important not to get discouraged, but to begin learning all you can. Wherever you are, you have to take the initiative.

Experiences change who we are and how we look at the world around us. I don't know how our family would have fared without our faith in God. But please don't get me wrong here. I have seen many a family in which God isn't openly a vital part of their heritage of experience endure horrible circumstances and fare very well.

I feel God will care for His children whether or not they know where the help is coming from. No matter what your beliefs are, don't put this book down just because your beliefs may be different from mine. There is a message for any reader who has even reached this early point of the text.

America is a melting pot of many cultures and traditions. United in our family structures we are mothers and fathers who love our children dearly. I feel each generation of American parents should examine what it means to be a parent with a child who is challenged with special needs.

Let me use the Americans with Disabilities Act of 1990 (ADA) as one example. The passage of ADA was and is an important benchmark of legislation that justifiably helped to level the playing field for those with disabilities in our country. However, creating law and more fully understanding the nature of disabilities are not the same actions. Understanding disabilities is not something that can be legislated. Society needs to continually review standing documents to assure continued relevancy. We can't assume our culture interprets the Americans with Disabilities Act in any one particular light.

Culture is a living and changing entity. Whether or not your children are physically challenged, the strength of the American family unit is being disputed. We need to stand up for our children. Ask the question "What is this culture demanding from *my* children?" Families are unique and we may have to take another look at what "a normal American family" is.

America, perhaps we need to redefine and simplify what a normal American family should look like. Instead of defining a normal (middle-class) family in economic terms, we might better describe this nation's personal successes in psychological terminology. Imagine the implications of measuring society's success in terms of "love and respect" as opposed to monetary standing. Are America's normal families producing offspring who love and respect other people regardless of income levels? A capitalist philosophy of acquiring more and more money satisfies only one of our essential needs. Society has clearly demonstrated that no amount of money can secure contentment or happiness. Money can't buy love and respect, either.

Reality has a way of changing in the blink of an eye. One day you may be in a place of contentment; the next, because of circumstances beyond your control, you may be in a different location and learning all you can about a new place you didn't know and don't understand.

We are, by nature, creatures of habit. Perhaps the question to be answered after you read *Rearing Up America* is this: "How prepared are you for the unexpected?" A lot can change very quickly, especially in consideration of circumstances beyond your control. Changing a habit can be the hardest thing we ever do! But changing a habit may be necessary in order to meet an unexpected challenge. In the blink of an eye, you may find yourself in a new reality and change is something you'll have to consider.

Journal Entry

In this first journal entry you are invited to write down your thoughts connected with any needs and concerns you are experiencing. What are the difficulties you are enduring now? What are the stress points? As you write them out you are preparing yourself to address a number of the additional issues that will be discussed in the following chapters.

Journal Entry

Chapter Two
Fatherhood and Dreams Actualized

My first experience as a new father met all of my expectations and was, I imagine, like that of many if not most new fathers. I was full of energy and an excitement I hadn't felt before, and I loved every minute of it. The anticipation of holding our newborn baby was pure happiness. The thoughts of our child's playtime, her learning and growing through early years, brought a real sense of purpose. My wife, Lee, and I had been married about two and a half years when Joy was born to us while we lived in Southern California.

Lee's was a normal pregnancy and our daughter was born right on her due date. Joy weighed 5 pounds, 14 ounces, was 18 inches long, and appeared to be perfectly healthy except for a little bit of trouble with eating (nothing alarming). She was released from the hospital after the traditional twenty-four hour evaluation period.

Joy is the first grandchild born out of a total of nine siblings in our generation and the whole family was elated. Lee and I were both employed: I worked full time for a major airline in Customer Service and my wife worked part time as a Med-Surgical RN. Into this world Joy had come. We were excited new parents and loved caring for "our little Peanut", as I sometimes referred to her.

In six months, however, we noticed Joy wasn't passing many of the milestones of infant development that were expected. We brought our observation to the attention of our pediatrician. He advised us to continue observing her skill's development patterns and to wait to see how she progressed over the next few months.

While other infants were busy crawling on their hands and knees, and even walking around at the age of twelve to fifteen months, Joy was only able to roll over. She wasn't able to move herself into a sitting position. We would place her in a seated position and she could hold it for a short time, but then she would roll over to her side. Joy was able to commando crawl, pushing her legs back and forward in excitement to propel herself forward on her stomach, but she couldn't sit up.

During our daughter's first twelve months, we took her on quite a few trips since we loved to travel. Joy was mellow and easy to care for so we showed her off whenever we could. Eight trips, is the number I can recall. However, now I can only remember where we went on four of them.

The four trips that I can remember were each from our home in San Diego to San Francisco, Chicago, Hawaii, and London, and they were all managed on the smallest budget possible. Because I worked for an airline we were able to fly at no cost if a seat was available. Lee isn't a big fan of traveling standby for vacations due to the unknown element of arrival time, or if we would even get to our destination at all. However, the price is right.

It may sound expensive, but it is amazing how much fun you can have by simply going somewhere. Just being in a new place is 80% of the experience; the remaining 20% of the trip I categorize as fluff. We could forego the nicer hotels and fine foods and still have a wonderful time. I reasoned, "Why work for an airline if you just stay at home?"

We traveled to San Francisco in one day to see three of my sisters-in-law off on an Alaskan cruise. We took the Chicago trip to attend an extended family function. Hawaii and London were more like real vacation times. On Maui we shared a condo with another young family who had two small children. I worked with the father at the airline and his wife was a nurse so his wife and Lee had a lot in common, also.

We had a lot of fun in Hawaii, and I recall that we packed far too much stuff. Joy was six months old and very fair skinned, so as a new father no effort was too much. I designed and built an infant size cabana to protect Joy from the sun when we went to the beach. It had a roof and four sides with a slit door that could be fastened shut when she needed a nap. Four large wooden dowels served as the main supports, one at each corner. Two smaller dowels crossed each other on the roof of the cabana. Each wooden dowel slid into a fabric sleeve to hold them in place.

Our only souvenirs are memories and the photos that we took. One of my favorite photos was of Joy dressed in a bikini top and a Hawaiian grass skirt which was sold as a costume for a doll. She looked precious.

In the fall of the same year we also decided to see London. We knew Joy's care would get more involved as time went along, and Lee had never been to England. I had been to London on several occasions prior to knowing Lee, and loved the British culture and dialect. Lee and I decided we weren't going to over pack like we did for Hawaii, and for the most part we did quite well. The one area we couldn't foresee, however, was baby food. Isn't baby food around the world all the same? Well, no it isn't. We found out the hard way.

Joy was then ten months old and was weaning off of breastfeeding. Jars of baby food are heavy and breakable. We planned to take enough baby food for the flight and an extra day then we would buy the rest in London. The stores did stock a few vegetables and fruits, but where was the chicken? The Brits were more into lamb and strangely seasoned beef. Joy's digestive system didn't take too well to the new diet.

We were staying at a bed-and-breakfast in a residential area on one side of London. The majority of the tourist sites were on the other side of the city. One morning we took the London Underground to see St. Paul's Cathedral. The trip took 30 to 40 minutes. The station we got out at was about two blocks from the church.

As we passed through the elaborate entrance with its tall carved wooden doors, the large main worship hall filled our sight with wonder. The beauty, reverence, and sense of history were overwhelming. We stood in the back for a minute or two, and as we began to step forward, we heard it. Every parent knows this sound. It was the sound that comes from a poopy diaper. And in this case it was a large diarrhea poopy diaper.

Lee was holding Joy in her arms and quickly moved her a few inches away by positioning her hands under Joy's arm pits. As discreetly as possible, Lee whispered to me, "We have to get out of here. It's leaking out through the diaper into her jumper." We got out in record time.

It was bad. A public cinder block type restroom was not far away and all I can remember is saying, "Oh my, oh my!" all the way to the restroom and laughing nervously. Once we arrived at the restroom we realized we hadn't brought any diapers or the wipes. When we changed her the last time at the hotel we forgot to put the diapers and wipes back into the bag. Our morning outing was over. Lee cleaned Joy up the best she could and we headed back across London to our room. No more exotic foods for Joy!

The remainder of our London adventure was enjoyable, though we missed seeing St. Paul's Cathedral. It's fun to get away and heartwarming to return home. There's always something special about sleeping in your own bed.

During the next two to three months at home we found that Joy still wasn't making any significant strides in her development. At the age of thirteen months her pediatrician recommended that we start her on physical therapy. By twenty-four months occupational and speech therapy had been added.

All the appointments were conducted in an annex building next to the children's hospital in San Diego, but normally these weren't back-to-back appointments. We made multiple trips to the hospital complex, even two or three a week. These therapies began to address Joy's difficulties with fine motor planning and low muscle tone, as well as her speech delays. Oh, by the way, when Joy was about sixteen months old, Lee became newly pregnant with our second child.

It took about three months of physical therapy before Joy began crawling on her hands and knees. She took her first independent steps at about 30 months of age. Her walking was unsteady and we needed to watch her closely. With our second child, James, on the scene, we were, for the most part, carrying two children around, transporting them in and out of the car as we went shopping, and to church, just about anywhere that speed or safety was an issue. Holding Joy's hand was a must and carrying her was definitely the easiest way to go. Carrying her helped to avoid pedestrian traffic jams and made maneuvering over or around uneven surfaces and through entrances and exits easier. Walking around in the house, however, was more manageable.

So far, we were handling the situation well. We knew Joy was a gift from God, like all children, and accepted her developmental delays with the faith that God would help Joy as she strived to reach her full potential. During these early months Joy showed significant delays in her gross and fine motor planning, chewing, cognitive skills, and speech. No parent likes to hear the words "cognitively delayed" but this was becoming reality.

At age two, her pediatrician gave Joy the general diagnosis of Cerebral Palsy (CP), to qualify her for the appropriate and needed medical assistance. At age three, she could say “Pop” for father, but wasn’t able to say “Mom.” The ‘Mmm’ sound required more motor planning than she was capable of at the time. She first started addressing Lee by Lee’s first name. After Joy learned the ‘Mmm’ sound, she addressed her mother as “Mommy-Lee.”

Joy is a young adult now and somehow she has dropped the word *mommy* and refers to her Mom as Lee, once again. Lee would much prefer being called “Mom” but repeated suggestions to Joy haven’t produced the desired change. I am still called “Pop” with the vowel sound drawn out nice and long.

Joy could also say a handful of other words like some of the names of domesticated animals (cat and dog), some colors and object names, like chair. At this point of her speech development, she was limited to pronouncing single words and short phrases. And the majority of her speech was responsive, as in a “repeat after me” format.

To augment the therapies, she began an early intervention services program at a special needs pre-school. They met on a half day program schedule to better maximize her skills prior to starting kindergarten.

We were living in San Diego at the time. Although much of our family also lived there, too, the opportunity came up for us to move to Pittsburgh, Pennsylvania. My employer, Pacific Southwest Airlines (PSA) was bought out by USAirways. We had hopes there would be more opportunities for job advancement in the new home office. After much consideration and prayer we made the decision to move. We put our home up for sale.

I had to report to my new Pittsburgh office thirty days after we had made our decision and at the time of the move our house hadn't sold. All of the child care then fell on Lee while I moved to Pittsburgh. I stayed with some friends from work who had already been there for a year.

One week prior to starting work in Pittsburgh, I flew back to purchase a vehicle. There was no time to drive my old Toyota pickup and I had many doubts as to whether the truck could even make the trip. A close friend in Pittsburgh said he knew of a good dealership and a salesman that could help me. I had only one day to buy a vehicle and wanted another truck. With the upcoming move, our budget for a vehicle was small. The salesman said he had a great deal on a Ford 150 which had just been turned in. I drove it and noticed the oil was leaking. "Don't worry, we will fix the leak." The price was right and I bought it.

Well, we did keep the Ford for a few years, but I ended up putting a quart of oil in that beautiful machine about every three weeks. In the winter it slid around on the ice pretty bad so I bought three hundred pounds of kitty litter (on sale, I might add) to put in the bed of the truck to weight it down. That helped a lot, but at the time we didn't even own a cat. After we sold the truck, we had three hundred pounds of kitty litter left over, but it came in handy on icy sidewalks and driveways.

Well, how much detail about the move do I need to include here? It was a complicated moving process. To make a very long and difficult story shorter, the house in San Diego sold after three months on the market because there was an unexpected decline in the housing market. The escrow process was punctuated by one delay after another, so it was sixty days later before escrow closed. It was a combined whopping total of five months to finally sell our home.

During these months I commuted across country every week on my days off and never missed a single weekend. Because I worked for an airline, my only option was to travel standby. Although I sometimes needed to connect anywhere in the country that would possibly take me to my destination in a roundabout way, I was never late for work on my Monday shift. The weekend stay in San Diego normally didn't exceed eighteen hours.

Lee never complained about the house not selling or the child care for which she had become mainly responsible. On each weekend visit I also packed a few boxes so we would be able to move when the time came. When an acceptable offer was received for our home in San Diego we also made an offer on a home we had located in Pittsburgh. It was advantageous for us to keep in close contact with the escrow company so we could plan our move in the most efficient manner. With Joy's special needs we didn't want to stay in a hotel for a week or more unnecessarily.

When the house we wanted to purchase went into escrow, I started to ship twelve to fifteen boxes by air freight each week to Pittsburgh. Employees received a good discount with the understanding that all other air freight had shipping priority. I rented a mini-storage unit and thought I would be saving a lot of money by minimizing the weight that we would be shipping with a moving company. Meanwhile, the escrow company repeatedly stated we would close in 30 days. They kept saying 30 days—over and over and over! So I kept on shipping air freight and made the arrangements with a moving company for the major balance of our household contents. I would never recommend this plan of action to anyone.

We had planned on moving our belongings across the country just prior to escrow closing in San Diego so we would be ready to fly to Pittsburgh. We figured we would then be able to close escrow on the house we had found in our new town and move in with our furniture, all in one easy simple process. Well, remember the earlier reference to the terrible escrow closing? The household goods departed with our moving company about five days before the scheduled closing date. I was so proud of my organizational skills. Even two days before the closing date the escrow company assured us the house would close on the arranged date. The closing date came. Nothing happened. Absolutely nothing!

The following day I called the escrow company and asked them what was going on. The manager finally revealed to us that they didn't know when the closing would be and the buyers hadn't even qualified for the loan. I was incredulous. I asked, "Not qualified?" I was told that one of the main issues was that our buyers were trying to qualify for a brand new loan program being set up for Asian Immigrants in California. I reasoned, “Why weren’t *we* informed?” Loan qualification is one of the first steps that must be completed in the escrow process and they had told both of us and our real estate agent that we were closing on the 30th day of escrow. Did I mention that before?

All our furniture was en route to Pittsburgh with no place to put it when it arrived. We had to inform the escrow office in Pittsburgh that we needed to delay our closing date. Our sellers in Pittsburgh were thinking of backing out of the deal. After a lot of negotiation, it was agreed we could extend the closing for 30 days and that we could rent the garage of our new home to store our household goods—but the garage only—we couldn’t enter the house. In short, we began paying for their mortgage payment in the form of garage rent and our San Diego mortgage, as well. We were in a tight spot. Can you imagine our difficulties if these escrows had fallen through? We would have a house in one state and furniture in another state over 2500 miles away. I don’t even want to think about it.

My mother graciously offered her home that December for Lee and the children to stay with her. My father had passed away after a long fight with cancer three months before our son, James, was born. Even though the children are her grandchildren, my mother did make a brave as well as a loving decision. It is one thing to visit and quite another to live with your grandchildren. They lived with my mother out of a few suitcases for over a month.

The San Diego escrow finally did close at the end of January. So with our children, who just turned ages three and five, we jumped onto the first standby flight we could find, traveled into the cold winter of Pittsburgh, and arrived in our new home town. The Pittsburgh escrow closed the following day.

We were able to selectively move our boxes and furniture from the garage into the right rooms, and begin to settle in. Lee was great at contacting the school system and the medical community to get Joy into local therapy programs and a wonderful pre-school program that specialized in helping the severely challenged. The school also had a policy which included non-challenged students of the same family, in their enrollment, to provide a positive role model for the core student population. So our son, James, also participated in Joy's class. It was a good experience that helped both of the children acclimate themselves into their new environment.

Once Joy graduated from preschool, she went to a regular school which offered a special needs classroom which focused on life skills. A few hours of each day the special needs children were integrated into the regular classroom. That particular school was not in our school district, so Joy's bus ride was long. After one year, she was then placed in a regular third grade classroom in our school district with the assistance of an aide. The staff and students accepted her with open arms and involved her in some way in all of the class activities.

In one school play, I remember when she was dressed up in a sun costume and walked around the stage holding another student's hand. The kids were great, and Joy loved school.

The elementary school was within walking distance of our home. On weekends Joy loved taking walks up to the school. We would talk about what we saw as we observed class projects through the windows and as we passed through the playground area. There was a large map of the USA painted on the playground asphalt and we would regularly stand in the Southern California section and then walk all the way to the section labeled Southwestern Pennsylvania. We would talk about who lived where and how everyone lived so far apart.

Joy was a happy child, well adjusted, and she had a great sense of humor. She loved to laugh even though her speech was limited. She loved to see all the local wildlife in Pittsburgh. It was an unusual day if we didn't see a rabbit in someone's front yard. Our new neighborhood was very different from urban Southern California. It was carved out of a wooded area and, for the most part, there were no fences around the yards. We felt at home and comfortable.

At this point of our parental journey Lee and I were still doing fine. Well, I use the word *fine*. When Lee first read this her immediate response was, "Fine! Fine? I wasn't fine. You can take my name out of that sentence." I don't wish to be mean but I will leave the word as it is, to point out one of the fundamental differences between men and women.

Guys like to get to the point and as brief as possible, whereas women will go all out with their vocabulary to use any adjective necessary to make their thoughts and feelings clearly understood. Marriage brings together diverse combinations of personalities and collections of words into a wonderful dialogue of "he said, she said" conversations.

Well, I suppose I should say that Lee and I were still *coping fine.* Perhaps that conveys reality a little better. We were able to hire child care occasionally to go out on a date, and we felt comfortable that our children were well cared for. Each day's routine was well planned, and we shared all domestic duties.

James was fun loving and enjoyed being outdoors and playing with the other children in the neighborhood. We were living right next to a young family with two boys about James' age. They included him in many activities and we were so thankful for their friendship. James and his friends respected our neighbor's property, so the children were able to run around and play in a park-like setting right around the house.

Joy, however, needed to be watched far more closely. She was ambulatory, but because our house was split-level construction we always needed to watch her around the steps. It wasn't too hard, though, because she didn't move around too frequently. Even at age eight, she needed assistance with just about everything. Her gross and fine motor skills hadn't progressed greatly; she couldn't dress herself, or bathe or operate any device without assistance. Joy was able to feed herself with a spoon only, but again the difficulty with fine motor planning prevented her from being able to cut her food or even move it about on her plate.

Joy never has played with toys as other children love to do. She did enjoy stuffed animals a great deal, and still enjoys them. We would play with her by selecting a stuffed animal and animating it with voice and action. Joy loved it when one of the animals would read her a story. As hard and steady as we tried, we were unsuccessful in toilet training. She simply seemed to not sense that she needed to go. This always posed a planning uncertainty any time we went out.

Joy was cognitively aware of oral communication. Although she was unable, in most cases, to respond back verbally, her non-verbal, physical responses, were always appropriate. At special holidays, such as Christmas or on birthdays, Joy would really get into opening the gifts. It was a toss up as to whether or not she enjoyed ripping off the paper from the gift or the gift itself, more. Laughter and excitement always filled the room.

These first eight years of Joy's life could be described as a bag of mixed emotions. We enjoyed many happy times as a family yet with that came the realization of the added effort it took from both parents to provide the needed child care. It took longer to do anything or to go anywhere, and we generally needed to have Joy right in sight or not very far from it.

As for me, being a dad and husband was exactly where I wanted to be. The experience was fulfilling even though the daily challenges were mostly of the unexpected variety and required creativity. Balancing time was always an issue. We tried to be as fair as we could with each member of the family and still meet the obvious needs before us.

One of the things I regret, however, with regard to the extra time it took to care for Joy, is that it caused a decrease in time that could and should have been available for James. Especially if one parent was working and James wanted to go out somewhere, we weren't able to say "yes" nearly enough.

Joy went to bed earlier than most kids. To begin with, she had her own internal alarm clock and woke up at 6:00 AM every morning. I don't know how she did that. Then with the combination of an active school day and her low muscle tone, she was tired by the end of the day.

Attention span and weather, such as the wind (tactile issues for Joy), were all factors as to whether or not we could take James to where he wanted to go. I wish that our support system would have been different during those critical years for James, so I could have spent more time with him.

He says that he understands, but I don't believe he realizes how much it played out in his development. How could he know? He has only had this one experience.

If this would have made up the end of our story, I don't imagine I would have written a public journal at all. But this is far from the end of the story. All our efforts and the skills we had acquired during this time could not have prepared us more for what was about to happen in Joy's life and, consequently, to everyone in our family.

Journal Entry

What has changed in your daily activities which may have caused an increase in your stress levels or those of your spouse or other members of your family? How have communication levels between you and your spouse or others increased or decreased as a result? Are you feeling out of control or are you managing well?

Robert Glenn

Journal Entry

Chapter Three
Epilepsy—The First Four Years

In 1995 Joy was almost nine years old. Shortly after Thanksgiving that year Lee, Joy, and I were sitting around the kitchen table. Lee and I happened to be looking in Joy's direction and noticed a very small head-nod. It was much too quick to have been a voluntary movement. We looked at each other in confusion and held a brief discussion concerning what we had just seen. We didn't know from that brief observation in our kitchen our lives would literally never be the same.

As each day passed, the little involuntary head-nods continued. At first they appeared to occur only once per day. When Joy was in school the nods could be easily missed in all the activities within the classroom. But soon the nods were noticed multiple times a day and we suspected they might be some kind of a seizure. We started by seeing her pediatrician and indeed he did refer us to a neurologist.

Getting the neurology appointment was easy, but it would be a long time before we would actually see the doctor. So, while the appointment was still weeks away we began to take notes concerning our observations. We didn't want to forget anything of importance. The neurologist, who was with the Children's Hospital in Pittsburgh, concurred with us that the nods were most likely seizures, and scheduled Joy for an Electroencephalogram (EEG), to document the brain wave activity and make a definitive diagnosis.

It's impossible for me to recall the details of that first EEG because Joy has now had many of them. Sometimes when we went into the EEG Lab, they would place twenty or so electrodes on to different areas of the scalp with an adhesive. They would run the test, which varied in length, and then remove the electrodes with a chemical substance, which still left the hair all sticky and gooey. Following this, we would go home. Other times, the EEG was administered as an overnight test and Lee would stay with Joy at night to help with her awake and personal care time. Then there was also a third type of test which was also overnight, but it was sleep deprived. That one was not fun at all.

