THANK YOU FOR

*WALKING*

*THE*

*WALK*

*WITH ME*

By

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# **Forward**

**America, it is an honor and privilege to bear and raise the children of our great nation but doing so always comes with a price. As parents, we need to put ourselves aside for the sake of the entire family unit. The needs of a family are the same as those of a married couple yet totally different at the same time; let me clarify this point. When children are born healthy and strong, the family has the propensity to thrive through the normal application of love and patience. But what happens when a child isn’t born with good health?**

**Genetic anomalies aren’t something parents feel they signed up for when planning a family. When anomalies occur, parents enter a new and totally unique reality. Their situation, though similar in nature to other families, will be theirs alone. Making the appropriate mental and physical adjustments becomes a high priority.**

**Our family has journeyed with a special-needs child for more than thirty-years now. I feel there may be many families who are trying to make sense of difficult situations like ours. Therefore, this book is my attempt to reach out to others, to definitively acknowledge *‘you are not alone’*. Our daughter was born with a rare genetic brain malformation which has changed our lives; our entire family. This reality needed to be embraced from its’ onset, but it wasn’t easy.**

**Beyond the basic need of medical care, we found being an advocate for our child was necessary to protect and nurture our child’s development. Every single child is unique and is not to be placed in generic boxes in any treatment venue. Now in a later stage of life, I can say with confidence to special-needs families of all ages: welcome to a new reality. Welcome to the opportunity and challenge of rearing a special-needs child! Welcome to an abundance of love and patience!**

**This walk with your child will most likely be a hard, rough trail to follow, but walk with your child none-the-less. Whether or not your child is verbal, I believe your child will be embracing a special love for you in their heart.**

# **Dedication**

**“Thank You for Walking the Walk with Me” is dedicated to my loving family. We walk together at all times and pick each other up as needed.**

# **Introduction**

**Why another book focused on supporting a social cause? Maybe because the “word” hasn’t yet penetrated or hasn’t saturated our culture to the point it should. Maybe there are just too many causes out there and certain segments of society are somehow left out, lost in a cloud of dust. Perhaps misunderstood, or under-understood are a part of the issue. I know it’s not because our American society doesn’t care. We are a very generous people.**

**And we the people who are the essence of this country have entrusted a leading body, which we call our government, to skillfully organize the super-structure of our nation to better maximize America’s strength, health, and financial durability.**

**Government has become an extremely complicated organism over all the decades of our existence and was never intended to be the solution for all our social ills and challenges. Candidates for government offices promise many things but deliver on only a few of their original campaign platforms.**

**Why? Well there must be bi-partisan cooperation after any election in order for positive change to occur. Party politics seem to be the driving force these days, which leaves all the electorate in a trailing heap of dust and muck. Cooperation which translates to concessions is not the prevailing strategy in state and federal circles these days, party lines rule. This leaves any special lobbying group in a dilemma.**

**Oh well, enough of those thoughts for the moment. Government may and must play its part, but the point here is we the people must be the driving force to grow, strengthen, and care for one another, not government. Government, at best, will only play a small part in the strength of our country. Many of us have simply laid aside our responsibilities, and for what – an unfulfilled political promise? It’s time to step back into the game. It’s not any one prevailing party which makes America great, it’s the people, you and I.**

**The focus of this document is for the needs and welfare of our children, and especially those with special needs. I feel these individuals with medical and intellectual disabilities are still ostracized to a degree, and certainly misunderstood and/or under-appreciated by many in our country.**

**Special-needs individuals, by their very being, strip away the complexities of any culture, and focus our thoughts back to the essentials of life itself. Both special-needs children and their families desperately need to feel a more inclusive relationship with mainstream society. And I will be setting aside the structured government programs, because I am addressing those things we can do as individuals.**

**How we treat those in need is the thermometer registering the humanity of our nation. I’ll be sharing with you many of the issues special-needs families face on a daily basis via our own family story, and the failures and successes which permeate the dynamics of our daily lives.**

**For any special-needs parent who maybe among my readers, I hope you will find an increased sense of hope, encouragement, and comfort to realize you are not alone. All parents have struggles even when their children are born healthy; however, caring for a special-needs child takes everything to a higher level.**

**And lest we forget, special-needs children grow into special-needs adults which bring a whole new set of issues for ageing parents.**

**If parenting were a selectable college major, we would be able to delve into an organized curriculum. There would be lectures setup for most scenarios, or at least a reference periodical for parents to address the issues of life. Well, there is no such major.**

**So, why would you consider my comments at all? I do have a Bachelors’ degree in Fine Arts (which focused in secondary education) and two minors (art and accounting). But I’m not a doctor in any field of study.**

**My impetus comes from being a special-needs father for over thirty years now. Our family is living out our unique reality. I use the word unique, only because each child is unique. And although I will be addressing a variety of topics, you will still need to assimilate how each topic impacts your own family.**

**This isn’t another “How To” book designed to guide you through tough times. But if I am able to spark your thought process and therefore lead you onto a new or renewed path which seeks for a clearer understanding, I have done my job.**

**Some of you may be exactly where I and my wife are in life, while others may be brand new parents and are still in the initial shock stage. You may question how can you possibly care for a special-needs child?**

**The unwanted behaviors, the physical limitations, the seizures in many cases, how can I possibly live with these? Where do I even begin? These questions are honest and normal. The reality facing you, however, is not easy; but needs to be faced none-the-less.**

**Don’t give up or give in to your initial fears but take one day at a time and work through them. I’m not going into a barrage of divorce statistics, but I can tell you there are far more single moms than single dads raising special-needs children these days.**

**If I use a generic statistic which reports the average divorce rate in our country is 50%, then I’ll tell you the divorce rate in special-needs families is over 80%; very sad, but true.**

**It maybe fear, feelings of inadequacy, feelings of social rejection, or perhaps even guilt which may cause a man or a woman to jump to a conclusion the easiest way to solve the problem is to get out.**

**Don’t go there! There is help available and I will be dialoging about some of the issues here which feed those initial thoughts of distress. Always keep in mind, one key component is to consciously make it a top priority to put your marriage first.**

**The dialog which follows will explore five topics which require not only government support, but the support of every family in our country. These topics are:**

1. **Parental Health**
2. **Medical Advocacy**
3. **Educational Advocacy**
4. **Financial Advocacy and Sustainability**
5. **Family Dynamics**

**These core topics must be embraced by all in order to maximize the healthy growth of this country’s most helpless individuals. For those readers who are blessed to be in what I call a ‘normal’ healthy family situation, you have a very important role to play in the success of your neighbors.**

**Pardon me if you feel I am stepping on your toes with this next thought but look around you. Is your time being poured out to enrich the lives of others or mostly lavished on yourself? How are you using the hours of each day?**

**When I look around, I see many people isolated in little worlds of fantasy searching for fulfillment. Virtual reality will only produce a pile of unfulfilled dreams. Shut down the devices and re-engage with real people; relationships which will produce an abundance of satisfaction and true fulfillment.**

**There is much work in front of us as a nation and now is the time to face it head-on. Too many families are struggling while others sit on the side-lines in relative contentment. Let’s all open our eyes a little bit wider to see the community around us. The end-product, after a mountain of needed work, will be a healthier and stronger nation over-all.**

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# **Chapter One**

# **Parental Health**

**Perhaps the best place to begin here is to dialog directly with our special-needs parents. I’ll be very honest with you, I never felt like I signed up as a volunteer to be a special-needs father. The thought never entered my mind. So, what happened?**

**This may be a question asked by many parents. I don’t have a clear answer for you. However, I do know there is an answer; though we may not be privy to it during our lifetime.**

**It’s a harsh reality for any young family to face. But given even harsher realities, we need to stand firm and face them. Whether your child’s condition has a known or unknown cause from birth, or their condition is the result of a severe child-hood disease or head trauma, we must love our children to the best of our ability. Love is inseparable from other concepts such as commitment and responsibility.**

**It’s easy to say, but not easy to live out. That’s why I’m sharing thoughts and ideas with you. Maybe some of the things I and my wife experienced may help you on your journey.**

**So, for a few moments, get yourself a cup of coffee and find your favorite chair. I’m sitting in mine as I am writing to you. I’ll be addressing some issues you may have now and some which you may visit in the years to come. I hope some of the issues mentioned here will never come your way, but remember we only have to deal with one day at a time. Please, don’t worry about tomorrow.**

