

### **CFC Family Featured on PBS TV Show**

*By Nevada and Anthony Verrino, Milford, Michigan*

Many members of the CFC family remember our dear son, Anthony John Verrino, who passed away January 25, 2007 from complications related to CFC. He was 26 months old and suffered from a severe and uncontrolled seizure disorder. Parts of his and our journey through his death were documented in a film produced by Frontline (PBS).

Even though we were preoccupied with caring for little Ant. throughout the filming and were mourning after his loss, we agreed to participate in the making of the film. The intention was to highlight the journey of dying and the traditions that surround it. Death, especially for a sick child, is a topic that many people are very uncomfortable with, and one that we, through our son's journey, were living in the middle of.

The film, based on the novel, *The Undertaking*, was written by a local author, Thomas Lynch, who also runs one of the Lynch and Sons funeral homes. Because of a long and trusted friendship with the Lynch's, our involvement with Angela Hospice through which the film was produced, and the sincerity of the producers, we felt like we were meant to be a part of the project. We hoped that the mention of hospice might spread the word to many families with sick children, that they might consider the option of giving their sick child a comfortable life at home instead of staying on for experimentation and testing at a hospital.

We also hoped it could show that hospice is not only for the dying person's last few moments, but that they might help the person long before, once the family has decided that invasive medical procedures were not favorable for their loved one. For us, that moment came when Anthony was 12 months old, and the doctors wanted to give him potentially lethal doses of a seizure medication, put him in a coma and on a vent, to see if they could "reset" his seizure ridden brain. They did not know what to do with him anymore, and they told me that. Suddenly, I knew it

was time to take him home. If they couldn't control his seizures, at least hospice could keep him comfortable while he had them. We decided to keep trying to battle the seizures...like the Ketogenic diet, new medications, and continuing his existing seizure medications, but hospice allowed comfort medications for all those bad days.



**Anthony and Nevada Verrino with their son Anthony John**

Even though the final cut of the film did not focus on pediatric hospice, it did cover such wonderful themes about the traditions that help us grieve that we were proud to have been a part of it. The greatest treasure is the feedback we received from people around the

country about how the film helped them address grief in their own lives. A very close second is the archive of footage that we have from our son's living days, his funeral, and our grieving afterwards. We were too tired to film anything ourselves at that point in his journey, so besides a few photos, this record of our baby's last months will be a treasure to us for the rest of our days.

If you are interested in viewing *The Undertaking*, which aired October 30, 2007, you can view it in its entirety online at [www.pbs.org](http://www.pbs.org). Look for Frontline, then *The Undertaking*. There are also additional interviews, the eulogy, and letters from people across the country.

We are so proud of our little CFC angel and thankful, once again, for your support.

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We offer information, support, newsletters, an address directory, brochure and Parent's Guide. Our mission is to assist those whose lives are touched by CFC Syndrome and to improve lives through family support, research and education. The group is self-funded. Contributions are gratefully accepted and will help the next family to receive information about CFC Syndrome.

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## Message from the President

As often as I am used to sitting in a hospital recovery waiting room waiting for post op news, I never thought I would be there alone without my spouse and best friend Cliff. Cliff and I have endured years of medical appointments and procedures with Cliffy; the loss of my brother and mother; and recently a long past year dealing with my father's three surgeries, falls, and rehab recoveries. Today, I sit alone at University Hospital in Syracuse waiting for news on my husband's extensive surgery from a burn accident. Both legs are being grafted with upper thigh skin. I know that our family will have a long recovery period and Cliff will have to work hard to learn to walk and use his muscles all over again. As I sit here, I am thinking of the card we received from friend and medical advisory board member, Ines Kavamura. She wrote for Cliff to be good and for me to have patience. The one thing that our family has learned while dealing with a CFC child is that patience and taking things one day at a time is all any of us can do. We are very blessed that Cliff is alive and that his injuries were only to the lower body portion.

Receiving cards and E-mail messages from the CFC families and other friends has been a source of comfort to our family. I thank you all for the support. This upcoming holiday season we will be thankful to get Cliff home. The time alone with Cliffy is hard since he does not understand why we just can't bring daddy home and take care of him on a bed right out in the living room. He does not fully understand the depth of this whole ordeal. On a positive note, Cliffy is overjoyed that he can skip his growth hormone injections until daddy comes back home. For those of you who know me, I don't do well with medical procedures so we have taken a break from this nightly injection.

As I think back to when Cliffy was born, when he eventually came home from the NICU back in 1993, our first medical trip was to Upstate Medical in Syracuse to see a pediatric urologist over his kidney problems. Here we are back to this same area again, but this time I am really missing my partner and love of my life who has been my strength and best friend through all of life's challenges.

Thank you all for your prayers and support during this difficult time.

**Brenda Conger**

E-mail: [bconger@cfc syndrome.org](mailto:bconger@cfc syndrome.org)

## Donations

### Thank you!

CFC International is grateful to its supporters for their generosity. We extend our deepest thanks to the contributors listed below for their kind donations.

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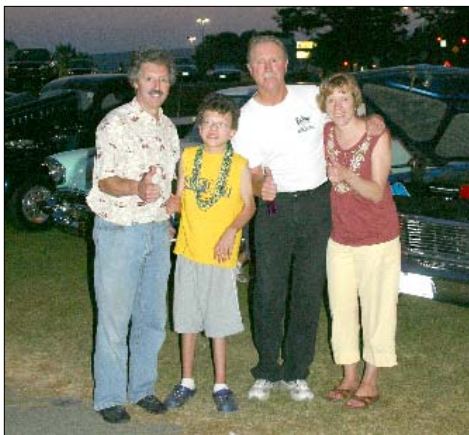
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## Cruisin' for CFC



Cliff, Clifford, Ron & Brenda

The Binghamton NY Cruisin' Buddies Car Club hosted their annual fall Memory Cruise on September 8th. The club has generously supported CFC International over the past four years. The evening started off with club and community drivers meeting in a parking lot in Endicott, NY. Each car donated \$5.00 to drive in the cruise over to Greenfield ballpark in Johnson City. The approximate 5 mile cruise from Endicott to Johnson City ended with a 50's type of rock and roll party with skits.