The first EEG did document that Joy was having seizures and her doctor placed her on an anti-seizure medication. That was the start of a four year journey which was extremely hard to live through. Each day brought the unexpected, the unknown, and new challenges that Lee and I tried our best to meet through teamwork and prayer. To begin with, the medication was to be given orally twice a day, morning and evening. Joy had difficulty lateralizing her food as she chewed. Lateralizing is simply the normal chewing process we use which involves a complex set of interrelated muscles. We crushed the medication because Joy couldn't swallow a pill.

Because the medication's outer coating was removed, it would taste horrible. So we found any type of food item we could think of which Joy would like and hid the medication inside. Among her favorites were chocolate and vanilla pudding cups and chocolate chip cookie dough (my favorite). I would get into the cookie dough, too… one tablespoonful for Joy… one for me!

We hand-fed her to make sure she swallowed all her medication. We also considered timing so we could maximize the chances when she was hungry. Often we withheld a snack until the medication was given. Joy's cognitive level wasn't high enough for her to understand the need for medicine. She had just turned nine, but cognitively I would say she was about three.

We found out quickly that Joy had the propensity to realize almost any side effect a drug label might include. Among these side effects were dizziness, drowsiness, irritability, or decreased appetite. Her appetite was very small to begin with and her weight has always been off the low end of the body mass index (BMI) charts for infants and children.

Plus, the meds didn't seem to be working well. It was hard for us to understand why we weren't seeing any seizure control. As the months progressed the seizures continued to worsen. The neurologist began to add medications or increase the dosage of a medication already in use.

As the medication dosages built up in her system, I could see more and more of her personality just slipping away. Before the seizures began, Joy laughed and smiled a lot. She had a vocabulary of about one hundred words, even though she could only speak in single words or short phrases. Occasionally she would surprise us with a simple sentence. If I were to open one of her beginner reading books and point slowly at each word, Joy would be able to read for short periods of time with sizable gaps of time between each word. There were a few words she still would need help with, in spite of the fact it was reading material she had gone over many times with her school teacher and with us.

After the seizures and medication began, her skill levels began to drop. The first to go was the ability to read, and she spoke with less frequency. Her short attention span became even shorter, and she was losing her ability to spontaneously express happiness. That was very hard for me to watch. I can remember many times over that next four years when I would ask her, “Can you smile for Pop?” and I would see the corners of her mouth curl up and then just as quickly they would relax. No other change could be noticed in her facial expression.

I would think about this often when I was alone, like when I would be driving to work. My heart would break and the tears would flow down my cheeks. Talk about the distraction of driving while on a cell phone—try to focus while driving and your eyes are full of tears. More than once I found myself wiping away the tears in the company parking lot and wondering if anyone would notice my red eyes. I knew Joy was still with us enough to hear and understand, but she could hardly respond to the world around her.

As we moved from the first year into the second year of her seizures, the episodes affected more of her motor skills. Not only was her head nodding harder and more frequently, but her arms were dropping simultaneously and her knees were beginning to buckle. Joy still was able to feed herself with a spoon which had a rounded thick handle, but the challenge became to allow Joy to maintain her independence as much as possible when other tasks became too hard. We managed as best we could. Flexibility and adaptability were always key components to daily success.

There were many mornings we would start by getting Joy ready around 6:00 AM—she was always an early riser. Joy had an interesting habit of banging her hand on the mattress when she woke up in the morning to get our attention. She wouldn't simply get up or call us, she banged her mattress. Once up and dressed we would escort her out to the kitchen table for breakfast. She loved having cereal and milk. Often her seizures would occur at meal time. When they did, her hand, arm, and head would drop so hard and swift that her bowl and food would go flying in any direction, and the milk would soak her clothes.

Most of the time it was her face which would impact the dishes and it's a wonder she never broke her nose. Back to the bedroom we would go to clean her up, change her clothes and return to the kitchen to finish breakfast before the school bus would arrive. At this point, we were feeding her and foregoing the self-care. This morning routine became a daily event.

Food is one of our earthly pleasures Joy really loves. She only has a few independent skills available to her that she can truly say, "I did it!" or as she might say it, "Did it, Pop!" So, we frequented our favorite restaurants. Although I wouldn't look around too often, I'd still wonder what the other restaurant clientele were thinking when Joy's face would hit her plate and French fries would go flying all over the place.

Eating out was a noisy event. We would check to see if she was okay, and everyone at the table diligently gathered up French fries. By this time seizures were observed on an hourly basis. Being out in public often brought with it curious onlookers. Most people wouldn't make any comments; they just looked and wondered. However, occasionally someone would express words of encouragement. We didn't feel like hiding in our home to avoid an embarrassing moment, although Joy's health did limit our mobility.

We were calling the neurologist's office quite often to report not only a worsening of the seizure activity, but an ever-increasing severity of side effects from the medication Joy had to take. Almost all her meds cause some form of sedation and some caused loss of appetite and general instability.

These side effects were certainly not good for her general health and made it extremely difficult to administer the medication orally, as well. If she didn't swallow a medication in the first few seconds, it could take any amount of time, up to twenty or forty minutes, for the swallowing to be completed.

She could spit the medication out at any time and the process would have to start over again. Joy's quality of life was on a steady downward slope.

Regularity and punctuality of administering her drugs were keys to keeping her levels of medication balanced. If you know about the addictive properties of these drugs, missing a dose can cause seizures just as much as overmedicating.

In April of 1997, during this second year of seizure activity, we received a call from Joy's school saying she had a grand mal out on the play ground. We asked, "A what? Had a grand mal seizure?" How could this be happening? Joy has never had a grand mal seizure in her life and she was on anti-seizure meds to help prevent the other seizures she experienced. We were very alarmed! It wasn't too long after the first grand mal was observed at school that we began seeing them at home, as well. We questioned, "What is happening here?"

The doctor was called again and Joy's meds were again increased. New types were introduced over the ensuing months in order to get this new threat under control. This was a tough period to handle. I know the grand mal seizures were hard on Joy's system and unpleasant for her. They were also hard on us, because we felt so helpless.

It was quite unnerving when Joy would have a grand mal while sitting in the back seat of the car and we were in the middle of traffic. Emotions raced as I would plan the quickest exit off the road. There is a measure of stress when you don't know what the next moment will bring. Sometimes we would see only one grand mal on a particular day which would last for ten to thirty seconds. On many days, we would see none.

Sometimes the grand mal seizures would be longer in duration and appear in clusters. Thank God this didn't occur too often, but when they did occur, the clusters could last anywhere from twenty minutes to three hours. In these times the neurologist would advise us by phone to administer an additional dose of medication, but the bottom line was, we simply had to wait it out.

All we could do during these times was to stay beside her to offer comfort and assurance that the seizures would pass and pray with her to that end. Eventually the grand mal activity would stop. On the occasions when they did cluster, Joy would be wiped out for the remainder of the day. She would rest or sleep in her bed or perhaps sit up in her recliner chair.

Even though Joy experienced grand mal seizures, her drop seizures continued, as well. We simply stopped keeping records of them when they climbed to sixty, seventy, and eighty plus, per day! Counting was no longer relevant.

Lee and I were at a loss. We didn't know how to make any sense of any of this. Look at where our daughter's health had gone in less than a year and a half. This period brought with it a new awareness of what it means to pray without ceasing. It also brought additional stresses.

I remember once during this period of time I landed in the ER. The cause probably was stress, related to a combination of activities at home and one of several restructuring events that occurred at work. On that day I started to feel pains shooting from my right lower stomach area. They were constant with less than a minute's separation.

As the day went on the pains increased and radiated out further and further from their source through my body. By late afternoon pains were also shooting up my spine and into my neck. The pains were so intense that tears were flowing down my cheeks; I had never been in such pain in my life.

A neighbor said he would watch the children, and Lee drove me to the hospital. Before we left the house, Lee suggested I take Ibuprofen for pain control. I did, and during the twenty minute ride to the hospital, all of the pain went away. I couldn't believe that the Ibuprofen would even touch that amount of pain.

I was given a chest X-ray in the ER, and the doctor said it showed I had pneumonia. Pneumonia? I'm still not convinced the diagnosis was accurate. No matter, I had no signs of even being sick and it was a strange ending to an unusual event. The pain never returned, either.

The next day after my ER visit I was scheduled for an in-house company interview as part of a company reorganization program. I answered the questions in line with my beliefs and work ethics; however, I wasn't successful in retaining a lateral position. That is all I will say on this topic. I was content with the new position I was given. Whether from work or what we had to deal with at home, both Lee and I endured a large amount of stress during this time. I am very thankful that was the only occasion where urgent care was required.

We entered the third year of seizure activity and more issues surfaced. The grand mal seizures relentlessly continued as did the drop seizures. The effects of the drop seizures had expanded to include her entire muscular/nervous system. Head, arms, and legs were dropping frequently and hard. Joy's body would drop to the ground as if the strings of a puppet were being cut away from the puppeteer's hand.

It seemed as though her brain instantaneously cut the communication waves to the body's muscular system. The body would just fall to the ground. There was nothing graceful about this fall. It looked as if the body was being thrust downward. You could be holding on to Joy's arm and still you wouldn't be able to prevent her knees from slamming into the ground. Her knees were constantly bruised.

We knew the neurologist was trying to help improve her seizure control through multiple med alterations, but by and large the help simply wasn't working. Thankfully, however, the grand mal seizures finally came under control after about twelve months of activity.

We entered the fourth year and it was much like the third year, only more intense. The frequency of med changes continued. Even though Joy was being given more medication than she had ever received prior, the drop seizures were still getting worse. Their frequency and strength were intensifying.

Through all of this Joy still loved to take walks in the neighborhood and up to her school, so off we would go. Everyone enjoyed themselves until the first seizure or clusters of seizures would appear, and then we would rest for a few moments and make our way home.

In the spring of 1999 my mother passed away after five difficult years that evolved from a major stroke. We returned home after Mom's memorial service in California with her wheelchair and began using it on our walks. It helped us change the scenery and activity for Joy.

At times during these four years Joy was taking three or four medications at once, and there was a short period of time that she was on five different medications simultaneously. Complicating our search for the right combination of medications was the fact that the drugs could only be altered one at a time and only altered by very small increments. In order to maintain a clear thought process, we kept records of all the changes of medications Joy was subjected to, which included the reason for the change and the dosage level that was being adjusted. Mind you, it wasn't as easy as taking an aspirin and waiting an hour for it to work. The total number of medication changes came to 86.

Side effects were constantly with us as meds were increased or changed. Dizziness was one. For example, a week could elapse since her last medication change was completed and Joy would be getting extremely dizzy. The doctor allowed us to reduce one med then, and that med reduction would require up to two weeks to get out of her system. The doctor would then raise one of the other meds to compensate for the loss of the prior med, and that change could take four to seven days to manifest itself in her blood stream. So, for three long weeks Joy would show signs of dizziness and there was nothing we could do about it.

To try and explain details of daily activities during these times is just too much for me. But I will attempt to share one example: bath time. There were periods when bath time was anything but pleasant. Due to the fact we really did need to bathe Joy and not simply give her a sponge bath, we bathed her in the tub. However, when she was feeling dizzy, even one inch of water would drive her crazy. She would scream from the moment she entered the water until she was removed. Before and after the bath, she was fine. We felt horrible about the experience but couldn't come up with a better solution. It was hard on us all.

The medication cycle was repeated over and over as each recurring side effect appeared. Normally in the end, Joy was on a higher dose of medication.

We learned that when it comes to certain medical conditions, treatment appears to look like laboratory experimentation. No two individuals will respond the same way to the same treatment. Joy's case was unique to her. So as long as we didn't have success, there would be constant anxiety over the lack of seizure control. Plus, a lack of knowledge contributed to our concern; we had no idea of the source of the seizures, either.

Lee and I had become totally on task. We knew the daily routine and the constant vigilance it took to help assure Joy was safe in her environment. The care was consuming, and the only time we even had to sit down and talk about the day was after Joy had fallen asleep. After about one hour of relaxation and communication we could hardly hold our eyes open. Knowing Joy normally got up early, we willingly found our own pillows with little effort.

Reflection has given me opportunity to express my feelings concerning a question: "How does it feel to have a seizure?" I have never had a seizure but I have witnessed thousands of them through the years. To my knowledge a seizure doesn't hurt, per se. By that, I mean it isn't like any type of a headache.

The brain, however, controls the nervous system. Sometimes the brain will temporarily stop communicating and that shutdown causes the body to physically lose control for a short period of time. Often this loss of control will only last for five to fifteen seconds. During this brief period of time, though, the risk of bodily injury greatly increases due to the heightened probability that a person could fall. Any object such as furniture or toys or a hard surface may cause injury.

If you have access to a computer, I would suggest you might search the web for the *Epilepsy Foundation*. Once located, search for the section for 'First Responders' and you will be on the right path to learn about what to do and what not to do to best aid someone during a seizure episode. While I cannot offer medical or conditional advice, this is what we have tried that has worked for us. Talk with the individual if they openly have acknowledged their condition. Ask them what type of assistance would help make them feel the most comfortable. For us, we quickly placed an arm around Joy's torso to evaluate her level of need. By touching her, we could quickly assess whether or not she was maintaining her stability or if she was about to fall.

Again while not offering medical advice, we have noticed that with people with whom a person is not acquainted, an assessment can be made by simply placing a hand on the individual's back, or just by remaining close to assist if needed. If the individual is stable, we have seen people maintain their position until the person with the seizure has become functional once again. If falling appears possible, we have learned that we don't attempt to move the individual to a chair or sofa, but simply assist them to the ground right where they are. If the seizure passes quickly, the individual will regain total control. But if the seizures worsen or continue by clustering, we have been counseled to call 911.

There are many types of seizures and some don't involve any shaking at all. Instead there may be a stiffening of the body accompanied by a lack of mobility. We have learned that the biggest mistake people make is when they don't react quickly enough. A slow response can often be a late response. The individual might fall and sustain an injury.

Most individuals know and recall they have had a seizure. Even Joy will acknowledge this. Often after she has had a seizure, I will ask her a question, "Oh, you just had a seizure, didn't you?" and she will give a nod or thumbs up response. I will then follow that question with, "Oh, we don't like seizures, do we? We hope they go away." And she will acknowledge that as well. I find it important to separate the condition from the person. After all, she hasn't done anything wrong. Hopefully by using this technique, Joy feels she is both supported and understood.

I mentioned my opinion that a seizure doesn't actually hurt; however, there appear to be consequences. Seizures cause a certain amount of stress on the body. From our experience, when an individual has a mild seizure the additional stress will also be mild and the recovery period will be quick. However, if the seizure is strong, or clusters of seizures occur, the body withstands higher levels of stress. Muscles tighten up and become more rigid as a result from electrical disruption occurring in the brain. This additional energy output takes its toll on the body. This is why Joy has a longer recovery period following any strong seizure episode.

We were nearly approaching four complete years of seizure activity. It was hard to comprehend the worsening frequency of the seizures, and Joy's condition was in a steady decline. One evening Lee and I were watching the PBS Television Channel and saw a commercial for a Vagus Nerve Stimulator (VNS). It immediately caught our attention. We learned that the VNS is a small implant device very similar in nature to a pacemaker for the heart, but in this case it was connected to the Vagus nerve in one's neck. Its primary purpose was to aid in the control of seizure activity without the use of drugs. We wondered, "Could this device be something that could help Joy?" We wanted to find out.

No One Knows

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I pray that life would go my way.
I've learned from words that You say—
"This life is not my own."
I turn from the pain
That I hold inside;
I've tried to run away,
But there's nowhere left to hide.

No one knows me like You do;
You speak to me words of truth.
I will never walk this world alone;
Lord, You give the grace to lead me home.

I walk in a world that has turned away.
The streets are cold,
Yet I hold to the promise You made;
That the darkest nights will fade.
I stand at the edge of a fire I've made;
Too close to the flames;
But I hear one still voice that reminds me, I am safe.

No one knows me like You do;
You speak to me words of truth.
And You lift me up when I fall so far;
Lord, You bring me back to where You are.

Release from me these chains, and set me free from myself;
And let Your will be done in me.

No one knows me like You do;
And my heart desires to be like You.
I will never walk this world alone;
Lord, You give the grace to lead me home.

Robert Glenn

Journal Entry

How are you coping when life seems to be out of control? Is help close at hand? Do you know where to turn or from whom to seek assistance? How are you handling the challenges? Do you feel you might be able to lend others some support?

Rearing Up America

Journal Entry

Chapter Four
Surgery! Could This Be the Answer?

In order to see if the Vagus Nerve Stimulator could help Joy, we needed to devise a plan. We called our neurologist to make an appointment for a referral to see the specialist at Children's Hospital who headed up the program involving the VNS device. At the same time we also called Children's Hospital to make the second appointment with the new specialist. We really wanted this process to move right along. Keep in mind our only goal was to search for information, in order to determine if the VNS device might be of some help to ease Joy's seizure activity.

The day came for the referral appointment and we were called into the doctor's office. During the opening remarks we explained our desire to obtain a referral to explore the possibilities of the VNS because the seizures were constantly getting worse. We explained that from what we had been able to learn the device was a non-drug intervention which looked very attractive to us on the surface.

The doctor then made a statement I will never forget, and was amazed to hear. He said, "Sometimes we just have to understand that an individual (referring to Joy) won't get any better." He didn't want to give us the referral for the VNS. My mind and heart were racing at this point and I tried my very best to keep composed. We had both children with us that day. What was he saying to us? That not only was she not going to get better but the seizure pattern would continue to worsen? I wondered, "And to what end? Joy's passing?"

We dialogued back and forth for a few more minutes. Only when we mentioned that we had already confirmed the other appointment did he concede to provide a referral. I'll repeat: *only when we mentioned we had already taken an additional step did he concede to grant our request*. Mind you, we are talking about a child who only has a generalized diagnosis of CP and hadn't had a seizure until the age of nine! I couldn't believe a doctor was looking at our child, almost in a comatose state from seizures, and was reluctant to offer us any hope.

I thought about that repeatedly in the days that followed and the more I considered it, the more it scared me. We began to refer to our neurologist, at home only, as our drug doctor, because drugs were his only treatment solution. I imagine he might have felt the need to spare this child the discomfort of a surgical procedure but the truth is I simply didn't understand or agree with his response.

A number of weeks passed before the second appointment time came. Although I was shaken up from the prior doctor's visit, the rigorous daily routine had left little time to dwell on it. Joy, Lee, and I arrived for the second appointment and met the new neurologist at Pittsburgh Children's Hospital. She soon rekindled hope for us. The meeting was relatively short. We briefly described Joy's medical history. And the doctor simply said, "Hold on here. There is something that doesn't make any sense. There is no explanation as to why this seizure disorder just appeared and then progressed as it has. Let's schedule a Magnetic Resonance Imaging (MRI) and see if we can find some answers." Finally, there was someone who had heard us and understood our cry for help!

Weeks again passed, but we were looking forward to the MRI. Due to Joy's condition, she needed to be sedated for the procedure, and it was still questionable whether she was remaining still enough in the chamber to satisfy the technician. Finally the technician said he had gotten a good image and we waited for Joy to wake up sufficiently to return home.

Time passed again. I don't recall how long. We were called into Children's Hospital for the results of the test. The doctor shared the news that Joy had Lissencephaly. Of course, we had never heard of or understood what it was. And our overall understanding didn't expand a great deal on that day. However, the doctor did mention that Lissencephaly often had a genetic origin and that the MRI confirmed the diagnosis by revealing an extra band of gray matter going across the interior areas of her skull, beneath the brain. We learned that this condition is also known as Double-Cortex Syndrome, or Subcortical-Band Hederotopia.

As I am writing now and thinking about this MRI conversation, I recall a conversation that occurred years before. It was at Joy's first MRI when she was only thirteen months old. It was early in 1988. We had just finished the MRI at the Children's Hospital in San Diego and were transporting Joy to a recovery area. One of the techs and I were merely carrying on a conversation and I recall that he mentioned seeing a small area of gray matter during the MRI. I noted the comment with interest at the time, but the term or condition never came up again. I don't even know or recall if I ever mentioned this to Lee or not because it occurred prior to the doctor reading the MRI and our discussion of the MRI results.

Joy's current doctor also mentioned that if we wished to learn more about her new diagnosis there was a family support group based in Fort Wayne, Indiana, and a medical research study being conducted out of the University of Chicago. In short, Joy was a good candidate for a VNS implant after all, and the doctor proceeded to provide us with additional information about the procedure.

We were given a twenty-five minute video on the VNS device, which in fact was produced by the manufacturer, and the doctor stated there was no conclusive information on whether the VNS would actually provide any seizure relief for Joy. Lissencephaly, it was explained, was very rare, and the genetic research being conducted was still in its early stages.

The doctor went on to state that VNS Implant surgery was a relatively straight-forward procedure as surgeries go, and the only other course of action would be brain surgery. I responded, “Slow up here for a minute. We have no intention of looking at brain surgery.” The doctor gave us a nod of understanding and proceeded to go through a general time line and explanation of the procedure on the VNS in more detail. We went home to absorb this new information and to view the video.

The video explained that the device was about the size and shape of a pocket watch. It is implanted in the upper chest cavity, just below the collar bone and just beneath the surface of the skin, on the left side of the body. A wire is fed from the device to the Vagal Nerve which is located on the left side of the neck. The Vagal nerve on the left side of the neck runs northward to the brain while the Vagal nerve on the right side of the neck runs southward away from the brain. With the aid of a small incision in the neck at the nerve location, a self coiling wire attaches the device to the nerve. The VNS is a computer through which the doctor may set the strength and duration of the impulses which the device creates and sends through the Vagal Nerve to the brain. The pulses will attempt to inhibit any irregular brain waves which may cause seizure activity and help return the brain to a more normal level of operation.

Besides the technical information provided on the video, there was also a section of personal testimonies from clients who were using the device. Among them were individuals who have had both good and poor results. The overall message conveyed was that results will vary in every patient. Some individuals may become free of seizures while others may experience moderate or little relief. In rare cases, the seizure activity could worsen. Talk about a comprehensive disclaimer, this was it.

The video went on to say that the VNS is approved by the FDA and the majority of clients do have positive results. Since 2000, the FDA had also approved the VNS for treating depression, and research was underway with the hope of having the device approved for weight loss, also.

After weighing the pros and cons of the VNS we decided to proceed with the surgery. Joy's condition was continuing to worsen each month. You know, I didn't like the general idea of surgery for a twelve year old child, but I had to consider where our situation had brought us. Month after month we had watched our daughter deteriorate. Yes, we had approached the doctor out of desperation! No one else had stepped up to the plate to offer us any choices. I wondered, "Why?"