**To begin, I need to introduce you to our special-needs daughter and her unique challenge. Her name is Joy and she has Lissencephaly. Lissencephaly (pronounced Les-sen-SEF-a-lee) is a rare birth anomaly and one which 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 the cognitive level 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 in even rarer instances, 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. We certainly didn’t. When anomalies occur, parents are in a new reality which is totally unique. Their situation, although similar in nature to other families’ situations, 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 includes 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. Patience is essential.**

**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.**

**Early on in our journey, we located a web site in which a very small group of families were exchanging thoughts and information, each family has a child with Lissencephaly. We are now among them and are communicating via email as time will permit.**

**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.**

**Oh, you may ask: What about family and friends? You’re certainly going to find a degree of support from them. The people close to you should always be considered the first line of defense.**

**And although family and friends are okay for sharing some things, the intensity and consuming nature of care for a child with a severe need can be overwhelming. The experiences may unknowingly reduce our ability to open up to others; even to our own family.**

**I would like to share a portion of one email with you which I received from one of our email group members. She is a single mom and has given me her kind permission to share her personal thoughts with you. Ladies, it’s okay to set a box of tissues beside your cup of coffee.**

**Here are her words:**

**“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.”**

 **My heart broke as I read this letter. She was in a place of great pain, yet even this letter to us is a wonderful first step she took 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 the true diagnosis. The day-to-day realities didn’t improve with our new knowledge; however, we were then a little more connected to a community who professed to understand 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 are able to cope will survive, and those who are unable to cope will fail or barely thrive.**

**There are sections of 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 this 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 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 such times, but there is a consolation in knowing others are feeling similar emotions and realities, and they are making it through. Perhaps if they can, my family and I can as well.**

**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 once it looks feasible, seek it out.**

**To start, make a list of people around you whom you trust and can call on if needed. Call them to determine their willingness and availability. Where you feel there are certain areas of support those individuals on your list can’t provide any assistance then brainstorm new ideas about how you might fill in those gaps.**

**Emotional pain and depression can create an impenetrable wall which may block a creative thought process. Recognize the blockage and move beyond it. This may involve some personal risk to open up in spite of past feelings. I reasoned: oh, what could someone do to hurt me anymore than I hurt now?**

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

**As we have moved around the country, from one state to another over the years, we have found there is a good chance our new medical community has never had a patient with this anomaly before. Information we initially receive from a new set of professionals may be generic comments which have been located on the internet. After a few relocations, these comments are not difficult to identify. It’s important not to get discouraged, but to continue learning all you can.**

**Wherever you are, you have to take the initiative in your child’s health care.**

**The English language, perhaps as other languages, is sometimes an inefficient form of communication. The words themselves say one thing, however the speaker’s intent may not have been clearly thought through prior to speaking. So, the listener only hears a fragment of the person’s true thought.**

**Does this make any sense to you?**

**The point here is - don’t feel embarrassed to ask questions; ask away. You will either receive a conformation you heard the speaker correctly or you will receive additional needed information.**

**America isn’t just one culture; it’s a melting pot of many cultures and traditions. This pool of talent further enriches our country’s potential. Communication is and will remain our most valuable tool. And just like any tool it may be used skillfully, or it may damage the project being worked on.**

**One case in point; I recently received a call from our daughter’s care provider stating she had hit her head on a windshield. My first thought was she had been in a car accident. Upon further dialog, I learned she had simply bumped her head against a window in the house. Communication is in the ear of the beholder; always ask questions.**

**Parents please remember the challenge to achieve clear communication begins at home. When communication breaks down, other relational issues may arise. To my point, you and your spouse won’t always feel the same way concerning some of your challenging issues. Your family may be facing some hard decisions; communication is a key element.**

**You must ask yourself some probing questions when these roadblocks occur: “Am I the one who needs to change or is it my spouse?” “Oh, how could it be me? I feel good about myself and what I’m doing and thinking.” “It has to be my spouse, or it has to be my children who must change!”**

**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 spouse needs to thrive under close companionship and feel encouragement and support.**

**As to children, the children need a role model which mirrors unwavering love.**

**The family needs to pull itself together to achieve the most successful outcome. Once in unity the family is better able to use the resources which are made available by local, state, and federal entities.**

**One of the areas our government has played a vital role is in establishing laws. New Laws are established to foster fair treatment for people groups who were previously disadvantaged. Let me use the Americans with Disabilities Act of 1990 (ADA) as one example.**

**The passage of the ADA of 1990 was and is an important benchmark of legislation which 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 synonymous concepts. Understanding disabilities is not something which can be legislated.**

**Society needs to continually review standing documents to assure continued relevancy. We can’t assume our culture today interprets the Americans with Disabilities Act in any one particular light.**

**Culture is a living and changing entity. How society interprets a piece of legislation written 20, 30, or 40 years ago could vastly very from the original intent. It’s perfectly okay to ask questions in order to fully understand how today’s culture understands a standing law. Once we understand each other, we will be better able to work together.**

**We are, by nature, creatures of habit. Perhaps some questions you may also consider are these: “How do I handle change? How prepared are you for the unexpected? How does one become comfortable stepping out of their comfort zone?”**

**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.**

**So, when confronted with difficult issues, here is a reminder for all parents before you jump into making any major decisions: start with the basics; parents don’t exhaust yourself over the new challenge without recognizing your need as well. Open up to others and address your needs and feelings up front. Take some time to ground yourselves emotionally.**

**Concerning the general public please remember, a broken tool can’t and won’t fix anything! There is a saying which goes something like this: You are either part of the solution, or you are part of the problem. You can’t be in a community and simply take a neutral stance. Look around our country and listen to the news each day; it’s not someone else’s problem to fix.**

**It’s your problem and it’s my problem as well; get involved in your community. If we all work together, we will be serving our nation and making it an even better place to live.**

# **Chapter Two**

# **Being A Medical Advocate**

**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.**

**This 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 brought a real sense of purpose.**

**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 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 Joy would roll over to her side.**

**Joy was able to commando crawl, in military terminology, which for her was pushing her legs back and forward in excitement to propel herself forward on her stomach, but she couldn’t sit up.**

**At the age of thirteen months her pediatrician recommended we start her on physical therapy. By twenty-four months occupational and speech therapy had been added. These therapies began to address Joy’s difficulties with fine motor planning and low muscle tone, as well as newly observed speech delays. Without a conscience thought, we were indeed medical advocates by proxy.**

**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. Each time we needed to use the car to go shopping, to church, or just about anywhere, carrying both children was the most time efficient method.**

**Becoming a medical advocate for anyone may be a scary thought, especially if you have no medical background. My wife is a Registered Nurse, but I was totally lost when it came to under-standing medical terminology. Learning for me literally began at ground zero with a newborn baby in my arms.**

**In retrospect we were already struggling to accept our new norm. It took some time before we settled into a slower and more methodical pace. We were handling the situation as well as one might expect; I suppose… I think through the remembrance of the blurring elements of time past.**

**We knew Joy was a gift from God, like all children, and accepted her developmental delays with the faith 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 had become 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.**

**Joy first started addressing Lee by Lee’s first name. I know in her heart my wife had a hard time not hearing the title of Mom from our first born. After Joy learned the ‘Mmm…’ sound she addressed her mother as “Mommy-Lee” for a number of years and then finally as “Mom”.**

**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-syllable words, generally, and then some short phrases. And the majority of her speech was responsive, as in a “repeat after me” format.**

**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. We were living in San Diego at the time. Although much of our family lived there, too, the opportunity came up for us to move to Pittsburgh, Pennsylvania with my employment. We put our home up for sale and in time had moved east.**

**Now living in Pittsburgh, Joy loved to see all the local wildlife in the area. 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. The views are beautiful, and we felt at home and comfortable.**

**At this new 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 sentence 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 just the right 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 Lee and I were still “coping” fine. Perhaps that conveys reality a little better. We were able to hire childcare occasionally to go out on a date, and we felt comfortable 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 or at a measurable speed. We just needed to remain diligent.**

**Even at the age of 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 with any degree of finesse.**

**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 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 and her joy was very contagious.**

**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 those times came the realization of the added effort it took from both parents to provide the needed childcare.**

**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 which 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 also went to bed earlier than most kids. With the combination of an active school day and her low muscle tone, she was understandably tired by the end of the day. And every morning, she had her own internal alarm clock and woke up at 6:00 AM. I don’t know how she did that.**

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

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

**For me, well I had many thoughts running through my head. I remember being thankful for the skills and comfort I felt from God; I knew all good things come from Him. I was at a point where I said to myself: okay, Joy has a lot of stuff going on, but I think with continued help I can do this. The future looks manageable.**

**If this would have made up the end of our story, I don’t imagine I would have written a public account 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.**

**Remember how I mentioned situations can unexpectedly change? Well we were about to see our parental learning curve sore to new heights. This is one of those scenarios I hope you will never experience.**

**For us, it was 1995 and Joy was approaching her ninth birthday. Shortly after Thanksgiving that year Lee, Joy, and I were sitting around the kitchen table having a snack. 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. The concept of a manageable life was soon flying out of the window.**

**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 Joy’s 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 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. The first EEG did document Joy was having seizures and her doctor placed her on an anti-seizure medication. This 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 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 no matter what the consistency of the food was. 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 found out quickly Joy had the propensity to realize a number of the side effects 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.**

**Also, 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.**

**After the seizures and medication began, her skill levels began to drop. The first skill to go was the ability to read, and she spoke with less frequency. Her short attention span became even shorter, and we got to the point she was losing her ability to spontaneously express happiness. That was very hard for me to watch.**

**I can remember many times over the next four years when I would ask her, “Joy, 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. 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.**

**You see what I meant about unexpected changes? Well, these changes had steadily grown to epic proportions. It was already hard for Lee and me to share all the details of this experience with others. We were merely trying to cope without any understanding as to why this was even happening to our daughter. In retrospect, we didn’t have a support group in place which we could turn to.**

**As we moved from the first year into the second year of her seizures, the episodes affected more of Joys’ 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 with each seizure.**

**Joy still was able to feed herself with a spoon which had a rounded thick handle, but the challenge then focused on whether or not Joy could maintain her independence at mealtime. We managed as best we could. Flexibility and adaptability were always key components to daily success.**

**For example, once up and dressed we would escort her out to the kitchen table for breakfast. Joy loved having cereal and milk. Often her seizures would occur at mealtime. 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 Joy and foregoing the self-care. Physical safety became the driving issue at mealtime.**

**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 for us. 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, forget about daily. 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 also calling the neurologist’s office quite often to report not only a worsening of the seizure activity, but the 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. Mind you, that’s one swallow.**

**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.**

**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 playground. We asked, “A what? Had a grand mal seizure?” How could this be happening?**

**Joy has never had a grand mal seizure 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 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 of meds 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.**

**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, however, 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 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 a good part 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 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 which 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 tears were flowing down my cheeks; I had never been in such pain in my life.**

**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 the pain never returned. It was a strange ending to an unusual event.**

**I am very thankful that was the only occasion where urgent care was required for either parent.**

**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. I guess the right combination of meds was found, but your guess may be as good as mine. This was far from the last med change we made.**

**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.**

**In the spring of 1999, we began using a wheelchair on our neighborhood walks. It helped us change the scenery and activity for Joy with an added level of safety. Walking had become too risky. Joy’s independent set of skills was at a new low.**

**At times during these four years Joy was taking three or four medications at once, and there was a short period of time she was on five different medications simultaneously. Complicating our search for the right combination of medications was the fact drugs could only be altered one at a time and only altered in very small increments.**

**Side effects were constantly with us as meds were increased or changed. Dizziness was one side effect she might experience. For example, a week could elapse since her last medication change was completed and Joy would be getting extremely dizzy on the new dosage. The doctor allowed us to slowly reduce one med 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 as parents.**

**We felt horrible, but we could only hold her tightly in our arms as we watched her discomfort.**

**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 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.**

**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. This decline wasn’t a yearly event, it was noticed each month.**

**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 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 which could help Joy?” We wanted to find out.**

# **Chapter Three**

# **What Is Going To Happen Next?**

**As parents, we were at a loss for words and our emotions were dangling off the edge of a cliff. The only thing holding us together was our Faith in God, because we knew no matter what the circumstances God was still in control. How He did it was beyond our understanding; however, it was still the source of our peace and our strength for each day.**

**So, we continued to move ahead. It’s important for any family to feel supported in all the areas of their walk and know they are not alone. A primary source of support should also include of course our medical professionals.**

**Open communication between doctors and parents is vital and should embrace a team effort approach for maximum success. If a doctor clearly sends the message, he has only one treatment solution and it’s either his way or the highway; in my book this should raise a red flag. I believe all options should at least be addressed, along with risk factors, to determine a clear course of action.**

**All participants on the team should be asking questions beyond the child’s general diagnosis. Questions such as: “How did this condition originate? Is it progressing at a normal or abnormal pace? From this point in time, what are all our options?” These and other questions should be evident and periodically reviewed in a healthy doctor/patient relationship.**

**Even though every diagnosis has a standardized approved treatment program, each client is unique. In other words: one size doesn’t necessarily fit all. Certainly, you won’t be trying all treatment options, but you should know what they are to make informed decisions.**

**Families across the country are certainly able to share their struggles and successes in this technical age for the betterment of all. The world is much smaller now in-regards to our ability for sharing information. We can now search the internet for just about anything.**

**Also, when we consider complicated medical issues, they often spread into multiple fields of study; as is the case with behaviors. Behavior issues are a major concern for parents with special-needs children and behaviors will be addressed as a separate topic a little later on. However, keep in mind medical and behavioral issues are interwoven. They aren’t separate issues, which may tend to complicate matters if you are trying to address them one at a time.**

**Right now, I’ll expand even further on issues which may develop surrounding medical issues and how to approach or should I say respectfully interact with Medical Professionals.**

**Any insights you may glean from our journey may be augmentation for your own experiences. These supposed ideas do have a measure of validity just as insights you may gather from individuals who survive drug addiction or cancer. We can learn from others without going through the exact same experience ourselves.**

**For us, we had seen a commercial for the Vagus Nerve Stimulator and we wondered if it could help Joy. 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. Each day is precious and for us was also challenging. 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 from what we had been able to learn the VNS 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 an individual (referring to Joy) won’t get any better.” He didn’t want to give us the referral for the VNS. (A Red Flag went up in my head.)**

**My mind and heart were racing at this point and I tried my very best to keep composed. 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 we had already confirmed the other appointment did he concede and provide us with the referral. I’ll repeat, only when we mentioned we had already taken an additional step did he comply and grant our request.**

**Mind you, we are talking about a child who only has a generalized diagnosis of CP at this point in her medical history 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.**

**A number of weeks passed before the second appointment arrived. Although I was shaken up from the prior doctor’s visit, the rigorous daily routine had left little time to dwell on the past.**

**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 which 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.**

**Eventually 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 this word before nor understood what it was. And our overall understanding didn’t expand a great deal on that day.**

**However, the doctor did mention Lissencephaly had a genetic origin and the MRI confirmed the diagnosis by revealing an extra thick band of gray matter going across the interior areas of her skull and beneath the brain.**

**This condition flattens out the normal peaks and valleys found on the cortex and thereby reduces the number of neurotransmitters which carry information in and out of the brain. We learned this condition is also known as Double-Cortex Syndrome, or Subcortical-Band Hederotopia.**

**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.**

**The doctor also stated there was no conclusive information on whether the VNS would actually provide any seizure relief for Joy. Lissencephaly, it was explained, is very rare, and the genetic research being conducted was still in its early stages.**

**The doctor went on to state the 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 timeline and explanation of the procedure on the VNS in more detail.**

**You see even though I like hearing options, hearing the words ‘brain surgery’ was more than I could handle at the time.**

**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 to help maintain a more normal level of operation.**

**The overall message conveyed was seizure control 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.**

**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! And no, 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. However, it was clear after a reasonable amount of time the VNS had no impact at all. Joy was no better or worse for having the device; she was simply continuing her deterioration.**

**To my recollection, Joy hadn’t spoken a word for a number of months at that point. Her only form of communication was occasionally pointing this way or that way with one finger.**

**Her drop seizures were so hard and frequent that with one of her seizures, she sprained an ankle. Simply walking out of her bedroom and dropping caused the injury. As a result of the fall, she was in her wheelchair most of the time. Caring for Joy was even harder, partially because she had become too heavy for one person to carry.**

**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. This thought alone brings a tear to my eyes.**

**It was out of this desperation we made a call to our new neurologist to inquire about the brain surgery she 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.**

**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 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 surgeries aren’t all successful, and there might be a wide range of outcomes. The result 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 neurologically.**

**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 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.**

**Well we knew she wasn’t going to hold a normal job, but his comment was sobering anyway.**

**Now Joy was in her wheelchair most of the time, due to her sprained ankle and with 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 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 a sitting position was the safest place for her to remain. Joy wanted to walk around with determination. 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.**

**The morning of surgery came on a cold January day in 2000. Joy had recently turned thirteen years old. 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.**