Fortunately, the surgery came and went without any complications. The device, however, was not able to provide immediate results. We were dealing with the nervous system and there was a two week waiting or healing period following the surgery before the device could be activated. When it was activated it would begin to work only at a very low level in order to avoid permanent damage to the Vagal Nerve.

After a few weeks, the strength of the device was gradually increased until it finally reached a therapeutic level. Joy's surgery was in August of 1999, and by late October she was actually realizing more seizures, not less. It was then the doctor suggested that the VNS be turned off to see if it was a cause, so it was turned off. It was as though the VNS had no impact at all. Joy was no better or worse from activating or turning off the device; she was simply continuing her deterioration.

To my recollection, Joy hadn't spoken a word for many months at that point. Her only form of communication was occasionally pointing this way or that way with one finger. In December, her drop seizures were so hard and frequent that with one of her seizures, she sprained an ankle. Simply walking out of her room and dropping caused the injury. By then she was in her wheelchair most of the time. Caring for her was even harder, partially because she had become too heavy for one person to carry and we had a half of flight of stairs to go down to reach our front door.

We couldn't understand what was happening. We were confused and, simply stated, we were desperate parents. We felt as if we could be losing a child. However, sometime between August and December of 1999, we made a call to our new neurologist to inquire about the brain surgery the doctor had alluded to earlier. What once seemed totally bizarre and out of the question was now being considered. As the saying goes, "Desperate times call for desperate measures."

Surgical intervention into the brain is something we had only read about. We had not thought it could be something we would actually experience in our family. But there we were. The impending realities of such a procedure were beginning to form in our thoughts.

We asked, "What is going to happen next?" We had feelings of fear and anxiety as well as loneliness. There was no one to help us through the decision making process, no one at all! Oh, the surgeon certainly provided all the technical information he could, but the decision was ours alone. We wondered, "What would the outcome of the surgery be?" The doctor gave us his percentage for surgical successes but to my knowledge he had never worked with someone who had Lissencephaly.

Every challenge in life needs a counter challenge to help balance human emotions. We found our balance through our faith and realized this balance in a variety of ways. Music and the lyrics to songs were and are a wonderful source of inspiration for us.

It's vital to hold onto the source of strength which is greater than yourself when faced with circumstances which will truly bury you. We must cling tightly to that which will never change. See if you agree as you explore the following lyrics to "Holding On" by Justin Unger.

Holding On

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There I was focused on the things I've made.
Here I am, knowing it was all in vain.
'Cause the value of Your Holy name surpassing all that I can gain;
And the fact that You will never change, keeps me holding on.

I'm never letting go. Now that I truly know
Your love prevails. Your promise never dies.
You take me as I am. And now I can finally stand.
This gift of hope, it keeps me holding on.

As we watch the glory of Your plan unfold.
Standing by, knowing You are in control.
'Cause the beauty of Your precious name is beyond what measure we can claim;
And Your perfect love that made a way, keeps me holding on.

I'm never letting go. Now that I truly know
Your love prevails. Your promise never dies.
You take me as I am. And now I can finally stand.
This gift of hope, it keeps me holding on.

I'll keep holding…I'll keep holding on…
I'll keep holding…I'll keep holding on.

Journal Entry

Every day is new! Are you able to take life one day at a time and not worry about tomorrow? Where do you draw your strength from? Do you get thrown off course when faced with the unexpected?

Rearing Up America

Journal Entry

Chapter Five
Oh, Not Brain Surgery! A Miracle or What?

It still amazes me that God tells us in the Bible He won't give someone more than they are able to handle. I believe the reality of this promise is played out differently for everyone.

Here is a portion of another contemporary Christian lyric entitled, "God Will Make a Way" by Don Moen which I can relate to.

God will make a way,
Where there seems to be no way.
He works in ways we can not see;
He will make a way for me.

He will be my guide;
Hold me closely to His side.
With love and strength for each new day,

He will make a way…

He will make a way.

Those brief few months after Joy's VNS surgery were crucial to our decision making process. Our choices had shifted into a new direction. By the time we reached the decision that Joy might be helped by undergoing brain surgery, it seemed like the logical next step. It was scary to step out to a place we had never been before. There was always the reality that surgeries aren't all successful and there might be a wide range of outcomes. The results could even be fatal. How could we anticipate what path brain surgery would lead us down with Joy?

The surgery recommended for her was called a Corpus Callosotomy. In the core area of the brain a corridor exists called the Corpus Callosum, in which the nerve fibers pass through from one side of the brain to the other and thus connect the two sides of the brain. This pathway for the nervous system is the main corridor between the two sides of the brain and makes it easier for the body to coordinate movements, such as alternating one's feet while climbing stairs, or joint left-right hand motor skill movements. It is also the main corridor taken by the nerves to produce the horrible drop seizures Joy was experiencing.

The neurosurgeon explained to us that normally he would cut only two-thirds of the nerves which pass through this corridor, but because Joy's disabilities wouldn't allow her to participate in the labor force, he recommended a full callosotomy and to cut all the nerves. I asked him if there was any chance the nerves might fuse back together, and he replied that with the laser technique used fusion could not occur. He further explained that there may be a reduction in her left to right coordination skill level; however, a number of the skills, if not all, might be relearned through therapy. This was a surgery that, for obvious reasons, would only be performed once and the doctor felt her seizures warranted this intervention for her maximum benefit.

Now that Joy was in her wheelchair most of the time, due to her sprained ankle and her ever-worsening seizures, we agreed to go ahead with the surgery. Again, days and weeks passed as we waited for the surgery date to arrive. We were by Joy's side, now, every waking moment of her day. Although she sat in a chair or in her wheelchair, she was ambulatory, and it was impossible for her to understand that a sitting position was the safest place for her to remain. We allowed her to move about any time she wished but we needed to be close at hand to minimize the possibilities of any additional injuries caused by repeated seizures.

Lee was working an average of one day a week in her part-time position. I needed to put in for a personal leave of absence from my job to be available for the surgery and the critical recovery days that would follow. We had to manage our time constraints.

The morning of surgery came on a cold January day in 2000. Joy had recently turned thirteen years old. We were awake extra early that morning—we had to arrive at Children's Hospital in Pittsburgh at 6:00 A.M. for her admissions appointment. Joy was admitted and we moved into the pre-operations room where her vitals were checked and she was changed into her hospital gown. After we met and talked briefly with the anesthesiologist, a nurse escorted us into a private waiting room. She told us the wait would be about forty minutes after which time Joy would go to receive the anesthesia and proceed to surgery.

Our pastor had made arrangements to meet us at the hospital to pray with Joy before the surgery, and he found us after we had been in the waiting room for about twenty minutes. He prayed and talked with us for a while. Then the nurse came in, as expected, after forty minutes. She calmly announced that an emergency case had arrived in the operating room and Joy's surgery was cancelled. There would no longer be any room in an already crowded Intensive Care Unit (ICU) for her. We were told to please go home and call to reschedule.

I couldn't think. I couldn't believe what we had just heard! After all, this was not a simple tooth extraction. Wasn't this *our* emergency? There was total silence as the nurse left the room.

What was racing through my head? I don't know if I can put the thoughts into words, exactly, but I have a picture. Hopefully this won't sound too melodramatic, but perhaps you can relate to this. It's one of the many pictures we all viewed in the immediate aftermath of Hurricane Katrina. It's the view from a helicopter, of individuals trapped on their rooftop, looking out at the seemingly endless water surrounding them, wondering what the next hour or day would bring and if they would survive at all. It's a picture of emotional numbness. That's what I had in the foreground of my thinking: it was like being trapped in disbelief.

Well, we said thanks and goodbye to our pastor and started to collect all the things we had brought with us. Joy was changed back into her street clothes and we went home.

Just getting to the day of surgery was an emotional journey. The only thing we had to focus on was the surgery, but it wasn't meant to occur on that day. We believed God knew best. End of story.

But when we called the scheduling department back, we found it would be three more weeks before a new surgery date: three more weeks of seizures, three more weeks of constant vigilance, and three more weeks of racing emotions. Compounded feelings of uncertainty and faith finally brought us to the second surgery date.

It was hard to put my finger on what was different about this new morning of scheduled surgery, but it did feel different. For one thing, we had been through part of it once before. We were up early again and into admissions by 6:00 A.M. Again our pastor was very kind and returned to pray with us. This time there were no big surprises in store.

The surgery was to require four to six hours so we settled in the waiting room with our pastor and a number of other families, to wait. We were aware we weren't alone in that waiting room. We knew these families were also at a crucial point and they helped me focus my emotions. My bottom line was the knowledge that I felt God was in control of our outcome. While experiencing many emotions, I treasured a sense of peace within that belief.

Finally the surgeon called us into a small room and told us the surgery had gone fine and Joy was in the recovery room. We would be able to see her in a little while in the ICU. As I recall, it was about 2:00 P.M. when we were allowed to see her, and although she was awake, she was still pretty drowsy. Joy was able to answer some questions with her standard "thumbs up or down" signals or by pointing at something, but no spoken communication occurred yet.

This surgery had been performed on a Tuesday morning and the plan was to move Joy from the ICU to a room as soon as she was totally awake. The afternoon passed by quickly, as did the evening, but Joy was still not fully alert. The decision was made to leave her in the ICU overnight, and only one of us was allowed to stay with her at a time. The rules of the ICU were that whoever stayed wasn't allowed to sleep, and there was no place to even recline. We were given a small family sleeping room on a different floor of the hospital, and Lee and I took shifts throughout the night.

Wednesday morning brought little change in Joy's condition. It was this way for the rest of the day, too. Her sixth grade teacher, Mrs. B., actually came down to the ICU that afternoon to visit, and it was wonderful to see her. Joy lit up as Mrs. B. approached her. She gave Joy a gift and a long "Get Well" banner which had been signed by the entire class. By Wednesday evening the ICU made the decision to move Joy into another room even though she still wasn't fully conscious. They needed the bed in ICU for other patients newly out of surgery.

Joy was moved to another room on Wednesday evening. This new room allowed anyone who stayed with her to recline or even sleep in a fold-out sleeper chair. I stayed with Joy on Wednesday night. Lee went home for a better night's sleep and to see our son, who was being cared for by his Aunt Jo. I stayed up as much as I could to watch Joy as the nursing staff would only come in occasionally. Joy was still drowsy, nonverbal, and totally helpless. Finally in the early hours of the morning, Joy stayed asleep and I dozed off for several hours as well.

Thursday morning we faced a new challenge. Even though Joy's vital signs were pretty good, we couldn't wake her up. She had fallen into a coma. The staff and doctors were alerted. Tests were started to discover the cause of the problem. After several scans and blood tests, it was determined in the afternoon that her sodium level was extremely low. The sodium level was raised in her I.V. and within one hour, Joy was fully alert. The doctors had a hard time pinning down the problem because a sharp drop in sodium is an unusual postsurgical reaction to begin with. When it does occur it normally follows within a few hours of surgery, not a few days. These doctors did some great detective work.

To see Joy now was nothing short of a miracle! She looked more alert and bright eyed than I could recall for a number of years. She smiled and laughed spontaneously and visually tracked everything in the room. Joy's personality had returned and we were all overjoyed at what we witnessed. We weren't seeing even one seizure, not a one! She was seizure free! It was the miracle we had been praying for.

The incision on the top of her head covered about two-thirds of the distance between her ears. It was a little unnerving to view the incision; however, this revelation appeared many days after the surgery. To start with, all we saw was a large white turban bandage.

It took a number of days for her strength to return. When it did, physical therapy started. This therapy began with walking and eye and hand coordination skills evaluation. She was showing no signs of any problem with the right or left motor skill brain function. The therapist even tested Joy's motor planning skills by walking her up and down the stairs at the end of the hospital hallway. When Joy was able to demonstrate that all her bodily functions were operational, she was discharged to come home. Her total stay in the hospital was ten days. There were no more seizures!

I was amazed at the level of her alertness. I had to rethink my perceptions of the effects of her seizure medication vs. the effects of the seizures themselves. We had seen the seizure activity grow from levels of nothing to devastation in a four year period, while at the same time dealing with the side effects of the medication. Almost all of the med changes had been attempts to minimize the extreme side effects that had further complicated Joy's daily life.

I consider myself to be more than a casual observer. I had viewed the seizure medication as a necessary evil. The medication was the cause, in my mind, of Joy's lower cognitive performance level, her dizziness, decreased appetite, and her occasional zombie like state (which might last for a week or more during certain medication change cycles). The term *zombie like state* is actually not an exaggeration. When she was in a state like this we could wave our hands about eight inches in front of Joy's face and she wouldn't flinch; she would just stare straight ahead.

But look at what we were seeing after the surgery! Her cognitive level was almost what it had been before the seizures started. I say *almost*, because her vocabulary level didn't match her pre-seizure vocabulary level. But her personality was back and she had no seizure activity! Considering what Lee and I had witnessed before the brain surgery, Joy's condition now was indeed a miracle, and our understanding of the past four years was taking a new shape.

Now what were we to think? The one thing that hadn't changed was Joy's medication. During the ensuing weeks the doctors said nothing about reducing the amount of medication she was taking. Joy continued to take the same dosages of four different medications she had been on before the surgery, even though she wasn't experiencing any seizures at all.

We had questions: "Was it mostly the seizures that caused all the major declines in her skill levels?" "Why were we not seeing the dizziness and other seemingly related side effects that we normally associated with the medications?" I still don't know the answers to these questions, but right then we were elated at the success of the operation. We were so happy to have Joy home again.

In You Alone

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I can't cause the sun to rise up in the morning;
I can't take this life and make it go my way.
I can't control the way the storm moves on the ocean;
I can't restore the hope I lost along the way.
But You can Lord,
I know You can…
You can.

'Cause You alone,
You are God and You're in everything.
You alone You are faithful to the end.
I won't place my faith and trust
In all these temporary things;
'Cause all eternity is in Your hand,
In You alone

You have opened up our eyes along this journey;
But even still we tend to lose our way.
In our weakness we have found that You are faithful
To give the strength to make it through the day.
Because You can Lord,
We know You can,
You can.

'Cause You alone,
You are God and You're in everything.
You alone, You are faithful to the end.

I won’t place my faith and trust
In all these temporary things;
‘Cause all eternity is in Your hand,
In You alone.

Robert Glenn

Journal Entry

When good things happen, where or to whom do you direct your thanks? How often to you wonder, "Why does life have so many up and down situations?" Have you ever wondered if it's your fault?

Journal Entry

Chapter Six
Behaviors—Years Five, Six, and Seven

As a result of Joy's surgery, our school district presented us with an option to place Joy into a different learning environment. Our school district, like most, is mandated to teach the basics, reading, writing and arithmetic, to maintain their government funding. Special schools exist which focus on life skills and we have always been aware that Joy's education would be better served in areas of daily living rather than academic fields of study.

We were considering putting Joy into the Children's Institute of Pittsburgh—Day School Program. Traditional schools' staffs usually include one or two Special Education teachers who pull the special needs individuals out of normal classes for adapted learning experiences but still focus on the academic basics. However, the Children's Institute was staffed entirely with Special Education staff and therapists. Their total focus was life skills. While they would still teach reading and math, they used practical tools and materials such as road and direction signage, money values, and measurements for cooking, or offered instruction on how to measure laundry soap.

Other subjects included self-care in the bathroom, how to put on and remove a coat, and other skills that normal functioning individuals might take for granted. For example: how does one put on a coat when motor planning is a big issue? Here's how: a helper may simply hold the coat out in front of the individual upside-down. Then the individual simply places their hands and arms directly into both sleeves and swings the coat over their head. The coat is on and the front is ready to be zipped up or buttoned. Try it, it works well!

One classroom at the high school level is a functioning kitchen and laundry room. By this stage the students were able to process laundry and make baked goods which were then sold around the school and the surrounding community. The students were also able to participate in money exchange. These life skill activities would improve their social interaction with others for many years to come. The student body is comprised of individuals like Joy who have been disabled from birth, or who have been injured in accidents, or disabled by major illnesses.

After a series of interviews, Joy was accepted at the Institute and in the fall of 2000 her school bus began a new forty minute ride across town to her new school. She loved having one main classroom, one set of classmates, and the teaching staff was terrific.

Students ranged in age from elementary school age, through twenty-one. The last two years of a student's experience at the institute focused on transitioning to an appropriate adult day program where they could perform at a job using the life skills acquired at the Institute.

Joy spent a total of seven years in their day program. She thrived under their loving and professional guidance.

Through the four years prior to Joy's brain surgery we pretty much had lived a day-to-day existence. We only sought and required strength and guidance for living one day at a time. We didn't know what tomorrow would bring. Normally, tomorrow would look about the same as the day before, but we didn't have the energy to worry about that. Living one day at a time was just fine.

We were looking forward to calmer days ahead. When Joy came home from the hospital, her care was still intense. I needed to assist with the care for several weeks before returning to work. The Family Leave Program, which allowed me to take time off from work for the surgery, was very much appreciated though I wasn't paid for the time off.

It didn't matter that I had over three months of sick time on the company books; I wasn't the one who was sick. When all the time was added up, I had been off work for one month. Money was going to be tight.

I had known a small group of my friends at work who said they were going to conduct a bake sale to raise money for us. I thought, "Okay, a bake sale. That was nice." To our amazement, they raised an amount of money equal to an entire month's salary I had lost. What a wonderful gift from those who unselfishly spent so much time on our behalf. We were amazed! Their friendship was priceless to us then, and still is.

We had renewed hope that Joy would continue to gain back her strength and resume the life style and cognitive growth pattern she had enjoyed prior to contracting epilepsy. Each week she felt a little better and we rejoiced every single day she was seizure free.

Joy was living at a higher cognitive level. She enjoyed activities she wasn't able to before. I am convinced through observation alone that her brain had been in a constant state of seizure prior to the surgery. Because there was no medical need to order another EEG I don't have any medical documentation to substantiate my belief, but I know what I saw.

Everything was going very well for the first five weeks after surgery. It was then we started seeing a new type of seizure. These came, totally out of the blue, as before. They were mild but still alarmed us. When the first seizures began they had been mild, too.

In these new seizures Joy's head and eyes now took a short, quick turn to the left and then would return to normal. As before, once we witnessed the onset of the seizure activity, the frequency and strength continued to grow and occurred on a daily basis.

Of course, we questioned, "Why had seizures appeared again? Why?" Mind you, these seizures weren't even close to the destructive levels the drop seizures created, but they were seizures nonetheless, and we paid close attention to them.

If an onset of new seizures wasn't enough, at the third month following surgery something else unexplainable happened. One evening, Joy simply refused to go to bed. Bedtime had been a fun time for us. Joy would listen to stories; we would sing songs and pray together. This new level of passive-aggressive behavior was something we weren't used to. Generally she would compromise if multiple approaches were tried. One of the best approaches we discovered was to use a hand puppet.

But Joy was nine years old prior to her epilepsy, now she was a teenager. Joy had emotionally changed. Her hormones were more active. Mom and Dad were around just too much. I imagine there were a number of reasons, but her mind was made up.

This situation of passive-aggressive behavior stayed with us; I will simply say that she didn't willingly go to sleep in her own bed for the next two and a half years. She had made up her mind that she just didn't want to move out of her chair.

Most of the homes in Pittsburgh aren't single story; our home was like most. Due to a number of reasons connected with her care, we placed both a recliner chair and a TV-video console in Joy's upstairs bedroom, another practice which now I wouldn't recommend.

Even though Joy wasn't going to bed at night, the medication did cause some initial drowsiness. Someone needed to stay with her after her evening medication was administered. We couldn't risk that Joy would stay clear of the staircase if she left her room. Also, because of her age, she was no longer easy to pick up by one person when she was sleeping. Being near to Joy's bed was important.

I normally took the last evening watch with Joy whenever I was home because Lee had provided the personal care earlier in the evening. Normally the last thirty minutes to an hour would go down as follows: already tired from the day's activities and from bath time, Joy would be relaxing in her recliner, watching one of her videos. Medication would be given orally around 8:00 PM.

As she continued to watch a video, her eyes would get droopy and her head would slowly fall to her chest. While this was occurring, I would slowly be lowering the volume on the TV, with the remote control, and would turn off the room light to aid her in falling asleep. The changes were so subtle she didn't even notice what I was doing.

Once she fell asleep, she was out for the night. At that point, either Lee or James would come upstairs and the two of us, one at the shoulders and one at the legs, would pick Joy up and move her onto her bed.

This sounds like a peculiar bedtime routine and it was. It happened seven days a week. As the months went on, bedtime became even more stressful. I'll do my best to communicate the next new behavior we encountered. Unlike some of the other behavioral problems that evolved, this new one was totally unpredictable and included some aggressive tendencies.

It would be Joy's bedtime. She had received her medication. The video was playing. Her room light was off. I was lowering the sound level of the TV. The room door was slightly ajar so I was able to see. Joy's eyes were closed and her head was relaxed on her chest. I would think she was asleep. The entire atmosphere would be calm.

Then without warning, she would jump out of her chair with incredible energy and speed, extremely irritated, and head straight for the door. I couldn't allow her to approach the stairs outside of her bedroom door when she was in that state of mind. So I would dash in front of her and close the door.

Joy remained irritated and might take a swing at me with her finger nails or worse yet start to bang her head against the wall or closet door. When any of this behavior would occur, I would move behind her, wrap my arms around her waist and lift her onto her bed.

Joy's energy level would remain high. I needed to restrain her arms with my hands and her legs with my torso. In only about fifteen to forty-five seconds Joy would go from a state of rage to fast asleep. There didn't seem to be any logical transition time. I could sense the point in which her will was relinquished, and in seconds she would be asleep. All I could do after one of these episodes was to remain seated on the edge of her bed and sob.

It was a heart-breaking experience to go through, and it was unexplainable. I guess the medication had produced a strong influence on her behavior, but we just didn't know. The behavioral episode would resolve itself almost as quickly as it had erupted. Fortunately this wasn't an every night occurrence; rather, occasional. When it did happen I became exhausted and needed to take something for my back which would occasionally torque out of shape from the position I had to maintain. So much for calmer days! If easier days were to come we reasoned we would have to wait a little longer for them to materialize.

The bedtime activities were only one example of the poor behaviors Joy exhibited. For example, she would let us know when she was hungry, but by the time her snack was prepared, there was a good possibility she would either refuse it or throw it on the floor. A similar behavior might occur at the dinner table. Instead of simply finishing her meal and exiting the table, she might throw her plate on the floor, and her cup would go flying across the room.

Occasionally, Joy would go to the refrigerator and after opening it up, she would just look around inside. She wouldn't select anything and she wouldn't voluntarily close the door. We tried to be caring and diplomatic about these behaviors, but eventually we decided that the visual trips into the refrigerator needed to come to an end. Sometimes correcting this was pleasant enough and sometimes it wasn't. Ignoring the behavior didn't seem to work, at all.