**The nurse came in, as expected, after forty minutes. She calmly announced 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.**

**There was total silence as the nurse left the room. What was racing through my head? Wasn’t this our emergency? I felt trapped in a moment of disbelief.**

**Once home we called for a new surgery date and learned the next available date was in three weeks. Okay, all we could do was to proceed with the daily routine we were so familiar with and wait it out.**

**Finally, the second surgery date arrived. 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. 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 to wait. We were aware we weren’t alone in the waiting room. We knew the other families there were also at a crucial point and they helped me focus my emotions. My bottom line was rooted in the knowledge I knew God was in control of our outcome. While experiencing many emotions, I treasured a sense of peace within my 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. 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 during the over-night hours.**

**Wednesday morning brought little change in Joy’s condition. And by Wednesday evening the ICU made the decision to move Joy into another room even though she still wasn’t fully conscious. They needed her bed in the ICU for other patients newly out of surgery.**

**Joy was moved to a room on Wednesday evening. This new room allowed anyone who stayed with her to recline or even sleep in a fold-out sleeper chair.**

**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 Joy’s 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. Each individual is indeed unique.**

**The 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, laughed, and talked spontaneously, and visually tracked everything in the room. In fact, her cognitive level had returned to a similar level Joy displayed four years ago prior to her Epilepsy.**

**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. There were no more seizures! Did I say that before? Did those words actually come out of my mouth? We were in a state of euphoria.**

**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 medication changes had been attempts to minimize the extreme side effects which 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 back to what it had been before the seizures started. And her personality was back; and she had no seizure activity! This improvement was acknowledged the moment she finally woke up from the surgery.**

**Considering what Lee and I had witnessed before the brain surgery, Joy’s condition 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 which hadn’t changed was Joy’s medication. Let’s think about this for a moment. During the ensuing weeks the doctors said nothing about reducing the amount of medication she was taking. Joy therefore continued to take the same dosages of four different seizure medications she had been on before the surgery.**

**So, let’s concentrate on this fact for a moment, I did have some questions: “Was it mostly the seizures which caused all the major declines in her skill levels and not the meds?” “Why were we not seeing the dizziness and other seemingly related side effects we normally associated with the medications?” Yes, we weren’t seeing any side effects during this time. “Could seizures themselves have an active role in the production of her unwanted side effects?”**

**Medications vs. seizures, pros and cons; for the seizures – well there are no pros, but are there more cons connected to seizure activity than we were aware of? And the medications; were we in the dark merely from the complexity of mixing four different meds at once?**

**I still don’t know the answers to these questions, but they did provide me a lot of food for thought. Analysis is a vital component in maintaining a clear understanding of the past, while we still focus on the present.**

**We were elated at the success of Joy’s operation and so happy to have her home again after a ten-day hospital stay.**

**While it takes a lot of reflection to be the most successful advocate for your child, we all need to somehow separate our emotions to properly address the medical reality at hand. And I don’t know how you might reach this point of separation, but I just lay the thought out there for your consideration. I can certainly get emotional any time I share these thoughts with others, even though so much time has passed.**

**It is so important for parents to become totally informed advocates for their children. A medical history doesn’t necessarily tell a complete story. Lee and I are the only constant source of Joy’s history as eyewitnesses. This fact is very important for parents to realize.**

**Even though memories can be very painful, remember them anyway. They are important! Our ability to remember history connects our special-needs children to the consistency they need.**

**As I review and remember Joy’s history, I know I wouldn’t be running all over the country interviewing doctors until I found one which will do my bidding exclusively. That wouldn’t be a healthy scenario for me to pursue.**

**I know my own medical limitations—they are many. On the other hand, I shouldn’t ignore the gnawing feeling which tells me every possible solution may not have been considered; for example, has everything been tried to bring Joy’s seizure activity under control?**

**Tracking any new seizures could indicate they might be degenerative once again. And in fact, they appeared to be just that. Joy’s new seizure activity after her brain surgery did worsen but at a much slower rate than her drop-seizures had prior to her surgery.**

**As a father, I have watched seizure activity start from nothing and escalate uncontrollably, twice now. 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 unless the seizures were somehow controlled, Joy’s prognosis wouldn’t be very good.**

**You know in hindsight we should have asked the doctors all the questions I raised earlier in this document and fielded other questions as soon as the success of joy’s brain surgery.**

**You see the one event in Joy’s history which continues to haunt me is the five-week period following 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. Why? Too much time has passed since then, and we have changed doctors several times. There is now no doctor who could be considered an eyewitness to Joy’s medical history.**

**I have a hope Joy’s brain surgery is still the totally successful surgery she experienced and the seizures we have witnessed since then might be perpetrated by the medication. That’s a wild thought, isn’t it? 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. Lissencephaly is itself divided into six levels. In the first five levels, the individuals are at a very high risk of passing away by the age of twenty. Joy is in the sixth level and is considered to be a genius. And although this level is purported to not shorten a normal life-expectancy; I am only aware of one individual reported to be in his forty’s.**

**Joy is one out of two-hundred individuals worldwide to hold her diagnosis. Who knows if anyone else with Double-Cortex has had a similar brain surgery? And even if there is someone else, has there been any collaboration discussing relationships between these cases? Why isn’t the cause of Joy’s Epilepsy ever a part of the treatment process? These questions and others are yet to be answered, yet alone clinically addressed.**

**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 Joy will live out the remainder of her life being medicated unnecessarily and suffer the consequences of taking unnecessary drugs.**

**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 their constant and dedicated 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 should only empower any advocate. Please don’t feel intimidated to ask questions and to obtain second opinions. These are our children we are talking about. Ask away!**

# **Chapter Four**

# **Being An Educational Advocate**

**Being an educational advocate for our children is in every parent’s wheelhouse. But please note this topic isn’t merely directed to our children’s education; it is also directed towards our own personal growth. Our learning curve doesn’t end with high-school, college, or post-graduate studies. I will continually embrace the concept of being a “life-long learner”.**

**To be an affective advocate, one must begin by working through what may be an extensive evaluation process. What are our children’s needs in each facet of their daily life? Are we able to identify their strongest skill areas as well as their weakest areas? Who might be able to best help us maximize our children’s goals and emotional stability?**

**When dealing with special-needs individuals, it is impossible to separate the concepts of physical challenges (like Epilepsy) and psychological challenges (which manifest as unwanted behaviors). Therefore, for me, these two challenging areas are not black and white, but are indeed forever linked in a self-sustaining gray mass. Finding the wisdom to maximize the most successful out-come is the challenge.**

**Education occurs through many facets, not to which is only found in the pages of a book. Experiential lessons are oftentimes the hardest ones to grasp but may be the most valuable ones we learn.**

**Our daughter’s cognitive skill level was definitely higher after her brain surgery and hence so was her ability to make her own choices.**

**We were over-joyed at our daughters revitalized skillset and had a renewed hope Joy would continue to gain back her strength and resume the lifestyle and cognitive growth pattern she had enjoyed prior to contracting epilepsy.**

**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 drop-seizures began more than four years ago, they had been mild too.**

**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 and so soon after her brain surgery?” Mind you, these seizures weren’t even close to the destructive levels the drop seizures had reached, but they were seizures nonetheless, and we paid close attention to them.**

**If an onset of a new type of seizures wasn’t enough, at the third month following surgery something else unexplainable happened. One evening, Joy simply refused to go to bed. 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 Joy’s mind was made up. And we, as parents, began to experience a level of behavioral issues we had not dealt with before.**

**This new situation of passive-aggressive behavior stayed with us; I will simply say Joy didn’t willingly go to sleep in her own bed for the next two and a half years. She had made up her mind and 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. This is not an idea I would recommend, but we couldn’t think of a better plan at the time.**

**Even though Joy wasn’t going to bed at night, the medication did cause some initial drowsiness. So, someone needed to stay with her after her evening medication was administered. We couldn’t risk Joy would stay clear of the staircase if she left her room on her own.**

**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.**

**Once she fell asleep, Joy 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 which 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 by small increments to hopefully allow her to fall asleep. The room door was slightly ajar, so I was able to see from light streaming in from the hallway. 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 such a 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 fingernails or worse, she might 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 moment her will was relinquished, and then 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 for all of us, 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.**

**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 Joy to refuse her food or to throw an object across the room. 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 her day school program there were only minor reports of any compliance problems. Most behavioral dysfunction occurred at home. We requested and were granted access to behavioral counseling through a wrap-around 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.**

**It was easier for Lee and me to believe 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 this was also the case with us. We were just around too much for our budding teenager and she was letting us know about it in the only venue available in her skillset.**

**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 and it was this: she no longer wanted to take her medication.**

**What is a parent to do? She never could share her feelings or clarify her reasoning verbally; rather, Joy communicated these through her body language. And that communication was very clear. Joy simply refused to open her mouth.**

**She knew 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 large 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 med-time was completed.**

**Med-time got so bad we reached a breaking point. We couldn’t do this anymore. I talked to Lee about the possibility of getting Joy a Gastronomy 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. At our doctor’s appointment we explained what Joy and the family were going through. She (the doctor) 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 try our best not to let go. It was another two or three weeks before the G-tube procedure date finally arrived.**

**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 clinic 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 a plastic tube and one 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 with the second flange on the outside so that the stomach lining is up against the outer skin wall. The 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 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 they would try to complete the procedure one more time. He said if they failed, we would need to schedule a regular operating room for the procedure.**

**Well, they were successful with their final attempt. 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 in a backpack 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.**

**This whole episode was a learning experience for us as parents. Even though you may think you understand what a doctor has communicated don’t simply say, okay. Try to dialog about what was said and fight off any feelings you may sound stupid or uneducated. We felt horrible Joy went through such a procedure while she was still awake. I do hope you never go through a similar event as this.**

**Things smoothed out for us somewhat after the G-tube procedure; but mind you, this feeding program occurred after we carried Joy to bed. She still wasn’t voluntarily going to bed on her own. This is one of the many 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 timespan 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 completely.**

**I can’t express the great joy we felt seeing Joy 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. Part of the reality of maintaining a low BMI for so many years was partially because her stomach was very small.**

**The more one eats the stomach will grow to accommodate the intake. This problem is closely related to the concept of discussing which comes first, the chicken or the egg. As parents, we need to try on any and every hat which is offered to us. You know? Simply saying “no” may certainly be problematic.**

**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 through this process there were no regular dialogues 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 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 is 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 the original flange and tube were going to be removed in a reverse procedure from that used to implant them.**

**Wouldn’t you think we learned our lesson from the first procedure; well think again. I was once more in a mental crisis mode.**

**I reasoned, “Oh, slow down a moment! Joy barely made it through the first procedure and you’re going to pull the flange back up through her esophagus while she was still awake? Isn’t there any other way to accomplish this replacement? Even if we ignored the fact 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. This was a much better plan, simple and easy. We decided to go with it.**

**Joy had no discomfort and the procedure took about five minutes. The new device was easier to work with and less visible under her clothing. All Joy’s stools needed to be carefully checked until the flange was found. Eventually, it was.**

**The only inconvenience was 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, this nearly always took three to five hours, including travel time and lots of waiting. It was a challenge when dealing with Joy’s short attention span. 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.**

**This 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/Mickey Button 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.**

**In Pennsylvania, there weren’t any options to bring a care-provider into our home. Taking on the financial responsibility of paying for personal care out of our pocket wasn’t possible. We had very little hands on help, actually none, 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 Verland operates from 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 classrooms. There are also about thirty-five off-site group homes which house two or three individuals each. The main facility is licensed for 94 individuals. Each of the ten campus 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 after her move we could put the stress behind us and pursue a healthier parent/child relationship.**

**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 a loving group of 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 which had taken their toll on all the members of our family.**

# **Chapter Five**

# **Communication Is Key**

**Up to the age of thirteen, Joy enjoyed all the benefits of our local school district. One of our top priorities in selecting our home in Pittsburgh was the rating of the schools in each township. The district we selected was top notch and supported both of our children wonderfully.**

**Most special-needs children will thrive very well in our public-school systems both academically and socially. Most metropolitan school districts offer skilled special needs programs for grades K–12. You may need to explore options if you live in a remote rural area.**

**However, some children need an even higher level of support which school districts may simply not be budgeted for.**

**As a result of Joy’s surgery, our school district presented us with an option to place Joy into a different learning environment. The school district in our area, like most, is mandated to teach the basics, reading, writing and arithmetic in an academic setting, to maintain their government funding.**

**Our school district realized Joy’s needs might better be fulfilled in an alternative learning environment. Special schools exist which focus on life skills. Unfortunately, you may find these schools only in larger metropolitan areas. Even though they do strongly promote the basics as traditional schools do, these special schools teach the basics through the concept of social/life skills.**

**We knew Joy’s education would be better directed in areas of daily living rather than academic fields of study. However, until we were approached by our school district, we had no idea this would be an available option for us.**

**We placed 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 within the guidelines of an academic structure. However, the Children’s Institute was staffed entirely with Special Education staff and therapists.**

**Their total focus is life skills. While they still teach reading and math, they also augment with 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 which 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!**

**At the Institute, 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.**

**Students range in age from elementary school age, through the age of twenty-one. The last two years of a student’s experience at the institute focused on transitioning to an appropriate adult day program or job where they could perform 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. We saw Joy functioning at her highest level during these years.**

**Joy’s participation at the Children’s Institute was wonderful for her, but it also heightened our awareness as parents to grow as well. 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 the behaviors we saw were uncalled for and unexplainable.**

**Now, as I look back on them, I realize 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 at home, I let the situation control me instead of my controlling the situation.**

**It’s so easy to get caught up in the moment and react without thinking through possible options. Responding properly through careful consideration is often not the first choice. I know now a proper response needs to extend beyond the capacity of our ears and patience is essential for the best resolution of a conflict.**

**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-age category, we would have had to think about Joy’s 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 a Saturday or Sunday to either go on an outing or bring her home with us to share a meal. Our relationship improved a great deal.**

**After Joy had lived at Verland for two years 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.**

**One reason is salary compensation; it just seems wrong to me people who care for special-needs individuals compete for salaries with individuals who are flipping hamburgers in a fast-food restaurant. Yes, both jobs may be stressful, but what is the consequence if one drops a hamburger on the floor vs. a special-needs individual who loses their balance and receives stitches or head trauma? We need to pay our caregivers a salary which is commensurate to their job responsibilities.**

**This is one area we still need to work on in our country; we need to maintain health-care staff who remain in the field for a full career and who are able to support their own families.**

**I had retired from a ground position with a major airline and learned Verland was going through one of these 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 as well. So, while doing research for my next career field, I couldn’t just stay at home each day 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 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.**

**Like Joy, the other clients were waking up shortly after my 6:00 A.M. start 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. It does take a little time to build up a level of trust with any individual.**

**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 by helping out in the other houses I was helping her house as well.**

**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.**

**Not many of the individuals are able to speak, but it’s still vital to verbally acknowledge each person when you enter a room. I remember one young lady I would greet by name and ask: “How are you?” After several months, I greeted her as usual and she looked at me and said “Hi”. I didn’t know she could speak at all.**

**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 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. 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 knew 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? Just don’t make the mistake of turning your back when you see a ball coming towards you; that can hurt.**

**It’s wonderful and reassuring to know we aren’t alone. It is also wonderful to know we can help one another. Support is available to anyone who will simply ask for it.**

**We all know humans are not perfect. Well, most of us know that! The realizations and the implications of this thought led me to more questions:**

* **“Have I really been making the wises choices?”**
* **“Can I do a better job as a parent?”**
* **“If I could do better, how can I change my old habits?”**

**The desire and struggle to alter habits may sound familiar. Changing the daily choices/decisions we make, may be 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. For one thing, there would be no accountability.**

**I don’t have all the answers to give you concerning behavior modification; I can only advise you to start looking for the answers. Sometimes it’s good to use an established program, and at other times self-reflection and humility may set you down a better path.**

**So, with that said one approach may be professional counseling or a class. Or you may start by recognizing your weaknesses as well as strengths; then simply get involved by interacting with others. Accountability is a wonderful and underused tool these days.**

**The mere fact one interacts, often opens-up a window to a world which has 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 which may ignite some positive changes in your life.**

**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 ballpark, 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 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.**

**As a message to 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 the 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.**

**Joy’s 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 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 here is: rather than a verbal response to a negative stimulus, a behavioral response might be observed instead.**

**Loud group noises evoke similar responses. 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 someone saying, “Let’s go, let’s go, come on,” and not get the response they wanted. Without knowing it, the caregiver is being impatient. 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 or 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 approach 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. 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 behavioral issues stem from boredom and can’t be expressed verbally. Especially with special needs, the good advice I can give is to remain focused and remain calm.**

**Oh, I did just give you some advice; well no one is perfect.**

**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 wouldn’t be able to bend over to pick up the cookies. Then with some verbal queuing and pointing from you, Joy will normally 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 or paper towel in front of her at the table with two or three pieces slightly separated. Now she would be better able to pick each one up nicely. If she were to throw these contents as well, 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!**