When Lee wasn't there for moral support, I sometimes had difficulty coping with these and other behavioral incidents. There was no rhyme or reason for her to refuse her food, let alone throw it away. Compassion for seizure activity comes easily for me, but understanding and coping with exacerbated behaviors presses compassion to a higher level. I couldn't understand them and occasionally would simply break down in front of Joy and cry. It wasn't an act on my part, and her predictable response wasn't put on, either. When Joy observed my sadness, she would sense my emotions, immediately calm down, and mellow out. She knew she had gotten to me, but more so, she was truly sorry. She knew I was hurting and whatever frustration had been building up in her before, dissipated. She was keenly tuned into emotions expressed through vocal intonation as well as physical posturing.

When Joy was attending the Children's Institute-Day School program there were only minor reports of any compliance problems at school. Most behavioral dysfunction occurred at home. We requested and were granted access to behavioral counseling through a Wraparound program with the county. Our caseworker was cordial and knowledgeable. She was able to help us curtail a few of the undesirable behaviors, but overall not a lot improved.

For one thing, appointments were mainly during daytime business hours. Most of Joy's undesirable behaviors happened in the evening so were not observed by our caseworker at all. We managed to arrange one visit in which the caseworker came at 8:00 PM and listened outside of Joy's bedroom door. Joy fell asleep in her chair that night and there was no evening follow up visit. I considered the caseworker's presence in our home to be mostly moral support and parental education; but again, successes were marginal.

It was easier for Lee and me to believe that Joy's behavior problems were hers alone, but wait a minute—she was doing fine at school. We had to ask, “So what was different?” For one thing, we were there, the parents. But to say it was our fault was too simplistic.

One of Joy’s main sources of pleasure was, and still is, other people. She loves to interact with others and simply observe activities around her. Joy is by nature a loving individual. School and outings in general were enjoyed. Joy had less activity or visual stimulation at home, and she was generally bored.

Psychologists often say conflicts between individuals are not one-sided and I believe that was the case with us. We were just around too much for our budding teenager and she was letting us know about it.

You have probably heard the old adage, “When you think nothing can get any worse, it does!” Well, it did!

One day Joy made a new decision. It was that she would no longer take her medication. What is a parent to do? She never could share her feelings or clarify her reasoning verbally; rather, she communicated these through her body language. And that communication was very clear.

The medication was already disguised to taste as good as we could possibly make it, that hadn’t changed. Really, nothing had changed except Joy’s thinking. She stopped swallowing her medication and began choking or spitting it out during each administration time. She knew that meds were coming, once in the morning and once in the evening, and there was no fooling her.

We love our daughter very much and couldn’t simply give in and allow her to go through drug withdrawal and the possibility of increased epileptic activity. So what was our solution? Without causing physical harm, we would have her lie down on her bed with her head on a pillow, and one of us would straddle her torso, pinning her arms against her side with our legs. That wasn't an easy position to hold for an unspecified period of time while not applying any weight on her stomach.

Then we would administer the medication orally with the use of a syringe, with water only sweetened with corn syrup, and we would steady her head and wait for her to swallow. It might take a short few seconds or many minutes; sometimes Joy would spit it out and we would need to start the process over again. It was an emotionally draining experience for all.

It may sound like bizarre behavior on our part and in some circles might be viewed as abusive. But had you been present I believe any concerns you might have would be satisfied. Although difficult, the atmosphere remained loving. Appropriate hugs and kisses were dispensed after each time.

The emotions at medication time certainly didn't mellow; they got worse. They got so bad that we reached a breaking point. We couldn't do this any more. And the trauma wasn't just relegated to administering meds. It concerned her eating, too. Joy was able to eat and drink but her consumption was very small. Techniques weren't working so I talked to Lee about the possibility of getting Joy a Gastrostomy tube, or G-tube as it's commonly referred to.

Lee quickly agreed we should try and made an appointment to obtain an evaluation from a gastroenterologist. As always, it took weeks until the actual appointment day arrived. Each day that passed was emotional torture. It was tough on everyone, but it was interesting to note that before and after the medication warfare, Joy was fine. There were no hard feelings.

At our doctor's appointment we explained what Joy and the family were going through. She immediately approved the placement of the G-tube and I naively thought we would go directly from the doctor's office to a clinic for the procedure. Wrong again; there was yet another waiting period! We were hanging off the edge of a cliff with a tiny little rope and once again we had to grip harder and not let go.

It was another two or three weeks before the G-tube procedure date finally arrived. Every day had been a challenge. When I would reach the end of each day I would place my head on my pillow and thank God for all of His help. I could finally rest. I would close my eyes and sleep but not before dialoging with God as to why all this was happening and wondering what was to come. Thankfully, I never lost my faith. Along with Lee, James, and Joy, my faith kept me going.

On the day of the procedure to insert the G-tube we arrived at Children's Hospital and checked in. The doctor scheduled an anesthesia in which the patient remained awake. That struck me as an interesting scenario right away. They weren't equipped in the out-patient department to put a patient totally under. Lee and I gave each other a knowing glance.

The doctor was to implant a standard G-tube into Joy. The device consisted of two rubber flanges with about a twelve-inch plastic tube which extended out of the body. The implantation required a two-step process. The first step was to feed the plastic tube and flange through the oral cavity and down through the esophagus and into the stomach. The second step was to make a hole in the skin and then on through the stomach wall.

After locating the tube in the stomach via the new incisions, it is pulled through both holes and out of the body. Once the tube is extracted through the hole, it's pulled taut so that the stomach lining is up against the outer skin wall. A smaller flange on the outside of the body helps keep everything in place. The tube is clamped off with a movable clip.

My opinion is that because Joy is on so much medication she doesn't get as sleepy as others might from anesthesia. It would be scary for anyone to be awake during this type of procedure and Joy wasn't giving in easily. She fought it. After several attempts the doctor came out once to inform us they had given Joy the highest dose of anesthesia they could safely give her, and that they would try to complete the procedure one more time. He said that if they failed, we would need to schedule a regular operating room for the procedure. Well, they were successful. We were able to go in and comfort Joy from the trauma she was feeling.

The doctor went over the instructions for tube usage and care, and then gave us a script with instructions for a twenty-four hour feeding program. While we knew Joy was way under weight, the doctor hadn't mentioned putting Joy on a feeding program. We mentioned to the doctor we were fine about implementing the feeding, but because of Joy's cognitive level we felt having her carry around a feeding pump all day wasn't going to work well. The doctor was understanding and adjusted the script to a higher flow rate, to be administered on a night schedule while she slept.

We brought Joy home along with a hospital I.V. pole, a pump, and cases of a food supplement. She was to receive four cans of the supplement each night for an unspecified length of time. Lee is a nurse so she was very familiar with the equipment, but it took me a little time to get used to it. Whenever Lee would work a second shift, I was on my own and learned to work through any unanticipated surprises. However, the main use of the tube, for us, was for administering Joy's medication and that was an immediate success.

The struggles were gone, and Joy was very accepting of the tube and didn't try to pull it out or even play with it. Along with the medication, we were also able to give her additional fluids to assist with bowel movements and, of course, the food supplement. The tube extended about twelve inches out of her body and we needed to tuck it under her shirt for privacy.

The I.V. pump was fairly easy to set up. The food supplement would be poured into a plastic bag which was hung on the pole. A long plastic tube would be woven through a directional path along the exterior of the pump, and it was attached to the end of Joy's G-tube. Both tubes were primed with liquid to eliminate any air, and the pump was turned on.

Joy is a quiet sleeper but occasionally she would turn a certain way and pinch off the tube. When this happened the pump would start beeping with a soft but high pitched noise. Joy wouldn't wake up from the beeping noise. I have some hearing problems so I started getting paranoid about whether the pump was actually running or not during the night.

Each time I woke up I felt compelled to get up and walk down the hall to check on the pump's operational status. It didn't matter how tired I was feeling. If I hadn't got up, I would have felt worse if I didn't check. Mind you, this feeding program occurred after we carried Joy to bed. She still wasn't doing this on her own. This is one of many of the multi-tasking experiences we had become programmed for.

We were thankful for the success of the G-tube. After several months of night feeding, Joy began to gain some weight. She was about five feet, four or five inches tall and only about eighty-nine pounds when she first received the feeding tube. After a time span of about seven months, Joy's appetite started to kick in, and we started reducing the amount of food formula we gave her. Around the ninth month she began eating a normal amount of food for the first time in her life. A few months later we discontinued the food administration procedure.

I can't express the great joy we felt seeing her eat a normal portion of food. For the first thirteen years of her life she had eaten like a little bird and drank even less. Now, though we were able to discontinue the food supplement, we continued giving the fluids and the other items previously mentioned. After a year and a half Joy was a healthy 120 pounds. She looked and felt better than she ever had.

I should relate that through this process there was no regular dialogue with the doctor. We made the decisions to adjust the amount of food to be given, by carefully monitoring Joy's progress. It certainly helped that Lee is a nurse, but as parents we mainly needed to apply common sense and implement any changes with a conservative approach.

The G-tube was getting a lot of use and the wear was showing. The end of the tube would stretch out of shape, and we would snip it off with a pair of scissors. This process was needed to avoid any leaks. In time, the end of the tube was getting pretty short. The doctor told us it needed replacing. The replacement device would be what is called a Mickey Button.

Instead of the rubber flange and tube, the Mickey Button was a device which is inserted from the outside of the body. It has a small inflatable balloon which once inserted is filled with a sterile solution. It is the inflated balloon which holds the stomach wall up against the outer skin membrane and the Mickey Button in place.

The day came in which Joy was to receive her first Mickey Button. We once again ventured to Children's Hospital. We got all checked in and when it came time for the procedure, the doctor began to explain that the original flange and tube were going to be removed in a reverse procedure from that used to implant them.

I reasoned, “Oh, slow down a moment! Joy barely made it through the first procedure and they were going to pull the flange back up through her esophagus while she was still awake? Wasn’t there any other way to accomplish this replacement?” Even if we ignored the fact that the esophagus could be damaged, it would be very sore, as would her throat.

After dialoging back and forth, it was decided the doctor would simply cut the G-tube as short as possible and push it into the stomach. The new Mickey Button would be inserted through the opening, the little balloon inflated, and the procedure would be complete. The worst case scenario would occur if the flange got stuck in the bowels. In that case, surgery would be required to remove it.

We talked about the likelihood of that actually occurring. The doctor thought most likely the rubber flange would pass through the bowels in a few days. That was a much better plan, simple and easy. We decided to go with it. All Joy’s stools needed to be carefully checked until the flange was found. Eventually, it was. Joy had no discomfort. The new device was easier to work with and less visible under her clothing.

The only inconvenience was that the Mickey Button would fail after about five months because the stomach acid would eat away at the balloon. Once the balloon would break, the button would fall out. The first few times this happened we needed to take Joy into the E.R. to have the new one inserted. Well, that nearly always took three to five hours, including travel time and lots of waiting. The actual replacement took three to five minutes after the doctor on duty finished reading the instructions on the box which came with the new button. That routine got old in a hurry.

We made an appointment with her doctor and sat down with him to receive training so we could do the procedure ourselves. The training consisted of reading the instructions in the presence of the doctor and signing a statement. This new method saved Joy and us a lot of time, and she would have the replacement in the comfort of her own bed in a matter of a few minutes. I have done the procedure alone on several occasions and have had no problems. For one thing, there is no blood, only the possibility of some stomach contents leaking.

The G-tube was and still is a tremendous blessing, but it didn't solve all our problems. There were still plenty of behavior problems which made every day stressful. Our caseworker asked us one day if we might be ready for Joy to live outside of the family home, and we agreed it would be a good idea. Mind you, it wasn't our preferred choice to have our daughter live outside of the home. Joy was only fifteen years old. We had very little hands on help in the home and were emotionally stressed nearly to capacity.

We realized any placement takes a long time for approval, so we were ready to begin. The caseworker brought up the topic because she heard there was an opening for a young female through an organization called The Verland Foundation, Inc. We wanted to know more.

We learned that Verland has a main campus. It consists of ten single story homes, all handicapped equipped, an office building, and an activity center which houses a gym, nurses' station, therapy pool, physical therapy center, and eight class rooms. There are also a number of off-site homes which house two or three individuals each. The facility is licensed for 94 individuals. Each of the ten homes has four bedrooms.

It was Mid-August of 2002 when we initiated our housing request. We knew Verland had only one opening. We were realistic about our chances for not being accepted since this was our first attempt we reasoned there would be a waiting list. In September we visited Verland for the first time and were interviewed by an entire team from their staff.

The team consisted of a social worker, house supervisor, nurse, and representatives from their physical therapy, aquatic therapy, and equestrian therapy departments. Their aim was to see how Joy would fit into their program with the individuals with whom she might be placed. The opening they were filling was for Mid-December. After the interview, we were given a complete tour of the campus.

Whether it was right or wrong for us to be overly excited about Joy's possible acceptance at Verland, we were. When we left Verland on the interview day we couldn't stop thinking about it. It appeared to be the perfect living arrangement for Joy and the home was only thirty minutes away from our house. The activity level in a house with nine individuals and staff was very similar to her environment at school, which was a positive experience.

We waited with hope for the outcome to be announced, and in October it came. Joy was the applicant accepted for the opening. We were so elated! We felt that after her move we could put the stress behind us and pursue a healthier parent-child relationship.

Joy was invited back to Verland for a series of evaluations by each of the therapy departments. They began to set up behavior plans and developmental goals. Each house was set up with a street address number, just like any other community, and her house was number 309. Even numbered houses were on one side of the street and odd on the other. Joy likes numbers, so the house soon became known as simply '3-0-9.'

Staffing in the houses was setup in three shifts; 6:00 AM to 2:30 PM, 2:00 PM to 10:30 PM, and 10:00 PM to 6:30 AM. Staff size was based on a client-staff ratio of about three or four to one during the day and two staff members on third shift. On the third shift the individuals were sleeping most of the time and the staff was required to remain awake and check each individual every fifteen minutes. Each individual would also be cleaned and changed as needed to keep their skin healthy. If an individual was exhibiting an extreme behavior problem or an extreme health concern, staffing on first and second shifts would be made available on a ratio of one-on-one. The campus housing was only available for severe disabilities.

Our original assessment of Verland was right on the money. Joy loved living at Verland from the get-go. She loved the hustle and bustle going on around her, and had very few behavior problems. Boredom was no longer an issue. We were able to see her two or three times a week on average.

It was a wonderful transition for Joy and us. We were able to work toward improving our parent-child relationship and move the caregiving to the professionals. The timing couldn't have been better because our son, James, was then entering high school, and we were able to give him more of our support for those important years.

There will always be the days which bring unexpected surprises and challenges, but after Joy was accepted at Verland our lives calmed down a good deal. This ended seven years of intense day-to-day activities that had taken their toll on all the members of our family.

Will You Wait

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Silent I am waiting, watching for the sky to clear.
Looks like nothing's changing here,
Sorrows never fading;
Forcing me to face my fears,
From a distance I can hear…

Will you wait for Me?
Will you wait for Me to come?
Will you wait for Me?
I promise I will come.
Will you wait for Me?
Like the rising of the sun
Trusting faithfully,
I promise I will come.

Even as the wind moves, something's stirring deep within.
I can feel You moving too,
Although I can't see You;
I know You will see me through,
I still hear You asking me…

Father, You know I need You.
You can hear me crying out;
I'm giving all that's left away.

I will wait for You.
I will wait for You to come.

I will wait for You.
I know that You will come.
I will wait for You.
Like the rising of the sun
Lord, I’m trusting You;
You promised You will come.

Journal Entry

How do you deal with difficult behaviors in someone else and in yourself? Does patience come easily to you or is it a struggle? Where and how do you think more patience may be obtained?

Journal Entry

Chapter Seven
Life Moves On

The poor behavior we experienced at home during the three years following Joy's surgery was harder for me to deal with than the epilepsy was. I found it easier to connect a medical condition like epilepsy to a diagnosis of Lissencephaly than to connect it to a behavioral dysfunction. After all, behavior problems can occur in any child-parent relationship. I felt we were kind and caring parents, and that the behaviors we saw were uncalled for and unexplainable.

Now, as I look back on them, I realize that behavior was Joy's main form of communication. Although I don't know how I could have responded differently than I did to diminish unwanted behaviors, I let the situation control me instead of my controlling the situation. I know now that listening needs to extend beyond the capacity of our ears.

I also know regardless of the degree of conflict we were dealing with, Joy's move towards independence was a timely event. Although I don't consider Lee or myself in the *old* category, we would have had to think about her future without us eventually. We needed separation from Joy as much as she needed it from us. But it didn't mean we were emotionally disengaged from her at all.

We had attended one Lissencephaly conference by that time and were learning more about this genetic disorder. Our ability to step back a little and monitor Joy's health issues allowed us to better prioritize her needs. We stayed in very close contact with her. Along with multiple weekly visits to Verland, we regularly picked her up on Saturdays to either go on an outing or bring her home with us to share a meal. Our relationship improved a great deal.

James was quickly growing up and it was wonderful to spend more time with him, as well. At the end of 2004, I turned fifty-five and made a decision to take an early retirement from my job where I was working at the airport ticket counter. Many of the airlines had taken massive cutbacks in the wake of the attacks on the World Trade Center buildings in New York and the Pentagon in Washington, D. C. on September 11, 2001. These attacks only damaged further the financial picture for an already struggling airline industry. I was back to working second shift with weekdays off and I felt with over ten years of employment ahead of me, I would select a new career and move on with my life.

Lee was supportive of my choice and moved to a fulltime position at the hospital. This gave me time to decide on the career I would enjoy and one that might also return me to a salary level comparable to the level I had earned with the airline. I must admit that for a male it was a new experience to get up in the morning and not go to work, but I never sat around to watch TV. I started researching job fields, picked up more of the duties around the house, and enjoyed spending more time with the entire family.

Joy had lived at Verland for two years by then and we knew the staff and the activities at Verland very well. The healthcare industry can have a rather high turnover rate of staff for a number of reasons. As my retirement moved into its fourth month, I learned that Verland was going through one of its cyclical low staffing periods. I knew I didn't want to be a permanent caregiver, but I did have a perfect background for it and some extra time on my hands. I also knew if the staffing at Verland was low, then the staffing in Joy's house was low and I couldn't just stay at home each day on my research project and do nothing to help out.

I contacted Verland's employment office and made an appointment to see their recruiter. After the introductions, I explained that I was interested in part time and short term employment to help them out while still retaining a portion of my week to continue my career search. They were interested and hired me for a three day position, pending the results of normal background checks which were required.

The training class began on a Monday and was scheduled for eighty hours. It was two weeks of in-depth training on a variety of topics including agency rules and regulations, emergency first aid and procedures, Cardiopulmonary resuscitation (CPR), client rights, the Health Insurance Portability and Accountability Act (HIPAA), how to fill out a multitude of the reporting forms required by state and federal offices, and the list goes on. We had eight people in the new hire class and, as the days progressed, several people quit on the spot and walked out.

Being a caregiver isn't for everyone! It requires a combination of both professional and personal skills. It isn't what one might think of as "easy money." There is a great deal of responsibility in caring for those with severe special needs.

After two weeks, four of us remained. Outside of a campus tour and one observation session, the entire two weeks of training was in the classroom and then it was time to start work and meet the clients.

It was late spring. After breakfast Joy was bused to her normal school. I began my shift by saying "Good morning!" to Joy in house 309 and giving her a kiss before I went down to the gym for check-in. It was interesting being a client's father and an employee. I worked first shift, from 6:00 AM to 2:30 PM, and each shift began with a group briefing. After the group briefing it was off to my assigned house for the day.

Like Joy, the other clients were waking up at that time. Most of their skill levels were low. Even though I had cared for our daughter from her birth, it took something different inside of me to clean up the bottom of an adult male, dress him, lift him into a wheelchair, and do the required morning health care. Not everyone enjoyed having their teeth brushed or even their face washed. And for a while I was the new face in the house.

Joy's house was the only one designated for children and young adults. The other nine houses were for adults and, unless they moved, this was their permanent home. I knew due to conflict of interest I wouldn't be scheduled into Joy's house. I kept reminding myself that by helping out in the other houses I was helping 309 as well.

With the morning personal care completed, everyone was gathered together in the dining room. A few individuals were able to feed themselves, but many were not. I enjoyed feeding those that needed assistance and learned quickly that I had better keep my eyes peeled for those individuals who enjoyed eating more than their own portion. They may be seriously disabled, but they can be fast.

For all the individuals over the age of twenty-one, there was a day program set up in the classrooms on campus. So, after breakfast, we escorted everyone to their classroom in the Adult Training Facility. The houses compose a community and the fresh air is great for them spring, summer, fall, or winter. Those who are ambulatory walked and everyone else were pushed in wheelchairs.

The classes are set up by skill level. For some individuals their goals might include tasks like being able to accept an object, like a ball, from the teacher; hold it for a while; and then hand or throw it to another individual. Some will have lesson plans which include auditory input and sensory input, like being touched by objects and smelling different aromas. Those individuals who were able to complete tasks were in a different classroom filled with a creative variety of puzzles and small work related projects designed to increase their hand and eye coordination skills.

Everyone ate lunch in the Adult Training Facility dining hall and then, after more classroom time, returned to their homes at 2:00 PM. This period of time between 2:00 PM and 2:30 PM was also the change of shift for the staff. I enjoyed working in the classrooms. As the spring moved into summer, Joy's normal school ended, and she, too, had a day program on our campus. Then I was able to take my lunch up to 309 and we would both sit outside on her patio to eat and talk and enjoy the warm summer breeze.

I was amazed at the abilities of each individual on campus. Although each one was severely cognitively and physically challenged, they were fully aware of who they were and where they were. Some relationships were clearly closer and friendlier than others and each made their personal desires known by the subtlest physical movements. Each sound uttered or eye movement was considered as a form of communication.

Looking into their eyes was like looking into our daughter's eyes. These special individuals represented a cross-section of American families who have, at some point, been through similar situations that our family had faced. Each one was so special I found myself wondering about their family members: How are they doing? Were they able to visit their loved one? Were they even still living?

Focusing on the individual as a whole person with challenges, instead of anyone less than a whole person, made my job easier. It seemed to come naturally at this point in my life and I am thankful for that. I wouldn't want anyone to look at our daughter in any other way.

While working at Verland, I decided to go into the field of accounting. I have always enjoyed math, and learned that college classes would be starting soon. So after three months on the job, Verland's staffing was at a better level once again and I gave my two week notice to terminate employment. Through Joy I had met some extraordinary people I probably wouldn't have otherwise known.