**So, a point here to remember: Be a life-long learner. The more you learn, the more you will be able to pass on successful techniques; why, because they worked.**

**And lastly a thought concerning one’s level of collective learning experiences:**

* **Is knowledge itself considered to be wisdom?**
* **Is wisdom achieved only at one particular level of accumulated knowledge?**

**To me, wisdom is much more. Wisdom is the collective expression of many components. These are a blending of knowledge, kindness, peace, compassion, empathy, and love. In fact, the presence of wisdom might be assessed without addressing the topic of knowledge at all. One example might be: I feel many individuals with Downs Syndrome instinctively display a measure of wisdom as they act and react to their environment out of honesty and love.**

**There is humility in wisdom. There are also other attributes associated to wisdom. Think about it if you will. Loving and caring for special-needs individuals should come naturally, so it must be us, not them, who must take the initiative to change.**

# **Chapter Six**

# **Maximizing Your Child’s Financial Sustainability**

**We found out rather early in our walk most of the care available to our family was 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? Our state of Pennsylvania was not structured to provide in-home personal care.**

**Unless you are financially well off enough to afford private care, or you are in a hospice situation, there is little professional or financial help available for services in the home. Each state is structured differently, and you should find out just what your legislators have established in your state.**

**We asked many questions in our attempts to obtain help. Through Social Services, Respite Care was the only option for us. Respite Care was granted for fifteen hours per month. This averages out to about thirty minutes a day.**

**Understandably, 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, at least not currently in our state. 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 group home.**

**Funding, such as SSI funds in our state, cover expenses for an individual to live outside of their family home, so why not for certain expenses inside the family home? I think that’s a good question. There has been a little progress in this area concerning senior citizens, but not enough for special-needs individuals as far as I know.**

**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. Perhaps my math fails me, but I also think it’s a wiser and more prudent use of funding. After all the family would still be covering many of the over-head costs instead of the state or federal government.**

**Think of the cost savings of one employee for six hours of work compared to the over-head and salary cost of a care facility. If an independent care-provider needed to buy even one new group home site and modify it for special-needs individuals; it could cost them 200 to 500 thousand dollars of overhead.**

**That amount of money (although not directly government funds) could go a long way in caring for an individual in their own family home. Funding programs need to be re-imagined for the sake of all. Perhaps even a designated care provider may be granted authority to provide care staffing in a private family home until space is available at one of their group-home sites?**

**Isn’t a family home the epitome of the term ‘inclusion’? The system falls short of being a family friendly provider in this crucial area. This is certainly an area where bi-partisan cooperation could go a long way.**

**One more thought on this subject; please remember there are many families now waiting for an available group home. They are struggling on a daily basis just hanging on to hope that their need for personal care will be answered soon.**

**Let me move on now to another issue. We knew when our daughter became eighteen years old, she was considered to be an adult. We get that, but as a family we simply continued to work with the medical and social institutions to provide the assistance our daughter needed. For us, nothing significantly had changed when she reached the age of eighteen. Oh, but it had changed.**

**A whole new chapter opened our eyes in only one day’s time. In 2009, in the daily delivery of the mail, 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 expressed 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 the account was fraudulent. I suggested 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 however was simply to confirm the form of payment on Joy’s account. Their legal protocol was nothing short of ridiculous in my eyes.**

**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.**

**I went down to the county courthouse 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 a petition with the court. The filing fee was $146.00. If we were granted guardianship, I believed from my talks with the lawyer there would be no additional costs involved.**

**We were advised we would need to submit an annual report to the court concerning Joy’s care after we were awarded guardianship. If for any reason we weren’t granted guardianship, then we would be subject to pay some court costs.**

**The court assigned us 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 rather short in length 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 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 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.**

**Through a number of phone calls, we learned of a lawyer who 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 brief 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 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 established as Joy’s legal guardians.**

**The reality is bad people may 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 for guardianship 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 thought: begin to plan before your child reaches eighteen so you will know what options are available to you in your state. As parents, our children must hold our highest attention and our deepest concerns. Remember, we are their main advocates!**

**Now that we were Joy’s legal guardians, other topics such as wills, and a trust for Joy all entered the picture. We were always aware these items needed to be handled at some point in time, but money and time always reared their ugly heads.**

**Education is a broad term and may cross through many disciplines. I certainly can’t ignore the topic of a child’s finances; which can be a complicated issue each family should address.**

**We learned it is one thing to leave your estate to a healthy child, but totally different if you have a special-needs child. I’ll do my best here to clearly express my understanding of this complex issue.**

**The concept of being an individual’s legal advocate can’t be separated from that of a financial advocate as well. I feel for the sake of all of your family members, each family should sit down and figure out how to develop a fair financial plan for all members of the family.**

**Why is it individuals with severe special needs are mandated by law to live in destitution? I had never given this idea consideration before, but I think it’s a good question. The law mandates for an individual to receive SSI funding they are only allowed to have a very low amount of personal wealth.**

**If they go over the maximum amount allowed by law their SSI funds are actually with-drawn until their funds are brought back into compliance. (The maximum amount varies slightly by funding source.)**

**Really, how can this be?**

**What other group of individuals are treated so harshly? Aren’t other groups of financially needy individuals encouraged to improve their financial status? Where does this leave a family who wishes to provide for their special-needs child/adult prior to the parents passing-away?**

**There are no easy answers to these questions. This is why I mentioned earlier, healthy children are treated differently than special-needs children. So, what does this really mean?**

**Normally parents will establish a will or living trust and when both parents have passed away their estate is passed on to their heirs in accordance to the standing legal document. However, for a special-needs child, they are not allowed to own assets at a similar level as their siblings. If they received an inheritance through normal channels, their SSI funding would stop until the entire inheritance was spend down.**

**Okay, let’s be fair about this issue of money. Special-needs individuals receive a lot of funds through the SSI program and medical health plans; housing benefits, food, therapies, medical care including costly surgical procedures. Why should they get all this for free? I view the SSI Program and health care as insurance programs. Are they insurance or something else? It doesn’t matter if the individuals are poor; they are being taken care of by highly trained staff.**

**Well that is one way to rationalize our current laws, but where does it leave the special-needs individual? As I mentioned before, special-needs children become special-needs adults. What happens to them when their parents pass away? Do they even have siblings or other relatives who are still living? What happens if their care-provider files chapter 11?**

**Our family is indeed thankful for the SSI program, please don’t misunderstand me.**

**If our country didn’t have a program such as the SSI program, many families would be living out in the streets because they couldn’t afford the medical care. Parents would lose their ability to support their families.**

**Law makers will be quick to point out: oh, by the way a family is able to establish a Special-Needs Trust for their loved-one. Yes this is currently the only option open to parents which I am aware of. Let’s take a close look at this option.**

**A Special-Needs Trust may be established for any qualifying individual as a safe place to hold wealth above the maximum state or federal limits the law allows for said individuals. However, is it necessarily a fair and equitable solution?**

**Here are some of the issues:**

* **The trust requires a specially trained lawyer to draft the document and may not be affordable for many families. (Once established-the trust may hold funds given by parents or any family member or friend in a completely secure financial institution.)**
* **However, there are rules governing the Trust – if any one of them is broken, all the funds are considered ordinary wealth and subject to SSI rules (the Trust is considered null and void).**
* **Does a Special-Needs Trust actually provide a practical value for a special-needs individual as a daily resource?**

**What are the benefits of a Special-Needs Trust? Under the guidance of an Executor, funds may be withdrawn to purchase personal items of need. But what about the bulk of the funds; how may they ever be used?**

**A special-needs individual isn’t allowed to buy a gift for a family member on their birthday or at Christmas, because the funds are for their personal use only. All SSI funds would cease until the wealth was spent. Their healthy siblings are certainly allowed this social and loving gesture, aren’t they?**

**Well, funds may be passed on, as in any will, to designated family survivors or to a charitable organization. Under the guidance of the Executor decisions will need to be made in the event the individual’s care-provider files chapter 11. I guess the most logical approach for an Executor would be to identify a new care-provider in which the individual’s trust funds stay where they are.**

**Unless the entire system folded why would an Executor go into the Trust to pay for care? Unless I’m not seeing the full picture here, generally once Trust funds become Trust funds, they will remain Trust funds until the Special-needs individual passes away.**

**The healthy sibling, however, has many more options. It looks like to me the current laws stand more as an emotional security blanket for families, rather than a viable financial tool for a special-needs individual.**

**Once again, I wish to express my deep gratitude for the many strides we have made in America towards the care of these lovingly innocent individuals, our special-needs children. But there is still much work to be done on their behalf.**

**I have been sharing about care offered in our country, but what about children around the world? Are the hopes and dreams of any child or family around the world any different than those living in our country? Should we simply ignore children in poorer nations? I recently traveled to Panama in Central America and learned more than I wished about the conditions special-needs individuals live under in a third world nation, if they survive at all.**

**America, with all her wealth and compassion, also has a responsibility to lead the way in education and medical care, to train others around the globe. My heart broke for the children of Panama. Let’s begin to even look beyond our own borders as well.**

# **Chapter Seven**

# **Family Dynamics**

**As parents, we will always support and protect our children no matter what age they are and no matter what their health condition. 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.**

**Family dynamics evolve naturally as the family grows from two to whatever size. And as the family grows the dynamics of family relationships will also grow. We need to continually address the weaknesses and strengths of the family unit.**

**Remember the single mom we had received the compelling email from? Well let’s talk about her feelings and try our best to bring this whole discussion about relationships into our own homes. For one thing, she was feeling a lot of pain through confusion, fatigue, and isolation.**

**We know she was a single mom, because she told us so, but she wasn’t really alone. Not really. She lived in a community and it’s safe to say she had friends and extended family around. She simply got to such a low point of depression she cut herself off from the very people who could help her. I can’t even exclude the possibility she had other children.**

**If this mom was unable to open-up and reveal her deep emotions with an adult, how could she possibly open-up to her other children? I don’t know if she did have any other children, but how about you? Are you able to open-up to all family members so they will feel more a part of your life?**

**Remember it’s just not the special-needs child and the parents who are dealing with this; every member of the family is affected. Do you have extended family and friends you have withdrawn from? Become isolated from? Do you feel embarrassed or ashamed?**

**Recognizing such feelings is the first step needed towards healing. You may need to first acknowledge a broken tool is unable to fix anything. Have you ever picked up a hammer only to realize it has a seriously splintered handle? It might drive in a tiny brad, but the handle will most likely completely separate after a little more use. Are you currently like this broken hammer?**

**Simply stated: Are you on the verge of falling apart? It may be time to swallow your pride and humbly seek help. Help is actually all around you from your family, friends, and a variety of medical and social programs.**

**In the process of providing for your special-needs child, don’t leave out your immediate family members. Don’t feel as though you have to do it all by yourself. For your spouse and the sake of your other children, make every effort to get everyone involved. This will teach each member the valuable lessons to be learned concerning love and respect, which will follow them for a lifetime.**

**I believe you will be amazed by the amount of love and support children are capable of lavishing on their sibling. Start by talking to your children with the same honesty and sincerity you would afford any supportive adult and lavish your children with hugs, kisses, and verbal praise.**

**You see, your healthy 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.**

**Our nation has developed wonderful resources through the hard work of many advocates over the past seventy years. These resources are there for you, your spouse, and your children. Please take advantage of them!**

**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, whether the issue at hand maybe in the near or distant future. Occasionally there is little or no time to reflect before reality presents itself. Becoming a life-time learner is essential and beneficial for any family to thrive.**

**This brings me to a story outside our wheelhouse which was reported on a national news program in April of 2009. While we were then twenty-three years into our journey, this report revealed two other families who were just beginning theirs. It’s one of the stories I pray you will never find yourself in.**

**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 have been a Lissencephaly child. The actual diagnosis isn’t really needed here.**

**The second infant was one month old and was perfectly normal except 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 younger 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 to all parents who find this reality. The report concluded with this scenario: If the heart was to be donated, the first 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 us all. Seeking knowledge and wisdom are vital.**

**Some choices are difficult; no question about that. 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 in a single family?”**

**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 thirty years and, from our observation, we know her performance level is about that of a two-year old child.**

**Yet we ask, “What does she truly understand about the world around her?” We did have a baseline up through the age of eight; when Joy wasn’t on any medications, but that was a long time ago. Joy is now turning thirty-two and lives with a varying degree of drugs in her system.**

**Joy’s hearing is normal, so she has received input concerning issues such as family structure, emotional expressions like happiness and sadness. 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 going on 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.**

**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 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 its’ 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 those name tags and colors.**

**More recently we have become far more aware of Joy’s strength in her long-term memory skills. We moved from Pennsylvania to Arizona for five years and then back to Pennsylvania. Upon our return, Joy moved back to Verland, where she previously lived prior to our move to Arizona. To our amazement she immediately remembered not only the Verland campus, but the names of many of the staff who had worked with her.**

**Although Lissencephaly is a severe condition, I sometimes simplify it to a communication deficiency. For one thing, it is easier to explain her condition to a new acquaintance when there’s not a lot of time to go into a lengthier discussion.**

**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.**

**Joy’s 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. 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. This issue hasn’t totally been resolved. It comes and goes based on Joy’s overall health condition on any given day.**

**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.**

**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 hope you see from this brief dialog concerning family dynamics how important it is to work on strengthening the family unit. There are those issues which each family may address themselves and then there are areas in which neighbors and professional organizations may be able to play a vital role. Please remember we are made to be part of a community. We are not able to maximize our full potential in isolation.**

# **Chapter Eight**

# **Conclusion**

**For all special-needs parents and especially the younger parents, I hope you are feeling a spark of encouragement. This life is not meant to be easy and it’s not meant to be lived alone. We are designed to seek out relationships, as many as we can. Some of them will be of help to you and some will be help you provide to others.**

**As a case in point, I would like to share part of a story line from an older movie from the 1950s called “The Inn of the Sixth Happiness”. Maybe you have heard of it and maybe you haven’t. I’m not even sure you may be able to locate a copy anymore. The main reason I’m bringing it up is because the movie epitomizes many types of relationships in a newly developing cross cultural environment. It also illustrates patience, perseverance, and faith.**

**The main character is a young English woman named Gladys who feels called by God to go to China. She wants to do a work of value where in England, prior to WWII she is only qualified to be a household servant.**

**Making her own way to China, she learned of an elderly female missionary worker needing a helper. After many days traveling by train and on horse-back Gladys arrives in a remote mountainous village in central China to meet Mrs. Lawson.**

**Gladys is warned that the people in the next village are themselves considered foreigners and treated as such, but still takes her first walk through the village. While on her walk she meets a toddler, who has been knocked over by older children and Gladys stops to put the toddler back on her feet. The child’s mother is furious her daughter was touched by a stranger and along with several other women the mother chases after Gladys.**

**In her attempt to flee the angry women, Gladys ends up in the town square and unexpectedly witnesses the beheading of a convicted felon. Totally devastated she returns to the Inn and Mrs. Lawson explains there are many short comings in any culture, but that is exactly why they are in China to try and help; one person and one day at a time.**

**Mrs. Lawson explained to Gladys it is a hard life for a young woman to pursue such work in a foreign country, but when you’re old and look back, it will only look beautiful.**

**Only look beautiful! Isn’t that a wonderful goal for all of us to experience when we look back over the years we’ve spent? Be brave and look towards your long-term goals.**

**I was recently asked by a friend: “How do you know when you win?” He was referring to the challenges of trying to help improve any issue for special-needs individuals or their families. He had asked others the same question and didn’t get much of an answer.**

**Well I thought for a brief moment and replied: “For me, it’s simply when I get a smile or hear laughter where there wasn’t any before. That’s exciting for me; that’s when I know I’ve won.”**

**Just keep in mind you will need to be patient. Moments such as these may appear as often as a cool stream of water in the desert.**

**My wife and I had one of those winning moments just last Thanksgiving Day morning. Our daughter has lived in an ICF (Intermediate Care Facility/group home) for a number of years now. We see her frequently and picked her up that morning to celebrate Thanksgiving together at our home.**

**While driving home we noticed she had a congested cough and asked her to cough it out, if she could. After a little thought, she gave us a big rattled cough and said the number “one”. Okay, that was an interesting response we hadn’t heard before. Without commenting on the number we asked if she could cough some more. She thought about it for a while and coughed, follow by the number “two”.**

**My wife and I just looked at each other, smiling. We asked our daughter if she could cough any more. In another 20 to 30 seconds she coughed again and said “three”. Well she then continued to cough and verbalized the number four, then five, six, and seven; all numbers were preceded by a cough.**

**We were elated for this was the first time we had ever heard our daughter count from one to any number without a prompt. Mind you, our daughter was then thirty years old. We couldn’t hold in our joy.**