Life can throw us some wild and crazy pitches, can't it? But it is wonderful to know we aren't alone. It is wonderful to know we can help one another. Support is available to anyone who will simply ask for it. I'll talk more about this later.

Make Me This Way

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The way You guard my soul
I'm never alone.
I'm on this narrow road;
You're leading me home.
The vision of this child I've become, reflecting all the work
You've done.

But Lord I am broken
By the things I question.
Who am I that I should understand?
Your secrets are shown to those who fear You;
Belong to those who love You
And call upon Your name.

Your glory is seen by those who trust You;
And known to those who seek You
And hunger for Your word.
Make me this way.

Shattered by this world
You heard my cry.
You brought me from the dark
And into the light;
The way You humble me, makes me see the nothingness
inside of me.

But Lord I am broken
By the things I question.
Who am I that I should understand?
Your secrets are shown to those who fear You;
Belong to those who love You
And call upon Your name.

Your glory is seen by those who trust You;
And known to those who seek You
And hunger for Your word.
Make me this way.

Make me this way, Father;
To be holy is my desire.
Make me this way!

Journal Entry

How resilient are you at rolling with the punches? How much do you desire to think outside of the box? How flexible are you? Are you comfortable with the predictable and do you guide other family members likewise? What happens when the unexpected happens?

Journal Entry

Chapter Eight
What Is Lissencephaly?

At this point in the journal, I am going to digress from the time line and talk about what we have learned about Lissencephaly. The first time we had ever heard the word *Lissencephaly* was in 1999, from Joy's neurologist after Joy had received her MRI. Joy was twelve and a half years old and had gone through four grueling years of epilepsy.

The doctor had shared some information with us concerning a family support group in Fort Wayne, Indiana, and a research program being conducted then at the University of Chicago. I was very interested in learning all I could about these organizations and the new diagnosis; however, we needed to deal with Joy's seizures, first.

After Joy's brain surgery in February of 2000, daily life was calmer for a while, and I started doing some research on Lissencephaly. My first source for information was the Internet where I found articles on Lissencephaly. I also located the family support group in Fort Wayne, Indiana.

I called and spoke with the organization's founder who is also a parent of a Lissencephaly child. She sent us information on their biannual conference which was to be held in July of 2001 in Fort Wayne, Indiana, and provided information on a number of families we might wish to contact.

I learned quickly that we weren't alone in our struggles. There were too many families experiencing similar yet unique situations. I heard of one young lady about Joy's age whose experiences seemed to parallel Joy's. However, instead of the drop seizures, she had mostly grand mal seizures. My perspective was growing faster than I could imagine and reality was closing in. I still didn't know what to make of all this information.

It was clear to me after a while that many parents' goal was to simply care for and love their special needs child for as long as they were able. I knew our chances of meeting any of these folks were slim unless we took a lengthy trip.

I say a prayer for these families now whenever they come to my mind. Many years have gone by and I feel that some of these children may be in Heaven by now. I don't know—it's just a feeling. I also feel that without Joy's brain surgery, she, too, might be in Heaven. Her seizures escalated so rapidly in only four years; I can't imagine what they could have been like in fifteen years. I just think her body would have been unable to cope with all that stress.

I made arrangements to attend the Lissencephaly Conference for July of 2001 and was looking forward to it. Prior to the conference, which was scheduled for a Friday, Saturday, and Sunday, they gave us the option to schedule Joy for an appointment to see Dr. Dobyns, who headed up the program on Thursday, and we made that arrangement as well. Dr. Dobyns heads up a major research program which specializes in brain disorders. I was expecting the doctor's visit to be a 30 or 40 minute event at best, but I couldn't have been more wrong.

The reason for the conference, as it turned out, was twofold. There was education and support for the families, but the participants were also to become part of the research data group which was being studied at the University of Chicago. We were most pleased to be participating.

The doctor's visit was an eye-opening experience, loaded with information about our daughter's diagnosis and its uniqueness. In addition to meeting with Dr. Dobyns we also met with an international team of specialists who worked with him on the research project.

It was interesting that the team met Joy at this particular time in her life. She had already come through four years of seizure activity and had undergone the Corpus Callosotomy Surgery. The doctors weren't eye witnesses to her drop seizures, so all they had to go on was my ability to verbalize her history.

As the interview proceeded, we talked about all the difficulties Joy was facing, such as gross and fine motor skill problems, chewing problems, speech delays, problems with bodily functions, epilepsy, and scoliosis. Each time we would move from one topic to the next, Dr. Dobyns would bring in a specialist from his team on that subject. We spoke with a geneticist, a skeletal expert, and several neurologists. We came to a point in the discussion in which I mentioned that Joy wore orthotics, noting she seemed to have extra-long big toes and long thumbs. In fact, the right thumb acts more like a finger than a thumb because there is no evidence of a thumb pad.

At that point we turned our attention downward and removed Joy's shoes and socks, to examine her feet. It was explained that a condition of long thumbs and long big toes is also a genetic anomaly, noting it was even rarer that an individual with Lissencephaly should have a second anomaly. If I recall the conversation correctly, this second anomaly may have had a connection to a possible problem with an internal organ later in life. I decided I would need to research this item more.

Blood samples were drawn to genetically confirm the conditions which were physically observed. After all was said and done it turned out that the appointment had lasted over three hours. Joy's gene sample was also added into the research study gene pool.

I was so pleased we had made the effort to travel to Fort Wayne, Indiana and the conference hadn't even started yet. Half the day had already passed so we ate lunch, went for a walk through downtown Fort Wayne, and swam in the hotel pool before dinner.

The next morning the conference began with a general meeting in the main conference hall. My eyes roamed back and forth across the auditorium. It's hard for me to describe what I saw because we had only been around our daughter for all these years. Here was a whole room full of Lissencephaly children, a total of about eighty-seven families. Joy seemed to be the oldest and the highest functioning individual there. This revelation really took me by surprise and I kept looking around in disbelief.

Each child was in a wheelchair, most had a G-tube, and a good number of the children had respirators and needed their oral cavities cleared out occasionally by a suction device. What is this Lissencephaly? I had heard the doctor say at one point in Joy's pre-conference examination that her case was on the mild side. Although there is nothing mild about it, viewing others in that room gave me a better understanding of his remarks.

During the ensuing sessions, I learned there are six levels or grades of Lissencephaly. Levels one through three are the most severe and would most likely result in a shortened life expectancy of only ten to twenty years if the child leaves the hospital at all after delivery. Levels four through six are milder and don't necessarily affect life expectancy.

Joy is in level six which is also the rarest of the six categories. There are approximately 150 females and only 50 males who have been identified in level six across the world. My numbers may not be accurate by the time this book is printed due to new advances in MRI technology.

Level three is the most common one. I would take a guess that more than fifty percent of the individuals with Lissencephaly at the conference were in levels one through three. This means that they might all have a short life expectancy. Within level six, Joy's level, there are ranges from mild to severe that include the categories of gross and fine motor skills as well as delayed cognitive skills and epilepsy.

In theory it is possible for an individual with even a mild cognitive disability to be an undiagnosed Lissencephaly child. However, the child would most likely have many if not all of the other delays that Joy has. If the child wasn't experiencing epilepsy, there would need to be some other just cause to order an MRI scan. Only the MRI revealed Joy's true diagnosis. She was an undiagnosed Lissencephaly child for nearly thirteen years. Emotionally, it did help to know why we were experiencing all of these difficulties, but our day-to-day reality remained unchanged.

When Joy's doctor detected the extra band of gray matter in her brain, this discovery placed Joy in level six. According to Dr. Renzo Guerrini, who is a member of Dr. Dobyns' team and practices at the University of Florence in Florence, Italy, normally gray matter is found on the exterior part of the brain, just inside the skull. The Subcortical-Band Hederotopia (SBH) indicates there is an additional band of this gray matter passing beneath the cortex but separated from it. The presence of this additional gray matter disrupts the brain's ability to act and react to its surroundings (it lengthens processing time), and the thickness of the gray matter indicates the severity of the seizure activity to be anticipated. Dr. Dobyns indicated after viewing Joy's MRI that her band was quite thick.

The main diagnosis for Lissencephaly is found in the condition of the brain's outer surface. The term *Lissencephaly* means 'smooth brain' as I mentioned earlier. It was a little hard for me to contemplate this term. However, this explanation helped me. If you were to locate a picture of a normal brain you would see that the surface is full of peaks and valleys caused by the folds which occur around it. It's on these peaks and valleys that all the neurotransmitters are found which send and receive messages to and from the brain to the entire body.

When the brain surface is smoother, there are fewer places for the nerve endings to attach. A reduction of neural cell connections and of neurotransmitters will result in a lower ability of the brain to properly communicate and thus control its own body and the environment. The volume of communication is diminished. For level six individuals, it is my understanding the outer brain surface is minimally affected and the thickness of the SBH band becomes the main issue.

The cause of this brain malformation is a genetic change in one of Joy's X chromosomes. Because a female has two X chromosomes, the effects of the one mutated chromosome may be masked, or mellow out the severity of the condition. For this reason it is even possible for the mutation to be recessive. Therefore it may be a good idea for a mother to have the genetic testing to see if she is a carrier. The testing may be costly, but it is vital if the mother of a Lissencephaly child plans to have more children.

For males and the X/Y-chromosome makeup, the mutation of the X chromosome will always be a dominant trait. Because a male has only one X chromosome, the male will be affected more severely than a female carrying the same mutation. A male with Lissencephaly won't unknowingly pass a mutated gene on, because he won't be fathering children, unless he is mildly affected. For that matter, even a female Lissencephaly child, as a known carrier, will most likely not birth a child of her own if she is severely affected enough to experience reproductive disadvantage.

A carrier will most likely pass a mutated gene on to multiple male offspring, and there might be a fifty-fifty chance of passing a mutated gene along to a female. The study of genetics lays out the propensity of an individual genetic combination actually occurring. These are the facts as I understand them, and I encourage you to talk with your doctor about questions you have as well as new research being conducted.

Joy is considered to be a genius within the general diagnosis of Lissencephaly. This new information broadened our understanding. It helped us to realize the behavior issues we were experiencing were, indeed, a blessing in disguise!

I saw so many children who literally were unable to move their own bodies or even express a behavior. We didn't need to look any further to find someone who was having a harder time than we were, even though we didn't have the energy to pursue such thoughts.

All the sessions during the conference were conducted by specialists from the research team. Each session began with a core lecture from the speaker and was focused on educating the parents on every aspect of their child's medical needs. The speakers also went beyond a straight medical agenda and encouraged the parents not to sit back and simply let their local medical community totally run the show; rather, to become involved and act as an advocate for their child.

Lissencephaly is very rare. Most doctors don't know about the unique responses a Lissencephaly child may have to a traditional treatment approach, so it is important that caregivers get involved.

After opening presentations, a question and answer format followed which lasted for half of the sessions' scheduled time and sometimes even went overtime. There were a lot of questions. It was a great format and much appreciated by the parents. How many lectures have you attended in which the audience might be able to ask one or two questions before time is up? The parents addressed topics which affected the majority of the audience, and the speakers gave very direct and sometimes sobering responses.

During one session the neurologist focused on medications and pointed out that, according to their research, there was no indication a Lissencephaly client will benefit from any more than two different types of anti-seizure medications at any one time. He further explained that when more than two medications are used it becomes nearly impossible to determine what side effect comes from what drug. If additional seizure control is desired, it might be a better choice to eliminate one of the medications and start a new medication in its place.

The use of only two medications is a practice which isn't universally followed in the general medical community. And it should be noted that seizure medication recommendations will always be unique to each individual. There are, however, general guidelines from which the medical community draws its knowledge. Don't feel intimidated to enter into the dialogue process and express your general knowledge as well. Your participation will help to fine tune your child's treatment program. As I have mentioned earlier in the book, always work closely with your own doctors and always do your homework to obtain supporting information. It may be located online or in current periodicals. Try to learn all you can from as many sources as you can.

I remember in one session the dialogue moved in the direction of "family health." The question from the speaker to the audience was, "How often do you and your spouse go out for your own time together?" The overwhelming response was "never" or "rarely." The speaker couldn't believe the response was so universal and asked an almost rhetorical question, "Why?" In almost all cases the parents didn't feel comfortable leaving their child in the care of someone else.

This feeling came from two reasons. One was the feeling that no one within their circle was medically qualified. This statement is true in most situations but most of the parents themselves have no medical background, either. Just the fact that each parent had become a caregiver for their special needs child had placed them into a unique learning environment. They had been placed into a situation which exemplifies loveinduced learning at its best. No one else they knew had the same necessary depth of experience with a Lissencephaly child to care for them in the parents' absence.

The second reason was that the parents didn't want to submit someone else to the responsibility and stress levels which caring for their child would evoke. I can totally relate to that general feeling in the seminar hall. Caring for a Lissencephaly child is similar to a 24/7 job in an I.C.U. unit in an urban hospital. There was a period of several years when we didn't go out alone, as husband and wife.

Every session was exciting to attend and it was interesting to meet and talk with the other parents. Sometimes the communication with these acquaintances was limited to each bi-annual conference. There were also individuals who would exchange telephone numbers and start up lifelong friendships.

Entire families attend the conferences together and the Lissencephaly children are cared for and entertained by a large group of volunteers. Any capable and willing sibling was also invited to be a volunteer, if they wished to be involved in this way. This made it possible for the parents to really relax and benefit from each of the sessions.

The 2001 Lissencephaly Conference was more beneficial to our overall understanding of Lissencephaly than I could have imagined. I'm so thankful we were able to attend. The conference organizers try to set the conference up in different cities every two years in an attempt to make it easier for certain families to attend. The 2003 conference was held in

New York City, and to my disappointment, circumstances prevented us from attending that year. However, we were back again in 2005.

The conference in 2005 was once again in Fort Wayne, Indiana. It is traditionally held during the summer months. That year the conference dates were July 15th through the 17th, and Joy's personal appointment was on July 14th. Unlike the first conference, I wrote down some extensive notes about what I learned from this second conference after we returned home. Here is a condensed version of those notes.

Joy was seen again by Dr. William Dobyns who heads up the Lissencephaly research program, now located at the University of Washington in Seattle, WA and by Dr. Guerrini, a neurologist formally from Children's Hospital in London, U.K., now residing in Florence, Italy. We reviewed Joy's medical history and the fact that she was seen by both Dr. Dobyns and Dr. Guerrini in 2001. The six levels of Lissencephaly were once again reviewed by both doctors.

Dr. Guerrini gave us some helpful insights concerning Joy's seizure activity. We learned that within the family of Lissencephaly, seizures are very hard to manage. The drop attack seizures Joy had initially endured are particularly difficult to control. Medication seemingly had no noticeable impact on Joy's drop seizures at all. However, it was noted the medication did eliminate the grand mal seizures she experienced.

It is the research team's belief that originally, when the drop seizures were unchecked, Joy's epilepsy was acting as an epileptic encephalopathy, a condition in which seizures cause cognitive deterioration by themselves. I had felt this was the case and was thankful they brought up the topic. For me it was a confirmation that my observation wasn't fantasy. Regarding her current and future seizure outlook, because of the successful full Corpus Callosotomy in 2000, Joy's seizures were no longer to be considered an epileptic encephalopathy. The slate was cleared, and seizure control should be viewed as possible, and pursued. Parents, you can learn to trust your instincts, but be sure to back them up with as much information as possible.

As of 2011, the Lissencephaly research team was studying about 6,300 cases which included all different forms of severe developmental brain disorders. The general group included clients with Microcephaly and Polymicrogyria. However, the team is preferentially sent cases involving Lissencephaly and these cases total in number approximately twelve-hundred to date (known living worldwide cases). Within this group are the two hundred cases with SBH, in Joy's level six.

Along with the earlier reported issue involving the number of effective drugs the research team had recommended for general usage, they also reported that Phenobarbital shouldn't be used in individuals over two years of age and, if used after age two, then only for a very short period of time. For example, the drug might be used to control a strong cluster of seizures. Studies have shown that long term usage causes long term reduction in cognitive levels, even after Phenobarbital is removed.

The references for the studies on Phenobarbital which Dr. Guerrini based the previous comments are as follows:

- Farwell, J. R., Lee, Y. J., Hirtz, D. G., et al. "Phenobarbital for Febrile Seizures—Effects on Intelligence and on Seizure Recurrence". *New England Journal of Medicine.* 1990; 322: 364–69.

- Sulzbacher, S., Farwell, J. R., Temkin, N., et al. "Late Cognitive Effects of Early Treatment with Phenobarbital". *Clinical Pediatr*ics. 1999; 38: 387-94.

They urged all parents in this group to strongly consider eliminating Phenobarbital as a treatment drug. The team pointed out that drowsiness, a common side effect of Phenobarbital use, may cause more seizures in children with Lissencephaly. In their opinion, Phenobarbital was a cheap and effective drug, but had little place in any developed country. I know this is a very controversial topic. Please remember the researchers are mainly focused on this group of individuals. Always work with your doctor.

The team also encouraged parents not to be afraid to change medications to improve seizure control. As long as the changes are done very slowly, the parents were encouraged to at least try. If an attempt of three or four weeks or months isn't yielding the desired results, they recommended trying it more slowly over six to eight months.

An extension of time may be needed if one hasn't been able to achieve seizure control. Also some anti-seizure drugs may act similarly to antibiotics. In these cases the body may develop tolerance and therefore another drug may be needed. I can't stress enough to always work under the direction of your physician.

The use of an Electroencephalogram (EEG) with regard to drug selection and dosage levels was also encouraged. For individuals with uncontrolled seizure activity, it was their recommendation that there should be two EEG's per year (up to age twenty), and one per year (after age twenty) until the seizures are under control. The use of an EEG provides information for the type of medication or combination of medications to be used, as well as dosages needed for best results based on the affected brain areas. EEG during sleep, even a short nap, is much more informative than EEG while awake only.

Practicing physicians don't use EEG's in this frequency or as a current diagnostic tool from my personal observation. Even today, physicians normally use the EEG as a documentation tool. And we aren't using this technique for Joy, although I would certainly like to. I'm sure there may be a number of predetermining factors including funding and available equipment. You might ask your doctors what they think about this approach.

Dr. Guerrini stated he would be very willing to review an EEG as a consultant for medication therapy. I offered this option to one of Joy's neurologists, and unfortunately he wanted nothing to do with the research team. I don't understand that type of closed or closeted mentality. The suggestion of consulting someone outside of his circle seemed to be offensive. It wasn't meant to be.

Dr. Guerrini felt if Joy was able to be removed from Phenobarbital that she may have a good response from a combination of Zonegran and Trileptal (dosages to be adjusted also on the basis of the new EEG data), based on the seizure type she was then experiencing. I could sense the compassion the research team was giving the families they talked to and they never rushed to be somewhere else. The team was exactly where they wanted to be.

At the closing ceremony a DVD was played. It was produced and dedicated to the memory of the children that had passed away since the last conference, two years prior. It celebrated their lives and the love they had brought into the world. I know there wasn't a dry eye in the house.

I feel my notes from the 2005 conference sum up not only my experiences from the conference, but are also a contributing factor to why I am writing this journal. My eyes were opened far beyond our family experience, and I know so much more can be accomplished to help the medically needy of our country and the world.

We need to shift our attention away from the unnecessary and focus our attention on the necessary. Helping others is fulfilling. It's fulfilling because it's right. We can't lose our compassion for a lack of empathy towards those who are innocently born with a disabling condition.

A Common Destiny

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There's a place for us we know
Where all pain and sorrows cease;
A place where tears will never flow;
A home that's filled with joy and peace…

Soon we'll see Jesus,
And when He sees us,
We will be like Him
And our eyes will finally see.
We have God's guarantee,
For all eternity,
To be with Christ,
Is our common destiny!

No troubled heart that we must face
For He said believe in Me;
A home beyond all time and space;
We have a common destiny.

We have a promise sure and true
Of a life that never ends;
And when our time on earth is through;
That's when our life really begins.

Soon we'll see Jesus,
And when He sees us,
We will be like Him

And our eyes will finally see.
We have God's guarantee,
For all eternity,
To be with Christ
Is our common destiny!

Journal Entry

How important is it for you to know all the answers to life's questions? Why? Can you rest without knowing? If you knew the answers would it be easier to reach out to others who didn't know? How easy is it for you to reach out to others with the knowledge you do have? Why or why not? Do you look at yourself as a giver or a taker?

Robert Glenn

Journal Entry

Chapter Nine
Advocacy and Choices

As parents, we will always support and protect our children no matter what age they are and no matter what their health condition is. Being a parent is continual from the moment our first child is conceived. It is a privilege, an honor, and a blessing of life to bear and raise children. In most cases, our children will one day reach the level of total financial independence and go out on their own. Levels of interaction concerning many of life's choices will understandably vary between parents and children when the kids reach adulthood.

When children have special needs, the primary parental responsibilities may not change a lot. Interaction and basic protection will remain vital. As parents advance in age, ensuing issues become apparent. Questions arise: "What will happen to our child when we are no longer here?" "Who will care for him financially and emotionally?" "How do I even start to think about and make such arrangements for the future?"

Choices will always be the topic of the day. A sense of urgency and the reality of choices stand right in front of you. Often there is little or no time to reflect before reality presents itself. This brings me to a new story which was reported on a national news program in April of 2009.

While we were then twenty-five years into our journey, this report revealed another family who was just beginning theirs. The story involved two infants recently born at a Canadian hospital. One child then two months old had a brain condition which didn't allow him to breathe on his own. In a three minute news segment, they didn't attempt to discuss a diagnosis, but the child might be a Lissencephaly child. The actual diagnosis isn't really needed here.

The second infant was one month old and was perfectly normal except that he had a bad heart. Both children were at high risk of not surviving. The parents of the older child were approached by the medical staff to inquire about their feelings of donating their child's heart to save the other child's life. The parents hadn't then made a decision and I haven't seen a follow up story.

It's a parent's worst nightmare, and my thoughts and prayers go out for them all. The report concluded with this scenario: If the heart was to be donated, the child's respirator would need to be turned off. He would need to pass away and in doing so the added stress on the heart may be too much for the organ to actually be an acceptable donation for the other child. Both might lose their lives, anyway. Both might live, as well, through circumstances yet to be revealed. The final results were in God's hands. The point: choices are right there in front of all of us. Seeking knowledge and wisdom are vital.

Some choices are difficult. Sometimes the available information we have may seem insufficient. Multiple medical opinions are helpful, but at times unavailable, as well. With Lissencephaly, this seems to be the case! There is really little we know about the cause of this genetic anomaly. We don't have answers to questions like these: "Why do genes mutate after many healthy generations?" "Why will Lissencephaly affect only some siblings?"

There are families who have had more than one child diagnosed with Lissencephaly, but normally the malady affects only one child. I personally know one family who has nine children of both sexes and only one male child has Lissencephaly. I have met another family which has four male children and all of them have Lissencephaly. The research team studying this anomaly is considering cases like this, asking, "Why?" and searching for answers.

Then there's the issue of those individuals who live with this disability. We know even less about the cognitive reality of this condition. We have only observed our child for twenty-five years and, from our observation, we know her performance level is below that of a five year old child. Yet we ask, "What does she truly understand about the world around her?"

Joy has always had the ability to hear, so she has received input concerning issues such as family structure, emotional expressions like happiness and sadness, so she has a good one-way exposure to societal issues through language. We take Joy with us to church as often as we can and I know she is aware of everything that happens in the service.

Usually we sit near the back of the auditorium, just in case we need to leave early. The pastor is never within close visual range and yet whenever Joy hears a word for which she can sign, she will normally sign the word for us. A word example would be *cross*. Joy will sign the word *cross* with her pointer fingers. Another word example would be *joy*; when Joy hears her name, she will point at herself. I must admit her cognitive reasoning is low, but she is intentionally listening. There is an old saying, “Garbage In, Garbage Out.” Well, I like to think of this experience as, “Truth In, Truth Out.” Joy is hearing God’s truth and hopefully it will influence her decision making process.

Sight also has had a great input on her learning curve. There is a wonderful innocence in the situations which bring her laughter, as well as predictable attention. Joy loves to see waving flags, red and green stop and go lights, stop signs, and animals of all kinds, including animated characters, such as Winnie the Pooh. She is drawn to anyone who is wearing a name tag and colors are also a big excitement for her.

If you are wearing an item of clothing which is the same color as something she is wearing, Joy will be quick to point it out. We continually emphasize to Joy that it's okay for her to point, but not to touch name tags and colors. It can get a little embarrassing at times, if you know what I mean. Joy does love matching colors.

Although Lissencephaly is a severe condition, I sometimes have a tendency to simplify it to a communication deficiency. For one thing, it is easier to explain to a new acquaintance when there's not a lot of time to go into a more lengthy discussion. It is an extreme deficiency, however, that goes far beyond normal skill levels of verbal and body language communication.

With this anomaly, the brain receives sight signals, auditory information, as well as messages from the nervous system, such as comfort and pain messages. However, the brain has a very difficult time in organizing the information and then responding to the messages it receives.

One example I mentioned before is toilet training. I'm convinced after spending over twenty years trying to toilet train Joy that she probably feels an uncomfortable pressure from her bladder. However, the brain doesn't consistently return a message through the nervous system to engage the proper muscles to constrict, and thus release the urine from the bladder. Eventually the pressure becomes so great the urine is expelled anyway. Rarely does this occur on the toilet, but occasionally there is success.

I briefly mentioned talking as well, but I can go into more detail here. First of all, very few Lissencephaly children are able to speak. We are blessed Joy is one with this ability. Her vocabulary was close to one hundred words prior to the epilepsy and she was able to read simple sentences. Joy lost most of her reading skills through a convoluted mixture of medications, current seizure activity, and brain surgery. She is able to read single words from an assortment of commonly used signage.

After fifteen years of epilepsy, I'm not sure if she will even approach her prior level of vocabulary again. I don't know.

In one of Joy's most recent speech evaluations, her therapist logged a number of objectives which have been on the table for years. Here are two of them:

***Objective 1**: Joy will use signs and words without prompting, to request, gain attention, and notify staff when she has to go to the bathroom.*

Progress: Joy has begun to spontaneously use words to comment, request, and draw attention to herself. She imitated 15 words which the therapist modeled. She spontaneously named four pictures. She is able to articulate one syllable words with fairly good accuracy, following an immediate model. She always claps her hands and shouts when saying a word and there is normally a pause of a few seconds before she imitates a word. (Notice the reference to a time delay, which is Joy's need to process the information her brain has received.)

Plan: Continue this objective until the skill is consistent and then the goal may be updated.

***Objective 2**: Joy will swallow her saliva consistently and independently, or with prompting from an aid.*

Progress: Joy has been managing her saliva independently, but will swallow when needed with moderate models and prompts.

Plan: Continue the goal.

It is interesting the therapist mentioned Joy's saliva control because that was a big issue when she was younger. Joy had the uncanny ability to hold saliva in her mouth for up to forty minutes or so without swallowing or choking. She might even resolve a forty minute hold by swallowing and not even gag. Her teachers would comment from time to time that Joy was talking great and then just stopped. We would suggest they check to see if she was pooling saliva. This issue hasn't totally been resolved. It comes and goes based on Joy's overall health condition on any given day.

Joy has been referred to as a *selective mute* for many years and I feel this term again is an over simplification, yet it conveys reality. Her brain can't sustain the level of conversation which other young girls are so accustomed to, so it isn't a matter of choice. With regard to the vocabulary she does have, I think Joy is generally a shy person and waits for the right time to talk.

If you were to meet Joy, it might be several months before she would say a word to you. If you were seeing her in a group setting, it could be even longer. She has never interrupted a conversation in her life. Even if you ask her to say your name, there will be a lengthy pause before the response if one comes at all.

In 2007 we moved from one state to another in order to be closer to our extended family. Lee's parents were experiencing failing health by then and we wanted to be close at hand. Certainly we wouldn't have left Joy behind, although she loved her group home dearly. The move upset her so much that she didn't speak to us for at least eight months. Joy was upset, confused and mad that she wasn't returning to her group home.

We talked about the move on many occasions before the actual event, but the reality of moving was probably still mixed up with the concept of a vacation. Finally Joy understood the concept and was getting used to a new schedule, so she started talking to us again. She was in her new day program for over a year before she said a word there.

When Joy lived at The Verland Foundation, she was very comfortable with all the activity there. Mind you, out of the nine individuals in her house, only Joy and one other person could talk. So when a worker came through the front door, there was no verbal competition in the house. Joy knew everyone's first name and would yell it out as soon as the person was identified and always with a big smile and lots of enthusiasm.

Speaking has always been encouraged and verbally rewarded. Joy has had speech therapy on and off since she was about thirteen months old. For awhile she was being trained to use an electronic device with pictures on a screen. The user is able to select a general category and, from the resulting picture display, press a communication button. The devise then responds by speaking the request or comment on the user's behalf.

After a few years of training, use of the devise was shelved because Joy was simply pushing buttons to hear the machine talk and not really using it for communication purposes. She is still able to pronounce a few words and points a lot to get her feelings across, like indicating menu selections in a restaurant. Joy also knows some basic sign language.

One more example of her brain's lower communication level with her own body would be an illustration involving the lungs. Individuals in Lissencephaly levels one through three may have difficulties breathing normally. It is my understanding that the brain isn't sending consistent messages of operation to the lungs, instructing them to inhale and exhale at regular intervals. To correct this communication imbalance, respirators are used.

Joy certainly doesn't need a respirator; she breathes with enough strength to be able to raise her voice quite loudly when she wants to. Still there is a question of control; Joy is unable to control the amount of air flow in and out of her lungs. For example, she can't blow out a birthday candle. She tries after observing us, but that is a skill beyond her body's ability. She is also unable to whisper, so her vocal levels are loud and louder.

I'd like to share an analogy to compare perception with reality. Consider a brand new post-graduate medical student at any university of your choice. This student registers for a full load of classes and attends all classes on a regular basis. However, he doesn't speak in any class, take any tests, or write any papers. He simply attends all the classes, makes visual observations, and listens to everything that is said.

What do you think the professors would think about this student, about his potential and his ability to absorb the detailed material they are presenting? Do you think it would matter if the student's under-graduate GPA was 4.0? Would they even question whether or not any learning was taking place at all? This is a serious student who is actually concentrating intently with his visual and auditory senses. He just hasn't been evaluated by his professors.

What would you think about this student? Must learning actually be validated to be called *learning*, or might learning be evaluated through some other unconventional means? Apply a similar thought process to the experience of an undergrad student, high school, elementary, or preschool age student. Is learning only realized if it matches up to socially accepted standards? Or is learning simply a prerequisite to life? Whether it's clearly measurable or not, learning simply is. Isn't it?

I have seen many Lissencephaly families. I have witnessed the love and devotion within their family units. To a casual observer it may appear there is very little quality in the life of a Lissencephaly child, but I know this isn't true. These children are capable of taking in the world around them and evaluating what it means for them. They are capable of internally asking, "Is the environment safe for me? Is it comfortable? Is it happy or sad? Is it hot or cold? Am I loved?" The list can go on and on.

The brain receives all sorts of input from its surroundings through the auditory and visual senses. However, with Lissencephaly it has a tremendous problem in acknowledging what it knows to observers. The issues are basic, but they are real. Our daughter is considered to be a mild Lissencephaly child, so the feedback we receive from her is more than other families may experience. But I am convinced the more you get to know one of these special children, the more you will grow to love and understand them.

I need to return, for a moment, to the issue of advocacy. It is so important for parents to become totally informed advocates for their children. A medical history doesn't necessarily tell a complete story.

To use ourselves as the example: we have moved from one state to another, as our circumstances have altered our doctors have changed, others have retired, and still others have changed positions. Lee and I are the only constant source of Joy's history as eye witnesses. This factor is very important for parents to take into account. Even though memories can be very painful, remember them anyway. They are important! They connect the Lissencephaly child to the consistency they need.

As I review and remember Joy's history I know I wouldn't run all over the country interviewing doctors until I found one that will do my bidding exclusively. I know my own medical limitations—they are many. On the other hand, I would not ignore the gnawing feeling that every possible solution may not have been considered, for example in efforts to bring Joy's seizure activity under control.

As a father, I have watched seizure activity start from nothing and escalate uncontrollably, twice. In these situations medication had not worked. I am a pragmatic man and saw the pattern of seizure activity over the prior weeks, months, and years. I concluded that unless the seizures were somehow controlled, Joy's prognosis wouldn't be very good. Tracking any new seizures could indicate they might be degenerative once again. It's hard to tell because an escalation of seizures can occur at slower or undefined rates.

The one event in Joy's history that continues to haunt me is the aftermath of her brain surgery in 2000. We didn't have the presence of mind to ask our doctor why Joy couldn't be weaned off as much of her medication as possible. She was seizure free at that time and we were still medicating her.

Too much time has passed since then, and we have changed doctors several times. There is now no doctor who could be considered an eye witness to Joy's medical history. I have hope that Joy's brain surgery is still the totally successful surgery we witnessed and the seizures we have witnessed since then might be perpetrated by the medication. It's most likely an idea solely based on the hope of a father's love, but it still beats in my heart.

Joy is a completely unique medical case. She is one out of two-hundred individuals worldwide to hold her diagnosis. Who knows if anyone else has had a similar brain surgery? While I think highly of our medical community, I disagree with what appears to be the general perception that epilepsy is epilepsy and, "This is how we treat it." My worst nightmare is that Joy will live out the remainder of her life being medicated unnecessarily and suffer the consequences of taking unnecessary drugs.

As a pragmatist, and in light of all the medication changes we have already experienced, we consider, "What would it hurt to try to wean her off of her medications?" We reason we could wean her very slowly to an undetermined level and monitor the results. If at some point Joy's seizure activity was to worsen, we would stop the reduction and establish a new medication baseline. If, however, she simply began to experience seizure control, that would be the best result for her future quality of life.

We certainly wouldn't try any change in Joy's treatment without a doctor's approval, of course. I don't know what the future will bring and Joy's medical condition is certainly in God's hands. I do know as parents, however, we must do *our* homework in all areas of concern for the sake of our children. We must become and remain her advocate.

We have observed and been through many layers of the health-care system and I must say it has its pros and cons. There are many gifted specialists in the system to help our children. This knowledge empowers the advocate. Please don't feel intimidated to ask questions and to obtain second opinions. These are our children we are talking about. Ask away!

We have found that most of the care available is outside the family home. Doctor's appointments, therapies, and certainly surgeries are conducted at the appropriate professional locations. But what happens when you come home? Unless you are financially well off enough to afford private care, or you are in a hospice situation, there is little professional help available within the home.

We asked many questions in our attempts to obtain help. Respite care was often the only option we discovered. Respite care granted fifteen hours per month for us. This averages out to about thirty minutes a day. No one would consider coming to your house for thirty minutes even if you asked them to. The respite program is designed for three to four hour weekly increments so parents may be relieved for a period of time to go out of the home for a breather.

The health care system as we know it doesn't foster a one-on-one concept of care. I wish it would, because we would have much preferred to have our daughter continue to live in our home rather than move her to a care facility. If we could have arranged for six to eight hours of in home care each day, Joy could have easily remained with us for another ten years. The system falls short of being a family friendly provider in this crucial area.

Writing this journal has been an adventure. Just when I think I have touched on each topic, another one seems to appear. I have talked about being a medical advocate for your child, but I certainly can't leave out the important element of also being your child's legal advocate. Joy was under eighteen years old when she went to live outside of our family home and legally she remained in our guardianship. However, when she turned eighteen, she was, by law, legally responsible for herself.

We didn't pursue becoming her legal guardians because we didn't feel we needed to at that point in time. Each organization Joy has stayed with has always respected us as parents and has kept us totally in the loop. Guardianship, wills, and a trust for Joy were always items we knew needed to be handled, but money and time always reared their ugly heads.

We have bumped those items up to a higher priority. In 2009 Joy began receiving bills in her name and at her address from a major network provider. According to the provider, she had an account and owed a past due bill. Clearly, Joy doesn't have an account nor could she have conducted any business on her own. We believed we were looking at a case of fraud and possibly one of identity theft. I called the network provider, and they also have their legal rights. They wouldn't tell me anything concerning Joy's account, because it wasn't my account.

I respectfully informed them of Joy's condition and suggested to them that the account was fraudulent. I told them that if there was a form of payment listed in her name, it could also be identity theft. They tried to entrap me by asking, "Well, what is your user ID?" several times during the conversation, and refused to accept my answers. Finally they said I would receive an affidavit to complete and return. The document they sent me was to confirm the form of payment on Joy's account. Their legal protocol was nothing short of ridiculous. I realized I needed to come up with a plan.

I started by asking certain friends for their advice and quickly learned I should start by filing a police report and then pursue legal guardianship. I filed a report with the police department and, as it turned out, it was identity theft. Joy's name and address were being used with someone else's stolen credit card.

A friend who knows a fiduciary in our area asked the fiduciary for information concerning an appropriate legal firm to use. She replied by stating that besides using a number of qualified lawyers in the area, we could apply for guardianship directly through the county court system if money was an issue. Well, money was always an issue, so I took her suggestion.

I went down to the county court house on my lunch break and learned there are a number of legal matters which can be pursued by filing petitions directly with the court. I purchased a one inch thick packet of paperwork for $7.50, to petition for guardianship of an adult and ate my peanut butter sandwich before returning to work.

I made an appointment with a lawyer in the county's law library. This service was free of charge. He advised me to fill out certain sections of the packet I had purchased and then I filed them with the court. The filing fee was $146.00. If we were granted guardianship, I believed there would be no additional costs involved and we would need to submit an annual report to the court concerning Joy's care. If for any reason we weren't granted guardianship, then we would be responsible for some court costs.

The court assigned a hearing date and we made sure we arrived at the courthouse with a little time to spare. We were a little nervous, but we were confident of Joy's need for guardianship and no one would be contesting our petition. The hearing was short and we did not receive the desired outcome.

We were the first case called and moved forward to the microphone. The judge asked us why we hadn't engaged a lawyer and a court investigator to represent Joy. I proceeded to explain that the lawyer I had spoken to had said because we were Joy's birth parents some of the forms wouldn't pertain to our case. The judge respectfully replied that he didn't know of any exceptions to the law and asked us to comply. A new court hearing date was set for two months later and we were dismissed.

Well, this was another one of those "okay" moments where regrouping is required. So, we learned we had made a mistake. The lawyer had given us incorrect information. We were granted two months in order to comply with the judge. I called the fiduciary back and learned that she handled investigations for the court. She also made a few recommendations for a lawyer that might negotiate a flat fee vs. an hourly rate for our case. After one more phone call, we were again making some headway.

Within a three week period, Joy had met with her lawyer and us for what turned out to be a fifteen to twenty minute meeting. We also met with Joy's investigator for a similar length of time. They were both satisfied with Joy's need for guardianship and stated they would recommend to the court that we become her guardians. That was good. How much could that cost us? Well, first we needed to return to court.

The second hearing went smoothly with Joy's lawyer present. The hearing wasn't any more than twenty minutes and we were once again established as Joy's legal guardians.

The reality is bad people will prey on anyone. It was the identity theft issue which motivated us to pursue guardianship. Even though any legal action would involve time and effort, it was great to know there are options available to accomplish a needed and worthwhile goal.

With all of the bills in, the total cost was under $600.00. I know if I hadn't begun the process by filing the original petition with the court, the bill would have been higher. Here's my advice: begin to plan before your child reaches eighteen so that you will know what options are available to you in your area. As parents, our children must hold our highest attention and our deepest concerns. Remember, we are their advocates!

Deep emotions will penetrate any parent when undergoing similar situations involving special needs children. I find it impossible to express exactly what it feels like to go through what we have been through, but let me try.

Just for me to write, then read through this material, produces a full range of very personal and emotional responses that I can't bring myself to fully put into words. I will call them *deep hurts*. These hurts are strong and have the potential to damage a healthy personality. You won't probably ever forget the deep hurts, but it's good and necessary to confront them. The same emotions which might tear a person down also hold within them the same components which build character, strength, and endurance. Confront them! This is what I do every time I recall the events just related.

God hadn't chosen to heal Joy's seizures, but this doesn't mean He didn't answer other prayers. He answered many prayers on a daily basis: He gave us hope, courage, strength, peace, comfort, wisdom, endurance, and resolution to face the many daily challenges we had to confront.

I shed many tears during the most critical seven year period of this journey; so did my wife, Lee. I dare say we may have been on the brink of a nervous breakdown on several occasions. Hope, as well as faith, was all we had to get us through, one day at a time. Confront with the strength God gives you, and never give up hope.

Our lives have been filled with both love and sorrow; let me tell you this is a good thing. I wouldn't trade my life with anyone. Emotions may get mixed up and tumble about from time to time. For example, the pride and love we feel for our son, James. He has a very special spot in our hearts.

James has accomplished a lot and has grown into a wonderful young man. When I look at certain events like his high school graduation and the fact he will graduate college, I simply burst with joy. While I think about James and how proud I am of him, other thoughts creep in, such as remorse for Joy.

What would Joy be like today without her special needs? What would she be saying and doing with her life? It's like a brief mourning period which passes before me. You might think after twenty-five years I would be past thoughts like these, but these thoughts still come and go. I always need to remind myself to stay focused on the bigger picture. Emotions need to be managed or they may lead you down paths you don't want to traverse, ones that are hard to leave.

Each child is precious! Balancing time and emotions may be difficult as a parent strives to be available to each of their children, regardless of their needs. I have tried my best, but realize there were periods of time where I was barely holding myself together.

On a larger and more inclusive scale, as a nation we need to learn how to be better advocates for our families. Whether your current need is for a medical or legal issue, I feel one should not place their focus on government programs for all the answers. Such an approach will certainly disappoint. The government, in all its complexity, can't possibly hold the answers for all our individual situations. The gaps need to be filled in by *We the People*.

Neighborhood communities need to step in and look after their own. Currently we may not even know who our neighbors are, so we have a lot of work to do. Too often in America we become part of a unique culture that has opted out of community and chosen isolation. How has this happened?

One reason likely is a misunderstanding of original intent of the role faith plays in daily life and in government. We have taken the concept of separation of church and state far beyond its original intent. The concept in its purest form was to be used as an organizational and structural tool, to equally govern the population. To continually grow and strengthen our nation we must maximize the benefits of both of these entities—not place them in opposition to one another.

We are free to speak our minds and to take action to help our neighbors. Let's take the concept of a Neighborhood Watch program to the next level, to meet the broader needs of our communities. The day in which we must choose between church and state will be the day that democracy dies. Democracy thrives where faith and government intersect at the right junctions. Community involvement will be a key element in the strengthening of America.

"We do not know what we ought to pray, but the Spirit Himself intercedes for us with groans that words cannot express." The following lyric was inspired by this verse, Romans 8:26 (NASB).

Closer to You

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Find myself in a familiar place;
I can't seem to find the words to say.
I've searched my heart;
I've searched my mind;
So many things I realize.

You have never left me all alone;
Or turned Your back when I was far from home.
Your awesome peace it never dies;
It's all I need to remind me…that it's true…

Your mercies are always new;
And there's nothing I need to prove.
Lord, You promise to see me through
And You're leading me…closer to You.

When I'm facing this reality
Of broken promises and shattered dreams;
This world can never satisfy;
Your faithfulness reminds me…that it's true…

Your mercies are always new;
And there's nothing I need to prove.
Lord, You promise to see me through
And You're leading me…closer to You!

Journal Entry

Are the issues of advocacy and choices easy ones for you, or are they more overwhelming? If you're shy, certainly they may be overwhelming. You may find it hard to dialogue with professionals if you're not lingo savvy. Our children, however, are worth every effort we make. What might be some issues confronting you that you need to address with professionals who can help?

Robert Glenn

Journal Entry

Chapter Ten
Maximizing Relationships and the Role Change Must Play

Our lives are comprised of a variety of relationships. These range from casual acquaintances to closer ones, such as those of our spouse and children. It's vitally important to be cognitively aware of our time and emotional responsibilities for each relational level in our spectrums.

As we naturally age, we learn that responsibilities are different in marriage than when we were casually dating. Responsibilities are different when we have children of our own in contrast to briefly caring for the children of our friends or other family members. Sometimes this sense of responsibility doesn't naturally mature and one is faced with the decision to change, or face failure.

Questions need to be asked and conditions considered. These can include, "Am I the one who needs to change or is it my spouse?" "How could it be me? I feel good about what I'm doing." "It has to be my spouse or it has to be my children!" Well, guess what? You may be an authority figure in your home, but ultimately the only person you can change is you!

You can guide, nurture, or discipline others to modify behaviors, but the process has limitations. When it comes to your spouse, your spouse married you to be loved and understood, not to be changed. Each partner needs to thrive under close companionship and feel their spouse's encouragement and support. As to children, the children need a role model which mirrors unwavering love.

When I mentioned to a friend I was documenting this story, he suggested I include a section on how all of this has affected our marriage. I thought, "Absolutely, that's a great idea which hadn't initially crossed my mind. After all, I did pray for a wife and family, so I asked for all of this, right?" Well actually, I could never have imagined this journey even in my wildest dreams. Statistics show that over eighty percent of couples who have a disabled child won't remain together. That's a staggering statistic and it includes both secular and religious couples.

If one parent leaves the home, I can safely guess it's the husband who is most likely the one. Unable to cope, he leaves his wife to care for the family and carry on without him. This is not a very good record in our culture.