**This is one of those “winning moments” and they don’t happen too frequently. I think it would be any parent’s desire and joy to see a winning moment on any given day. Wouldn’t you? I have hopes and dreams and pray that these special moments will never end.**

**Let me connect my last words and hope to the following thought. You see I have had the nauseous uncomfortable feeling for years Joy maybe over-medicated, and perhaps it’s the medication itself which may be causing her seizure activity.**

**I tried once to explain my feelings on this topic to our Neurologist and he didn’t want to entertain the thought. But then he hadn’t seen Joy seizure-free for five weeks after her brain surgery as we had.**

**After all, isn’t Epilepsy, just Epilepsy? We have to treat it! But let’s not forget the “why” question. Why is Joy having Epilepsy? She does have a very rare condition.**

**I have learned through observation our daughter’s cognitive level fluctuates up and down, not totally from the level of meds she is on, but rather the level of seizure activity she is experiencing. Please keep in mind the extreme complexity of this health issue. At this point in time, two unpredictable situations had emerged simultaneously.**

**To begin, Joy was in the process of being weaned down from the drug Banzel, which upsets her stomach and caused her to lose 24 pounds in about a nine-month period. The second situation was our Neurologist went on a three-month medical leave for a scheduled surgery. The result from these two events was that we were able to uniquely monitor Joy at a lower level of medication for a longer period of time.**

**If Joy’s seizure activity would have climbed, we would have consulted a physician to treat her accordingly. However, we had been witnessing fewer seizures and observing her cognitive skills were on the rise.**

**This was actually the first time we saw any positive change in her seizure activity as a result of a medication change. Even more interesting to me was the fact it was a medication decrease, not an increase. It also established that Joy’s seizures are not degenerative in nature.**

**If this continues to be the case, we could possibly seek to lower her other anti-seizure medications while carefully monitoring her progress. This would be a treatment option which hasn’t been considered or offered to us before.**

**It is my hope and prayer someday Joy might come off her anti-seizure meds completely or at least substantially lowered. Will this happen? I don’t know. It would give us great joy if this situation does come to fruition.**

**Let’s look at the complete range of possible out-comes here. One – Joy has Epilepsy and will be on anti-seizure meds the remainder of her life. If this is the needed treatment, so be it.**

**A second outcome would be even better in my thoughts. What if Joy’s brain surgery was and still is fully successful, and she doesn’t need the meds?**

**Joy will still have all her gross and fine motor problems and her cognitive delays, but she might be better able to maximize her potential and quality of life if she is it least on fewer medications.**

**We would feel badly if it turns out we mismanaged her med treatment for the past 17 years, however the thought of retaining the current treatment for the remainder of her life, when it might not be necessary, is a far more ominous scenario for me.**

**Winning moments, they come in many shapes and sizes. Even as I am writing to you, we are experiencing something new. I mentioned earlier doctors are practicing physicians, they aren’t in research. There is no way I could fault any doctor for following the industry standard of medical care.**

**However, with this said I was dealing with my own internal struggle. One of Joy’s newer medications is Onfi; it is a very strong medication. Whereas most meds are measured in increments of 100mg and therefore easy to calculate a patient’s total med level; Onfi is measured in increments of 1mg and I was informed there is no mathematical formula to combine both levels of measurement to determine a patient’s total medication level. This fact alone threw up a red flag in my head.**

**If you are a family dealing with uncontrolled Epilepsy, you also get this.**

**So, as we continued changing med levels with Onfi, our daughter wasn’t doing well on her higher doses. We needed to lower her dosage level to better control some severe behavioral issues we were observing.**

**To our surprise, as we started to decrease the medication, instead of improvement, we were seeing the unwanted side-effects increase, not decrease; so, the doctor wished to increase the Onfi once again.**

**Hold on here, I could only see this as an unwanted repetitious cycle.**

**For the sake of time, I’ll try to give you a short version of what happened next. I was having a hard time communicating my feelings to the doctor and felt the medication process being offered was not a good approach. So, through a friend I learned our healthcare system has a Patient Advocacy Department and I requested a consultation.**

**The consulting doctor agreed with me that Joy would be a candidate to lower her dosage levels, because Joy’s history shows no medication increase has actually shown a visual reduction in her seizure activity.**

**He had one other patient who had not responded to a med treatment and he was able to lower her from three meds to one med without negatively affecting her seizure level. Through the dialoging process, we decided to put Joy under this new doctor’s care and began to lower the Onfi again.**

**But wait a minute here; this wasn’t a clear-cut winning moment just yet. To my dismay her seizure activity was once again starting to spike instead of wane. Why was this happening?**

**After a lot of soul searching over the past five-month period of medication changes, the thought emerged that perhaps Joy was going through a drug withdrawal phase from being lowered from the higher level of Onfi she was on at one point. Maybe we were moving a little too quickly. Perhaps a few more weeks of monitoring will reveal an answer.**

**One night I couldn’t sleep and woke up at 1 AM. I revisited the question of why our daughter had Epilepsy in the first place. Lissencephaly is translated as “smooth brain”, Joy has far less Nero-transmitters on her cortex than a normal brain would have. Therefore, the question came to me: “How do Joy’s medications actually interact with her brain to achieve their desired result?”**

**I was surprised at the answer. Joy is on three medications for seizures; Zonisamide, Trileptal, and Onfi. Both the Trileptal and Onfi work through the nervous system, so they are trying to work through her Nero-transmitters of which Joy has very few. These two meds are about 90% of her med treatment. Both of these meds were trying their best to enter through her Nero-transmitters but were unable to find them in many cases. However, 100% of the medication was somewhere in her system; doing what, I don’t know.**

**Upon further dialog, the doctor then made a small increase of the third med, Zonisamide (which has a different mechanism of operation from her other meds) from 300mg per-day to 400mg per-day and we waited for the result.**

**To our amazement Joy had significantly less seizures within 24 hours of the medication change and she is so far maintaining the improved level. We are so grateful; this is now the very first orchestrated time in twenty-three years of treatment in which a medication increase has actually produced a positive outcome.**

**This is indeed a winning moment and we are realizing the onset of a new treatment plan. We don’t know what lies instore for Joy as we may now attempt to lower her other medications, but we have a new hope Joy’s quality of life maybe at least restored to the level she enjoyed prior to contracting Epilepsy.**

**You see our story still has no ending and is indeed complicated. The struggles, the challenges, the searching, the learning, the successes and failures will continue to unfold. It is still our job to continue on (to persevere) one-day-at-a-time and love our children the best way we can.**

**Lovingly and respectfully as possible, ask all the questions you can think of for the sake of your children. We are their advocates.**

**It is my belief that: “The more I learn, the less I realize I know!”**

**If you haven’t yet started to think outside of your box, then perhaps it’s time to start. No matter how hard it may be for you, I believe we need to put ourselves in the very last position and our children in the very first position. You may think you are doing that now. Well maybe you are and maybe you’re not. If not, it’s time to crack the box open.**

**I hope you are encouraged to learn and grow with your family. Reach out to others; this country of ours is unique in history and still has a great potential to influence not only the care of special-needs individuals in this land, but around the world.**

**Think about where you are now. Then begin to work on where and how to get where you would like to be. Just like Mrs. Lawson shared, when you’re old and look back, it would be wonderful to finally acknowledge everything does indeed look beautiful.**

**Should we be satisfied with unfulfilled political promises? Perhaps, but I think it’s time we all step back into the game. We aren’t merely the recipients of change and growth; we are the tools in which change will take place. Step up and step out into our country with a new vision and excitement which proclaims we can do this together.**

**I, for one, want to look back at the end of my days and see nothing except beauty in the lives of all those who carry on after me. What about you?**

**And please remember, this walk as parents won’t be easy…it isn’t easy. It may even take some gut-wrenching perseverance to make it through. Once again, I will express my urge for you to be a life-long learner; focus on the long term as well as the short-term reality your child faces.**

**I know first handed it can be hard not to call the doctor after your child has experienced a horrific day of seizures. We had one of those just yesterday.**

**Before you might call, ask some questions. Are these days occurring frequently enough to warrant a medication increase? If we do increase the medication, will we be risking a significant decrease in our child’s over-all quality of life? As in all matters of care, safety comes first and remember each child is unique.**

**And now one last thought before we end this dialog; this thought is for our children. Those with severe challenges are living their lives with limited verbal communication skills, however I have faith that one day they will all be healed.**

**When that day comes, I believe every one of these special children will look you in the eyes and say: “Mom…Dad…I love you so much…thank you for walking the walk with me. I couldn’t have done it alone.”**