I think there are two factors which helped Lee and me work through all of our struggles. One is a cultural factor, in that both sets of our parents gave us a legacy and example to follow. Both sets of parents had their share of marital challenges through the years and both worked through their problems. They persevered due to the marriage commitments they had given each other many years before. That wasn't necessarily the example they inherited from their parents, however. Regardless, the legacy of how marriage is conducted has a profound impact on the children. Each generation has a profound impact on the next. Don't make the mistake of thinking the choices you make won't impact others.

The second factor for us is definitely one connected to our faith. When we gave our vows to each other, these made up a covenant which included God, our Heavenly Father. Instead of having only two people to work out a disagreement, we have three. There is always a tiebreaking vote. This has made all the difference in our relationship. We didn't always agree on what to do or how to manage the challenges that have come our way, but we remained respectful and loving towards each other and worked through the issues. I love my wife more today than when we were first married, and it's not because life is a bed of roses. We both had choices to make.

Lee won't necessarily like to see this next statement in print; however, it needs to be said. Lee is a phenomenal woman and mother. She exhibits a great amount of strength, stamina, and faith which has been an inspiration for years.

While statistics show more husbands than wives abandon their families when hard times come along, don't be fooled. It's never easy for women to cope in these circumstances, either. It seems easier to blame a spouse instead of looking for the good in them.

Recently I heard a story in a public forum and the speaker wasn't the author. I have no idea of the story's original source. But here it is: a man went to his doctor and through the ensuing exam mentioned that his wife was losing her hearing. He explained that she was a very stubborn person and wouldn't seek any help. The situation was very frustrating and the man asked his doctor for advice. The doctor replied, acknowledging the man's concern, and stated there was a very easy test which would disclose the severity of the problem, and shared the testing process with his patient.

The man thought the test would work fine and might provide the needed incentive for his wife to pursue the help she needed. His plan was to test her that very evening. So as the dinner hour approached, the man found his wife preparing dinner at the kitchen sink. He moved to the far side of the room and asked, "What's for dinner?" There was no reply. He then moved halfway across the room into closer range. Again, he asked, "What's for dinner?" and there still was no reply. Now he thought the problem was more severe than he thought. So he moved right behind his wife and asked again, "What's for dinner?" His wife replied by saying, "For the third time, chicken!"

Issues and reality aren't always what they first appear to be, are they? It isn't our job to change people. That's one of God's areas of expertise. We are to love and accept each other for who we are. That is a task for which we lack ability, though. How do we simply love someone exactly as they are? It's not easy, but there is guidance available. We need to diminish the importance of our own ego to accomplish the goal. The needed assistance is, again, in God's area of expertise.

There are a number of Bible verses which show what a husband and wife relationship should be, but I come back time and time again to 1 Corinthians, Chapter 13 (NLT): "If I could speak in any language in heaven or on earth but didn't love others, I would only be making meaningless noise like a loud gong or a clanging cymbal. If I had the gift of prophesy, and if I knew all the mysteries of the future and knew everything about everything, but didn't love others, what good would I be? And if I had the gift of faith so that I could speak to a mountain and make it move, without love I would be no good to anybody. If I gave everything I have to the poor and even sacrificed my body, I could boast about it: but if I didn't love others, I would be of no value whatsoever.

"Love is patient and kind. Love is not jealous or boastful or proud or rude. Love does not demand its own way. Love is not irritable, and it keeps no record of when it has been wronged. It is never glad about injustice but rejoices whenever the truth wins out. Love never gives up, never loses faith, is always hopeful, and endures through every circumstance. Love will last forever, but prophecy and speaking in unknown languages and special knowledge will all disappear.

"Now we know only a little, and even the gift of prophecy reveals little! But when the end comes, these special gifts will all disappear. It's like this: When I was a child, I spoke and thought and reasoned as a child does. But when I grew up, I put away childish things. Now we see things imperfectly as in a poor mirror, but then we will see everything with perfect clarity. All that I know now is partial and incomplete, but then I will know everything completely, just as God knows me now. There are three things that will endure—faith, hope, and love—and the greatest of these is love."

I can only say if you are a husband or wife who has left your family, you can do something about it. When someone is remarried, certainly any new vow must be honored. There is always hope for forgiveness, however. If you feel deep down in your heart that you have abandoned your obligation to your children, pray about the ways you may fulfill those obligations and make the situation right.

As far as our day-to-day family dynamics, I can't speak for Lee, James, or Joy. I could simply ask them, but instead I think that I will continue on here with my take on reality. Lee doesn't recall all the details of our journey exactly as I do and I'm fine with that. As husband and wife, we are one in many aspects of our relationship and yet, separate in other areas. We are unique creations.

As individuals we will never be perfect, so how can we believe our relationships can be perfect? We need to be aware that relationships constantly change and grow, just as individuals do. So let me step back for a moment from the family unit and talk about some of our other relationships.

Given that our families must hold our highest priority, we need to place our many other relationships into their appropriate place. One of those other relationships may include the desire to know a Lissencephaly child or any child with a severe disability. Adding in such a relationship may be easy; however, you still must be willing to invest your time.

It needn't be a large amount of time. You might start with a one hour prearranged visit and schedule those visits on a weekly or biweekly basis. Planning a visit is good for you and also helps to establish a higher level of comfort for the individual you'll be visiting. Just like anyone else, most of these children love to have visitors.

Giving your time is a rewarding experience for all involved. Psychologists and clergy alike would probably endorse giving, in general, as a positive component of a healthy lifestyle. Giving is most beneficial when nothing is expected in return. A wonderful by-product of this process is the good feeling that comes with the act of giving. Whether anticipated or not, the giver always gets something in return.

If you wish to go so far as to schedule a percentage of *giving time* so you're better able to balance your schedule, it isn't hard to do. The math is simple. Let's say you devote ten percent of your wake time to giving, approximately 1.6 hours a day, or 11.2 hours a week. It's not much time, but it is time well invested.

Giving is anything beyond yourself, beyond your own ego. It's sharing outside of what you do for you. Giving to your family can be included as part of giving time. Giving is active, it's doing; sitting in front of the TV in silence doesn't count.

After you take a good look at your time expenditures, you may find you aren't even giving ten percent of your time to your family. Fix that shortage, first. Each member of the family may be going in different directions after work or school, or on the weekends, and you may be well below 11.2 hours a week. Make it a priority to fix that time allocation problem. Then you might consider how your family can spend some giving time on other worthwhile causes in your community.

I try to be very careful about how I use my time. When I recognize there is something I wish to do strictly for myself, I try to plan the activity during times which wouldn't detract from time with my wife or children. For example, writing this book. I did the majority of my writing during my lunch hour at work. Sometimes I would get up early in the morning and write while my family members were still sleeping.

Writing a book is slow and steady work. From its inception the project has taken over three years. Writing time has to be budgeted because budgeting time is just as important as budgeting money. As with most tasks, little can be accomplished without allocating sufficient resources. Budgeting sets up priorities and lets everyone in the family know what to expect and when to expect it. Budget *giving time* through a well thought out plan and stick to the plan.

The principle of giving is certainly a great idea with regard to your finances, too. Because finances normally go towards providing for our families, the giving described here is targeted for outside of the family unit. It's a healthy choice to budget a percentage of your income to give to a non-profit organization, a worthy cause you admire and want to support.

Our family has been budgeting for over twenty-five years. And I can tell you, as scary as you might think it is in a tough economic environment for you to give more, we have never missed paying one of our normal bill obligations. Through the budgeting process, you go through resetting expenditures and prioritizing them into a healthier spending program.

Here are a few suggestions for your family to devise and start a giving experience. Every large metropolitan area has a Children's Hospital. This is a wonderful place to lend your financial support and to volunteer some time. Another local organization may be the Habitat for Humanity, the Salvation Army, or the Make-A-Wish Foundation. It's interesting to note that the Make-A-Wish Foundation doesn't only provide wishes for the terminally ill, but also for any qualifying child with a severe illness or condition. Local food banks provide great opportunities for almost any age level to participate. Your local church is always a great place to start giving. Check out the web sites for these and other charitable organizations.

Visiting Verland may be difficult unless you live in the southwestern part of Pennsylvania or the surrounding area; however, you can check out their web site, www.verland.org. There are a number of ways you can lend them a helping hand financially if you so desire. One way is to make a direct financial contribution and another is to use a web site for your online shopping, called Goodshop. Goodshop is an on-line shopping site which allows you to support many non-profit organizations. Before completing your shopping experience you have the opportunity to select from a long list of charities. Your selected organization will receive a donation generated from your purchase.

Verland is a not-for-profit organization which is near and dear to our hearts. They care for those with severe needs in the most loving, home like setting they're able to create. Each of the ten main campus homes has a chosen theme and is decorated in excellent taste. Paintings and coordinated wallpapers and furnishings reflect motifs from a casual nautical theme in one house to a more formal décor in another. I take my hat off to Verland for showing such a high level of sensitivity towards persons with intellectual and physical disabilities.

Unlike Verland's high standards, I have seen a number of group homes which are painted in flat colors with little else on the walls. Why should anyone feel that just because someone is disabled and functions at a challenging level they aren't able to recognize or enjoy their visual environment?

We love Verland. I dream of a time when campuses and individual homes such as theirs won't be unique; rather, available for individuals all over our country and the world. They strive to provide a family environment in a group situation as well as to maintain a stellar health care program. It's a great combination.

Actually, now that I think about it, you may not need to look any farther than your own neighborhood to find out how you can give, how you can help. Is there anyone out of work? Is there a single parent? Are there elderly folks who rarely come outdoors? Who are the people who compose your neighborhood? Maybe you could start by exploring those near you. I believe everyone has their own story to tell and needs that are unmet, regardless of what the needs are.

To complete my list, here are some additional non-profit organizations who are also high on our family's list of charities: the Lissencephaly Family Support Group in Fort Wayne, IN., an equestrian riding program for the disabled called Horses with H.E.A.R.T. (located in Arizona), and certainly the research program studying Lissencephaly, which is located at the University of Washington • Center on Human Development and Disability, under the direction of Dr. William Dobyns.

If you are interested in learning more about Lissencephaly, there is a growing amount of information on the internet. Just search for *Lissencephaly* and you will find pages of web sites on the subject. Many are sponsored by professional organizations from around the world that are involved with these special-needs families, and there are a growing number of web sites where the families are sharing their own stories.

Feelings are difficult to express in words and I'm certainly not qualified to psychoanalyze myself. I do know, however, some of the motivations and fundamentals behind my actions and feelings. Our experience isn't a unique one, but the cause, the disability that has perpetuated the experience, is unique. One emotion was a sense of loneliness and another of being lost, and, for their parts, these feelings helped strengthen my bond with Lee. Our emotions could have easily torn us apart, but the desire to love was stronger than any desire to leave, so my choice was clear.

My challenge and consequence was to try and understand how I was to cope with all that was unfolding. While the underlying strength and motivation to do this came from my faith in God, I still faced the reality that I had to do something. I was the one who needed to act, to react, to support, to love, and to care for my family. I was just an ordinary guy who had been placed into an extraordinary situation. Just an ordinary guy! If I can do it, you can do it, too. Trust me. No, don't trust me; trust God! I do.

So, how does my daily life work out? Well, for one thing, I believe that ego has a tremendous role to play in success or failure. The desire for self-gratification has to be willingly set aside for the good of all. The main word is *willingly*. I had to ask, "Could I set anything aside, things like golf, bowling, painting etc. and know that I was exactly where I needed and wanted to be?" For others, things to set aside may include health issues such as use of alcohol, drugs, smoking, or abuse. It may be hard to put yourself aside for the sake of another. However, after you do it once, it becomes easier.

Thankfully, it wasn't a hard choice for me to make, but it isn't easy to live out, either. I concluded that the family must come first. Working out that conclusion was mentally and physically exhausting. Watching the seemingly unending seizures occur day after day brought powerful feelings of helplessness and depression. I knew that in order to continue, I had to deal with these feelings on a daily basis or I wouldn't have had a chance of surviving the unknown lurking in our future.

My dad was a living example of devotion and commitment. He struggled with rheumatoid arthritis for over twenty years of his life. There was a period of time when it was quite difficult for him, especially when his ankles wouldn't support his body weight after a night's sleep. He would literally get out of bed and crawl into the bathroom to get moving in the morning. His knees and hands weren't in any better shape than his feet and ankles, either.

He worked as an outdoor laborer for our local utility company and went to work for many months in this condition, in any type of weather. It was painful and finally it did become too much for him. His family and his sense of responsibility were central to his purpose in life and he was shaken to the core with thoughts that he would no longer be able to provide for his family. Dad was forced to take medical disability when he was only in his middle fifties.

Little did he realize in all his pain that his financial worries were not to materialize. Through a combination of company and government allocations his monthly income was only reduced by a small amount. He was so thankful and I could see the relief in his eyes.

Each person must wrestle with the concept of ego and where their values as a person come from. Each one must ask, "How much will I guard and nurture ego and to what extent will I release it?" Discovering where ego fits is not all that easy within societal evolution where the value of the person keeps morphing.

Social and cultural atmospheres are changing at unprecedented rates. We see this in two ways. One is through simple observation and the printed word. Another is comparing family interaction today with a family's history of interaction yesterday.

I don't need to go back beyond my grandparents. They were born in the late 1890s and lived through World War I. Their children, my parents, were young adults during WWII. My generation and I are the baby boomers of WWII, and our children are now in their twenties. In only four generations, the social atmosphere evolved more than it had in thousands of years.

The single largest contributor to this metamorphosis, in my opinion, was the rapid growth of the media during the twentieth century. The Industrial Age fueled the technological explosion that brought financial wealth, but the media molded society's opinions and worldviews.

Yes, the media, with its collection of books, newspapers, movies, TV, and now a vast variety of electronic forms of communication including the internet. While I recognize greatness in the last century's achievements and applaud the media for its contributions, I am also painfully aware of the damage the media has caused.

I have watched the social thermometer move its morality standard to one many think is preferable today. Television sitcoms illustrate this move. Two of these shows come to mind. The first was developed in the early 1950's, and the second during the 1990's.

The first sitcom was based on the experiences of a family growing up in the post-Depression era. The main focus was the children's struggle to grow and form an understanding of self actualization as well as the learning processes which contributed toward their growth. In short, their process tapped into the wisdom and knowledge of the elder generations.

By the 1990's the representation of the family unit had changed dramatically. The theme of the second sitcom was the same as the first; however, the plot was completely changed. Here the youth were totally in control and worked through their growing process as independent individuals. In fact, the parents are portrayed as blooming idiots!

The underlying question permeating this second sitcom was this: "Why should any young person trust an older generation for anything?" There was a total turnaround from reliance on the family unit, shared feelings and ties, to one of the individual ego and self gratification.

In the early years of the media explosion, creative minds held to social and moral lines with a minimal amount of change, and still managed to create a variety of entertaining shows. But soon the line of demarcation between acceptance and desire was erased, and we witnessed the results: they were good and bad. It doesn't surprise me crime has increased, divorce has increased, and individuals have more identity issues than ever before.

Through media influence the ego has been elevated to an unprecedented level of importance; just as the concepts in which *old* is viewed as invalid, and *new* is viewed as good and true. These concepts are oxymoronic: they have no validity in establishing right or wrong.

Somewhere in the late 1960's or early 70's the state of California lowered the highway speed limit from 65 to 55 mph. On the designated date everyone was legally required to drive 10 mph slower. The change was instrumented to save fuel consumption and lower accident fatalities. It worked—drivers slowed down. Initially I was skeptical and thought the driving public wouldn't comply, but I was proven wrong. Within a short year or two, however, most drivers were regularly driving 10 mph over the posted speed limit and the state went back to 65 mph.

What does this say? The reasoning behind the lower speed limit law was totally accurate! If one drove slower, gas consumption was lower and vehicle braking time was improved, lowering the fatality count. However, the law didn't provide a satisfaction level for a driver's ego. Motorists reasoned, "Driving faster will get me to my destination faster so if I'm being safe, who cares about the other person." Am I right?

So it goes with a variety of other social issues. The *me-first* ego ideology has a self-sustaining fuel reserve which seems to withstand most attempts to turn off the key. Selfishness is not easily thwarted.

Society is a living faction; we must take an active role in its growth. We must not sit back to simply point a finger at society and do nothing. If we want to change people's minds to an *others-centered* focus, we must act.

Complacency regarding social issues and social changes is not healthy. If anyone reading this believes complacency is acceptable, they are missing my point. Being okay with an absence of change for the better fosters a life without hope for improvement. One needs to believe tomorrow can be better than today, and work toward making positive change happen.

As a parent, I feel that younger family members must be understood for their needs and wants, then these should be blended with the needs and wants of their parents. Sometimes, these priorities simply don't balance, so adjustments must be made. Remember: you are the adult and you are ultimately responsible for your family's success or failure in terms of the model of parenting you create.

We must strive to understand each relationship for the benefit of all. Differences abound. Parents of special needs children simply have less verbal interaction with their child and more emotional interaction. Understanding the uniqueness of any relationship requires different approaches.

Joy's story is not meant to be an "Oh-my-I-can't-believe-some-families-go- through-stuff-like-this" kind of story. It is meant to bring hope and encouragement, and to be a help for those who are in need.

We are well aware of the fact that our story is not over. We are also attuned to the fact that the clock is ticking. I only know of one person with Lissencephaly even rumored to be in his forties or fifties. We have faith and hope that Joy might be the oldest survivor some day. We pray that future research will improve the quality of life for all Lissencephaly children. I also look forward to Heaven where one day I anticipate Joy will be talking nonstop and sharing everything that is in her heart.

Disengage

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To what advantage is a man who gains the world?
He holds a smile but inside his heart is cold.
Here am I standing in the rain all alone;
Here I am waiting for the strength to let go.

So I lose myself and I close my eyes
'Til the world begins to fade;
'Cause this broken shell is half alive
And there's no one else to blame.
So I finally think it's time to disengage
And I'll never turn away.

Amidst the hesitation trying to look ahead;
Beyond this mass confusion Your face appears instead.
And just when my head is held up high I fall again;
That's when I'm reminded of Your love that has no end.

So I lose myself and I close my eyes
'Til the world begins to fade;
'Cause this broken shell is half alive
And there's no one else to blame.
So I finally think it's time to disengage
And I'll never turn away.

Go on; go on, “It’s time to break away,” I keep telling myself
Go on; go on, I can finally separate these strings that hold
me down;
I’m finally found!

Inspiration for the lyrics of “Disengage” came from scripture, Luke 9:23-26 (NASB). It’s the irony of the Christian life: the more you disengage from yourself, the more you find yourself. And the self you find in Christ surpasses all that the world has to offer because faith is others-centered, a concept which appears, at first, to be hard to understand.

Journal Entry

How are you spending your time? Is it consumed on yourself, or on others? How possible is *giving* your time for the benefit of someone else? Explore some new ideas and ways to share your time.

Journal Entry

Chapter Eleven

Caring, Seeking, Finding—Which One Is for You?

We all know humans are not perfect. Well, most of us know that! The realizations of the implications of this idea lead to two questions:

- "Can I do better?"
- "How can I do better and how can I change my old habits?"

The desire and struggle to alter habits may sound familiar. Changing the daily choices we make, the decisions we make, is the hardest thing we ever do. Changing behavior is also something which can't be accomplished with our own strength. You can't do it if you try only in isolation.

I don't have the answers to give you; I can only advise you to start looking for the answers. Sometimes it's good to use a direct approach and at other times the indirect approach. The direct approach might be professional counseling while the indirect approach may be as easy as recognizing your strengths and simply getting involved and interacting with others. The mere fact that one interacts often opens up a window to a world which was not been previously explored or even known to exist.

For those of you who may think you are all alone in your struggles, you aren't. Let our family story be one of many examples of families who are making it through tough times. Families similar to ours are around you in every state and in every city and town, if you look. You may not see us as often in upscale restaurants or at red carpet events, but then again, you might. More likely, however, we will be at the ball park, the super-market, the mall, or going to a therapy appointment. We could be anywhere, but look for us! We would like to meet you.

For those who have been blessed with good health, I encourage you to go out and make a difference in someone else's life. This is one powerful way you can change your focus.

Reach out to others. You will find that once you do, it isn't as hard as you might have thought. God often uses people as His hands and feet. Don't just think about it, do it. Take control of whatever may be holding you back and care for someone else with the strength and resources you've been given.

For Joy's caregivers: we ask you to take good care of her. Don't be overwhelmed by what you have just read; rather, be encouraged. What you have read is yesterday's story. Tomorrow's story is yet to be written and you have a great part to play in that writing!

Joy is generally a loving and happy young lady, and she will always be a very young lady. Toddlers have a huge amount of pent up enthusiasm which seems to explode at a moment's notice. A loud sound or a visual surprise will trigger a plethora of laughter and energy. Joy reacts in a similar manner. The key to maximizing both Joy's and your positive experiences is careful planning and insightful observations.

Just as I mentioned earlier about her ability to visually respond to her surroundings, Joy is also highly responsive to auditory input. Her hearing ability is normal. However, her perceptual intake is about that of a one to two year old child. Even though her understanding and related output are similar to that of a toddler, the emotional message being conveyed may also complicate her response.

If one speaks gruffly or in anger to a very young child, he may cry, no matter what the actual content of the message is. We have never made Joy cry, but if she senses an angry tone or hears a message which she doesn't like, she will become quiet. She emotionally shuts down. The point: rather than a verbal response to a negative stimulus, a behavioral response might be observed instead.

Loud group noises evoke responses similarly. To her, they aren't only loud, but may appear disorganized, chaotic, and difficult to follow. If you are trying to communicate with Joy or another like her in such an environment, it would be better to move away from the group or move the group away from you.

Caregivers must also remember how important time is. In

Joy's case, try to provide unlimited time for her to respond to a request. Don't rush her if you really would like a response. I have observed from time to time that someone says, "Let's go, let's go, let's go" and not get the response they wanted. When treated with respect, Joy will respond as most of us do, with respect.

Let's consider *respect*. It is a challenge even in a normal family for a parent to discern what to say and what not to say about their child, especially when the child is present in the room. Some parents go so far as to tell their friends all the bad stuff their child is doing right in front of the child. At least a normal child can say, "Hey, don't say that!' A nonverbal child has no defense, but can hear everything being said.

We go to many doctor appointments and have to address the question of why we are there. I find it hard to simply rattle off a list of issues to the doctor in front of Joy, but I must. If I don't think about what and how I am to share the needed information, it might send nothing but negative messages to her. Individuals with special needs in general are more sensitive than the norm. Loving and respecting them takes an additional effort, or does it? Shouldn't we treat everyone in like manner?

I belong to the school of thought which believes behavioral issues should never be handled with punishment. Rather, a variety of positive reinforcement and behavioral modification techniques are better used to achieve desirable long lasting results. These techniques are acquired skills, for me. They didn't come naturally.

I would never want to hear, "If you throw that one more time, you won't get any dessert after dinner." That just doesn't work. Have you ever heard a mother or father in a supermarket say, "I told you 'No' and if you don't stop crying *now*, we're leaving this instant!" Then, off they go to the end of the aisle and beyond while the child screams his head off. Dialogues such as this are full of idle, empty, and harmful words.

Undesired behaviors are the biggest challenge to control—whether a child has special needs or not. Especially with special needs, the good advice I can give is to remain focused and remain calm. Behavioral modification includes techniques such as redirecting an activity or changing the communication method you are using.

You might say something like, "Why don't we go over there and look at a book?" Or when one suggestion doesn't elicit any response, you might change the mood by saying, "Oh, I have a *fun* idea!" Some of Joy's poor behavior issues stem from boredom and she can't express her feelings verbally. It's a great idea to not only think of a poor behavior as a behavior, but as a means of communication.

Even though I don't believe in punishment, there are consequences for poor behaviors. If Joy throws food on the floor, then she should participate in cleaning it up. This will also be an activity you will need to help direct due to Joy's limits with gross and fine motor skills.

Example: Joy throws a bowl of cookies on the floor while sitting at the kitchen table. After acknowledging the fact she shouldn't throw objects and she will need to help clean them up, Joy will need assistance to sit on the floor. She won't be able to bend over to pick up the cookies. Then with some verbal queuing and pointing from you, Joy will pick up each cookie and place them back into the bowl. A "Good job, Joy!" is in order when the task is completed and that should be the end of the episode.

So, should Joy still receive her snack of cookies? I would say, yes. The past is past and she isn't to be punished. But don't give her the same bowl of cookies. Try something different. The bowl may have been too deep and with all the cookies collected at the bottom of the bowl, Joy may not be able to pinch one cookie at a time from the group.

Instead, place a small flat plate in front of her at the table with two or three pieces slightly separated. Now she will be able to pick each one up nicely. If she were to throw the plate too, then something else is going on and this isn't the time for a snack. It's time to move on.

Learn all you can about positive reinforcement and behavioral modification. These methods work! Your employer should be able to support and provide you with any information which is desired or needed.

What father doesn't want the very best for his children? We pray for Joy and James on a regular basis. Not from any aspect of sorrow for their human weaknesses, but out of joyful anticipation for the wonderful adults they are becoming. May they choose the right roads to travel and touch each person they meet in positive ways along their journeys! And we certainly pray they love their Creator above all.

We love our children very much! God willing, Joy will outlive us, and she is precious to us. To her caregivers: love her as your own and give her the very best of care. She is our Joy. Once you get to know her, you will learn that she truly lives up to her name. She is an Angel of Joy!

To Know You Love Me

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Who am I in this great big world
That You should notice me?
I've lived my life
So lonely;
Emptiness was all I knew.

Your eyes of grace searched all the world,
Then for Yourself chose me.
Now I'm Yours alone
And my concern is You;
Just You…

Just to know You love me;
To have eyes that now see
All the mercy and grace
Which Your love has outpoured.
Makes me love You so much;
I can still feel the touch;
Of Your hand on my life evermore…

Now I thank You and I praise You Lord,
Because You set me free.
From a shattered world
So empty;
You have filled my life with peace.

When I look at the sky;
Hear a baby’s first cry;
See the moon and the stars;
Which Your hands have ordained.
Watch the sun and the sea;
Mountains call out to me;
And hear flowers that whisper Your name.

Just to know You love me;
To have eyes that now see
All the mercy and grace.
Which Your love has outpoured.
Makes me love You so much;
I can still feel the touch;
Of Your hand on my life evermore…

Robert Glenn

Journal Entry

Caring? Seeking? Finding? Are you exploring the possibilities which may lay right in front of you? When you decide to begin to give, a new beginning may be only a phone call away! Continue on that thought pattern a little longer. Choices! Go ahead and make a difference in someone else's life!

Journal Entry

Chapter Twelve
Change Begins with Loving Yourself

If you're struggling, you're not alone. But struggling in isolation is not right. For me, even after all we have gone through I believe if I have feelings of inadequacy or loneliness, it's my own fault. We are the adults. As adults we can and should reach out for help; it can be found. My advice: where possible, and it usually is, reach down deep inside you and take action by faith alone. Find help!

Faith in God is our ultimate source of help and hope. It doesn't matter to Him whether we are a diamond or a lump of coal. God loves everyone. And God has given us the same capacity. The truth of relationship we have with God is revealed in whether or not the love we receive from Him is returned to its original source.

There is a need for man to balance his daily life. This balance comes from exercising faith. If you don't take an active role in the process, I can almost guarantee you will be less than satisfied with the result. Stepping out in faith may be hard to do for some folks, but it needs to be done. Faith is the belief in the unseen, and it is sad to realize intelligence may be a stumbling block for some people to experience faith.

Everyone has faith is whatever they believe is true. The physical world is the easiest to believe in; after all, we can see a cloud, a mountain, a tree, or a book. But the spiritual realm is another story. How do you believe in something you can't see?

There was a period of about two years, somewhere around Joy's second and third year of epilepsy, where I really struggled. I would say a prayer multiple times each day, asking God to totally heal Joy of her epilepsy, and each day would go by and she wasn't healed. I knew God was able, so I asked Him over and over for a little more than two years. Again, I reasoned and prayed, "Why should a little child suffer so much? You can do it, God. Fix it! Please!"

Well, I was pretty naive. I still don't know the answer to the compelling question of "Why?" but one day it simply sank into my brain and heart, that God's plan wasn't my plan. No matter, I knew that He *still* loved and cared for us. I don't recall the date this revelation hit me, but I do know it was before we had hit rock bottom. The result was an unexpected sense of peace.

There is a wonderful poem by Mary Stevenson from which I have drawn comfort. It is called "Footprints in the Sand."

Footprints in the Sand

One night I dreamed I was walking along the beach
with the Lord.
Many scenes from my life flashed across the sky.
In each scene I noticed footprints in the sand.
Sometimes there were two sets of footprints,
Other times there were one set of prints.

This bothered me because I noticed
That during the low periods of my life,
When I was suffering from
Anguish, sorrow or defeat,
I could see only one set of footprints.

So I said to the Lord,
'You promised me Lord,
That if I followed you,
You would walk with me always.
But I have noticed that during
The most trying periods of my life
There have only been one
Set of footprints in the sand.
Why, when I needed you most,
You have not been there for me?"

The Lord replied,
"The times when you have
Seen only one set of footprints in the sand,
is when I carried you."

Peace like this helped me better cope with each day. Certain situations don't require knowing. At points we simply don't need to have and hold all the answers to life's struggles. It's enough to know that our Creator is in control and He will share that which is needed and withhold that which isn't.

Many people hold a conviction that faith cannot co-exist with logic. But they are not antithetical. Everyone can recognize certain people as being good natured and others as being cruel. This basic understanding is the foundation of recognizing a good or evil spirited individual. When this connection is made it's easier to observe a manifestation of the spirit world in action.

It may be difficult for some to connect good events as responses from a spiritual Creator, but what about suppressive events? If you have ever been to an area where individuals practice Voodoo, you would know evil is real. You can feel and sense it around you.

Let's look at some facts for a moment. This book doesn't compose a thesis, so going into enormous amounts of detail might not be useful. You know by now I encourage you to do your homework. Valid documentation usually leads one to logical and believable understandings for most issues.

The Bible documents many stories of spiritual interaction with man in both the Old and New Testaments. Historic documents outside of the Bible do as well. Research on both religious and secular web sites will corroborate this. Research will also show to what degree Bible manuscripts can be trusted when compared to other manuscripts of antiquity.

The reader may wish to begin research by accessing these web sites, the first from Oxford University, and the second from Liberty University.

1. http://www.bodleian.ox.ac.uk/philosophy/collections/manuscripts
2. http://carm.org/manuscript-evidence

The bottom line is this: from one century to the next, history has revealed encounters in which spiritual events have shaped the courses of mankind. These references are only a few of many which clearly document the interaction of the spirit realm with human beings.

Good and evil are real. The spiritual realm is real. Heaven and Hell are real, just as real as a cloud, a mountain, a tree, or a book.

The libraries of the world are full of books written on religion, and I certainly don't wish to pass myself off as a scholar in this area, but I do have my beliefs on this subject. My belief is in one God, one Creator, the Trinity, in Jesus, and at some point in time, I would encourage you to obtain a copy of the Bible and read it.

One of the stumbling blocks for people new to the Bible may be when they attempt to read it from cover to cover as if it were a novel. Soon frustration and confusion can set in. I don't blame them. The Bible is thick and obviously not a diary or play; however, it is also not a novel. It is a collection of stories and should be viewed this way. Here are a few reading suggestions.

First of all, obtain a copy in a current translation which won't require you to deal with words or phrases written for another generation. If you have a copy which contains both the Old and New Testaments, I would suggest you begin in the New Testament and select any one of the first four books. Remember the Bible doesn't read like a novel. Further, don't worry if you are pronouncing the names correctly. Many of the names used during these early years are no longer used today.

The Bible is an inspired book; however, the ultimate goal of reading it isn't just to acquire head knowledge. The ultimate goal is to obtain heart knowledge, the unseen and eternal truth which changes you from the inside out. After reading each story, it would be good to think about what you have read and ask yourself "What have I just learned?"

In every culture humanity has passed down stories from generation to generation. These stories weren't merely entertainment for the younger generation, they were meant to be instructional, life changing, and life giving. They taught lessons from history, including its battles and victories that showed the differences between right and wrong. These stories were presented so that younger generations wouldn't make the same mistakes the older generations had made.

Jesus used stories for the same reason. Many of them are recorded for us in the New Testament. The stories used material based on common experiences of that day and time, to convey spiritual concepts for all time. Some of the listeners didn't understand the stories as Jesus told them, because at first the story endings may not have been what they were used to hearing, and they put no effort into thinking about why the story ended so differently. Others thought about the stories Jesus told them and understood the deeper meanings which were designed to reshape their understanding of their spiritual health and actions toward others. The stories redefined what a healthy relationship with the Creator was meant to be like as well as showed what a healthy relationship with fellowman was to be like.

The phrase *heart knowledge* is not new. Consider the heart: it's actually incapable of holding any knowledge, it's a pump. Yet, it's associated with our emotional health. We measure a full range of emotions, from love to depression, from the state of our *heart*. The heart is in fact a better symbol for our spiritual health than any other organ. This meaning has eternal implications which greatly outshine the cultural usage of the heart as merely an emotional thermometer.

Know that perfection is not the goal. Don't fall into a trap of working toward perfection in yourself or expecting it from others. We will never reach perfection. You will always see some degree of hypocrisy or weakness in others, and in yourself. But don't let those limits discourage you.

Hope is the belief that tomorrow will be better than today; that ultimately God's eternal promise will be manifested in our lives. Just as faith should be realized and exercised now, hope should also be manifest in our daily life. It acts like a catalyst. We all need hope that the situations in which we find ourselves will somehow improve, that we might receive comfort and support as we make our way through tough times. Try to live each day with hope.

Life's experiences change us, shape us, and grow us into different people. Throughout our journeys, each of us is free to make our own choices. Remember earlier I suggested you take some time to reflect on your circumstances and evaluate your support mechanisms? Please do. Help is available for anyone who is willing to go and look for it. You and I may need help daily. You and I may need support which will never leave our sides, especially when we think we can't go on any more. Please don't ignore the spirit within you that says, "Go get help."

Take another look at faith. God is real—He isn't just a theological idea locked in the pages of a book. We weren't made to be alone. If we only feed our physical needs and starve our spiritual needs, how will we meet all the needs of our loved ones? If you struggle with the general cruelties of life, I would have you take a new look in the mirror. Stand there for a while and consider the nature of your spiritual health. You might not have a lot of information to draw from presently, but that doesn't matter. Try it anyway. God longs to have a personal relationship with you! When you sense that you are not complete, it's another sign that says, "Go get help, from God."

I'd like to quote for you now a part of the Christmas lyrics to the song, "How Many Kings" written by Marc Martel and Jason Germain from the group, **downhere**, to help illustrate my point:

Follow the star to a place unexpected
Would you believe after all we've projected?
A child in a manger lonely and small,
The weakest of all, unlikely hero
Wrapped in his mother's shawl, just a child,
Is this who we've waited for?

Cause how many kings step down from their thrones?
How many lords have abandoned their homes?
How many greats have become the least for me?

And how many gods have poured out their hearts
To romance a world that is torn all apart?
And how many fathers gave up their sons for me?

Only One did that, for me.

Faith works. It's the only thing that does. I encourage you to explore your spiritual side and, in doing so, I believe everything else in your life will make more sense.

The devil would easily instill the thought you're a failure because the goals you've planned haven't been actualized. He would say, "You are hopeless; you won't be anyone important. Who do you think you are? You are nobody and will never be loved." These are lies!

The Creator loves you with a passion. Every one of God's creations is special and precious. You are one of them. Joy is one of them. In all of her physical weaknesses, Joy still touches peoples' lives. How much more able are you than she to do this? To unlock this potential you must look past the seen to reveal the unseen, your spiritual nature. God is by your side, but you won't be able to see Him until your spiritual eyes are allowed to open.

I don't believe God is the author of the tragedies which fall upon us. This world is in a condition which will only tear us down and create hardships. When bad things happen to us, I believe God cries with us, in His own way. But then He does something about it. God is able to create good out of those things which might otherwise destroy our lives. He restores, comforts, sustains, strengthens, and creates new realties out of our rubble. He creates new realties which go beyond our wildest imaginations.

The story of Joseph, in the book of Genesis, is a wonderful record of God's restoring ability. Joseph found himself hopelessly trapped in an Egyptian prison after his own brothers had sold him into slavery. Joseph was falsely accused of a crime by his owner and put into prison. He was at his lowest point, but trusted God that somehow his life would turn around.

God fulfilled a promise He had made to Joseph years before and arranged his release from prison. Not only that, but Joseph was elevated to second in command of all of Egypt and was restored to his family. In fact, Joseph became their provider in the tough times! There is much more to the story of Joseph and I encourage you to read it.

The story illustrates that an individual may grow closer to God in difficult times, and that God uses people no matter where they are to touch others. Even though you may not realize now the impact you have on those around you, as the years pass you may be amazed at what is revealed through their lives as you touch them. Remember: what you say does affect everyone.

"…faith, hope, and love—and the greatest of these is love." 1 Corinthians 13:13 (NLT) The greatest sustaining factor by far, no matter the circumstances, is love. Love drives everything that happens during any given day. It is the core of our existence. Because God is love, He loves you and wants you to love others. It's really the essence of what productive life is all about.

My prayer is that you aren't focused on the words within these pages alone; rather, on the next pages of your own journey. Yesterday is behind and hope marks tomorrow. Be encouraged. Hold fast to hope. Embrace faith. Cherish love.

I asked you earlier if you had an adequate support system in place. That wasn't only regarding your child; the question was for you as well. When any family has a child with severe special needs their circumstance affects the entire family. Each member needs to be uplifted and reassured that the situation isn't their fault. Each person may be used as part of the solution, though they are not the cause of the difficulty.

Because so many emotions come and go, sometimes professional counseling may be of help. Family and friends may also be a tremendous support. The main issue is this: you must be the one to ask, to open up, and to allow these individuals in. Let people in, not to do the work for you, but to lend support to you. Someone to talk to, someone to go shopping with, another to do the yard work with, someone you can talk to, and someone you can trust.

Parents of special needs children are hopefully doing all they can to support each other, but they are also right in the middle of the situation. They may be in the greatest need of additional help. Talk shows and medical periodicals often address similar situations in which entire families are victimized or held hostage by one family member who struggles with a disease, such as Bulimia or Anorexia. The entire family can feel trapped. For us, there were many people whom we shared with outside of our home, and who offered up many prayers on our behalf. This helped us tremendously; however, as far as the daily activities unfolded, we operated much like the Lone Ranger. It was our choice, and as I look back over the years, it was probably not our wisest choice.

It may not be easy to open up and ask others to enter a chaotic situation, especially if it's yours. I only know the more people you have around you to lend support, the more it will help to minimize stress and maximize success.

This journal is my personal letter to you and your family. The writing process has been healing and restorative for me. Recalling the past has made it possible to work through issues I hadn't been able to address before. This has been a journey I would never have chosen to take, and writing about it would have been unthinkable in those early years.

Effects of special needs children cause us to look at the bigger picture of the special needs of our nation and our world. So America, how are you doing? One thing I know is that as a country we cannot continue to go down the same road over and over and think we will end up at a different location. Our nation must take a different road! The catalyst for positive change begins within each individual. For you, it may be to begin journaling, taking time for mental reflections, creating new candid conversations with family members, reaching out to others, or to simply realize you haven't been taking care of yourself.

I've heard it said, "It's not what you know; rather, it's what you do with what you know that matters." I love this thought. It conveys the reality that knowledge is a sedentary entity until it is put to some kind of use. To know information mainly implies existence. To see results, one must take action for change to happen. Don't be uncomfortable or hesitate when it comes to change. Embrace change. Then encourage others to do so, too.

Certainly I hope if you have never come to the realization that our existence is comprised of both a physical and spiritual reality, you may consider it now. Perhaps it's time to make new choices. These choices may come from considerations like these: "How does a parent understand why a long awaited beloved child is born without being healthy?" "How do parents grasp a new realty when their healthy child is severely disabled by a drunk driver or even taken away from them entirely by a perverted individual?" It's in these situations that the truth kicks in: God loves us in a way we can't fully understand, but by faith may accept, with no strings attached.

I would like to talk about what the Bible calls being *born again*. That term may sound unreal, and its use confuses many people. But it's not as confusing as you may think. We are comprised of mind, body, and spirit. When we accept God's free gift of love by faith, we receive a new spirit which is from God, and is different from the spirit we were physically born with.

This new spirit is in an infant state but seeks to please the Creator. This new spirit will continue to mature for the remainder of life according to the manner in which it is nourished. To someone who hasn't found a new faith, it might look ridiculous to trade one messed up life for another. Circumstances come to all. Some people reason, "People of faith are having as hard a time as I am having, so why even go there?"

Well, consider this. When a person receives a new spirit, he still retains the original body and mind he was born with. The body has the same physical problems it had before and the mind remembers all the stuff it remembered before. But the new spirit begins to work on and change the body and mind. Over time they, too, will change. The mind may experience the greater transformation, but the body isn't left alone.

The Bible also states that we are awesomely and wonderfully made in God's image. God uniquely exists in three persons, the Father, the Son, and the Holy Spirit, yet, He is one entity. We are comprised of mind, body, and spirit. Is this not part of how God has mirrored Himself in us? God as the head or mind, Jesus who took the form of a man for a short period of time, as the body, and the Holy Spirit who desires to direct our path and lead us closer to our Creator, as the spirit.

Almost everyone knows the story of the original Adam and Eve. When they took a bite of that apple, sin entered the human race. But what was the significance of the apple? In my mind it could have been any fruit growing on that tree. For me, it wasn't *what* they ate, but *why* they ate which was so significant. They made a choice to believe the snake, that what God told them was not true. God had said they would die if they ate from that one tree.

Both Adam and Eve listened to the snake and both made the decision to believe the creature instead of their Creator. As it happened, Eve was the first one to reach out for the fruit and take a bite. Then Adam, being further encouraged by the fact that Eve didn't die, also ate of the fruit. They both made their choices before they actually partook.

So was the snake right, or wrong? They didn't die, did they? Well, they didn't physically die at that moment, but they did die spiritually. Their eyes were opened to sinful thoughts, and the original spirit God had placed in them was gone. They did die!

That is why everyone since then has been born into sin, but God later revealed His plan to restore His original spirit into *your* life and the lives of all who will accept His gift of redemption and restoration. Again, this is accomplished only by an individual's choice.

Faith for everyone walks its own journey. All people of faith are simply at some point in their own journey—not perfect, and never will be, but on a journey nonetheless. Whether or not you have your original spirit or a new spirit within you, that spirit will live on after you die. The reality of your choices will determine if you spend your time with your Creator or not.

Please take some time and reflect on your spiritual nature. You do have one, everyone does.

Our spirits live beyond our physical bodies. When we die we won't merely be fertilizer for the next plant generation. We will live with our Creator if we trust Him.

We are all on the same ship, wandering in a dense fog. But for us, it isn't a case where the entire ship will be rescued; instead, passengers will be rescued one-by-one, by their own choices.

Let me encourage you to investigate for yourself; do your homework. Learn all you can from as many sources as you can.

One thing remains true: there is no hurt or sorrow that God won't help you through, if you will only ask Him. Moving out of your comfort zone will be the hardest and, yet, the most wonderful experience of your life! Your children are worth it. You are worth it!

Pray with Me

I love all my children so much and now I
realize that I am not in control.
My children are also Your children, Lord, and
You are in control.
My failures stem from a lack of trust and my
inability to grasp tightly to the hope and gift
that can be found in You, alone. Teach me to
trust You more. Teach me to love as You love
and not as this world loves.
Today, I am choosing to change my direction
and seek You.
Help me to grow daily in knowledge and
accept the gift of eternal spiritual life which
You offer us freely…no strings attached.

Amen

Journal Entry

Though this is the last journal entry in the book, I hope this won't be your final one. I hope the exercise of journaling will continue for you, that you create many new entries whether written or verbal.

What are your final thoughts for today? Are you ready to look at the days you have as only a few days, or are you ready to explore a never ending relationship with your Creator every day? Your situation might remain; however, how you perceive it will be brand new.

Journal Entry

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To preview or purchase any of the songs featured in *Rearing Up America,* to contact contributing organizations, and for all correspondence, please visit our web site: www.RearingUpAmerica.com. You may also contact the author directly at Robert.Glenn@RearingUpAmerica.com.

About the Author

Robert Glenn was born in southern Illinois, and then moved to Southern California with his family at the age of seven. There he was reared up, educated, and also married to start his own family. What more could a man ask for? Now really! He had a loving wife, two children, and a life of serving others. How can a life well spent be measured? It was well spent, but it was not easy.

Life can be difficult and Robert and his family passed many such markers of difficulty along the road. Faith in God has kept him on the right path. Many choices needed to be made as the family traveled without a map. Life never comes with a map.

Robert Glenn knew where he wanted to end up, but not where the road would lead along the way. He shares the story of his family with the hope it may have an influence on the choices his readers make in travels.

Robert Glenn earned a B.A. in Fine Arts at San Diego State

University focusing in education. After spending two and a half years in the field of education he moved to a career in the airline industry, serving customers for over twenty-five years. His primary heart focus though has always been serving his family and his church.