To everyone's delight, club president Ron DeHause entertained the crowd with his female impersonation of a singer from the 50's song, "I Ain't Got A Home". Cliffy was in his glory eating a hotdog and roamed through the crowd to pick up Mardi Gras necklaces that had been tossed out to guest during the evening. A total of \$600 was donated to CFC International. We thank all the members of Cruisin' Buddies and their board of directors for their continual support!

## Chicago Marathon - CFC Fundraiser in honor of Lillian Hux

Back in January 2007, I decided to run the 2007 Chicago marathon. I had never run before.

Shortly after I told everyone in my family I was training for a marathon, and after I convinced them I had not lost my mind, I found out that people use their marathon experiences to raise money for charities. That's when I was introduced to CFC International.

My niece Lillian Gracie was born on April 22, 2004. Her story mirrors that of so many of your CFC children. Through her short life, she has shown more courage than anyone I have ever met and has always had a smile for everyone. I'm sure the same is true of all your CFC children. So when her mother, my sister Glenda, asked me to adopt CFC International as my charity, I accepted.

The truth is I knew very little about CFC and the work of CFC International prior to this. I looked through the website and read as much as I could about it, in the months that my training lasted. I read the stories about other CFC families, smiled at the pictures of your beautiful children, and decided I would do the best I could to raise as much money as possible for CFC International.



**Kayra Johnson and Lillian Gracie**

As the months went by, the training became more challenging. I trained in the hot, humid Mississippi summer. I trained in the rain. I trained through the physical pain. I always kept in mind Lillian and all the other CFC children whose smiles had given me so much courage.

My marathon experience came on October 8, 2007, in Chicago. Record heat had been predicted for that morning, but I was excited to be there and to put myself through the test. I thought of Lillian many times through the course



**Kayra Johnson at the Chicago marathon**

when I felt like stopping, when I thought I couldn't go another step. I thought of all the CFC families who had emailed me prior to the race, of the pictures they had shared with me, of all CFC children. They helped me get through the miles.

As many of you know, the race was cancelled due to the heat. I was able to complete 17 miles before being redirected back to the starting line thus only able to complete about 21-22 miles that day, including the rerouted portion. I was disappointed that I was not able to complete the entire distance.

There will be other marathons, and I will have another chance to cross the finish line for myself, for Lillian, for all the CFC children and their families. It is your courage that helped me endure the training and the race.

Thanks to all of you who emailed me with your words of encouragement. Thanks to Brenda and Judy for all your help through the months. I was able to raise a total of \$1,700 for CFC International.

All of you have a very special place in my heart and in our family. I plan to continue running and to continue to use my running as a way to raise funds for CFC International. Thanks for all you do and God bless.

Kayra Johnson

***... no friendship can cross the path of our destiny without leaving some mark on it forever.***

*Francois Mauriac  
French playwright*



## 3rd Annual CFC International Golf Tournament

The wind was blowing and it was a brisk morning – the perfect day for golf, no, but everyone had a great time anyway.



**Ronnie Zeunen**

Over 72 golfers joined us at Olde Point Golf and Country Club in Wilmington, NC for our 3rd Annual CFC International Golf Tournament in honor of Ronnie Zeunen. During the round, golfers stopped by the practice green to

take part in a putting contest. After 18 holes, our happy golfers returned to the pavilion for a delicious BBQ lunch where we awarded prizes to our 1st, 2nd and 3rd place winners, men's and women's closest to the pin, men's and women's longest drive and our putting contest winner. In addition we announced our raffle winners as well as our silent auction winners.

As always the participants were enthralled with the Power Point Presentation which raises awareness of CFC at the event and encourages continued support for the upcoming years.

Thank you to our beverage volunteers: Angie Zeunen, Lainey Vitale, Rachael Riebe, and Malachi Gaddis who encouraged our participants to purchase beverages and raffle tickets throughout the day. We would also like to extend a huge amount of gratitude to Joyce Benton and Tina Godley who organized all of the raffle items, Edwin Benton who set-up and operated the AV equipment for our presentation, and of course Sarah Benton who generously donated her photography services at no charge.

We raised over \$8,500 in net proceeds for CFC International!

If you would like to see pictures of our tournament please go to our web-site at [http://www.advancedautomotiveonline.com/2007\\_Pictures.htm](http://www.advancedautomotiveonline.com/2007_Pictures.htm)

The Zeunen Family would like to thank all the volunteers, golfers, team sponsors and prize supporters for their participation in this years' golf tournament and fundraiser. We look forward to next year.

## 4-H Junior Leaders Raise Money for CFC

On June 21, 2007 the Ross County 4-H Junior Leaders sponsored a fundraiser in honor of CFC. It was a chance for local 4-H'ers to get together for a few hours and have some fun! Around 30 kids attended and paid a five dollar entry fee. The kids played corn-hole, made crafts, and practiced their line-dancing moves for the up-coming 4-H

summer camp. Isabella loved being the center of attention! She especially loved the line dancing and music. All of the kids were very sweet and interested in Isabella and CFC Syndrome. We had a photo board with pictures of other CFC kids and one of Isabella's scrapbooks on display. At the end of the evening everyone enjoyed ice cream sundaes and presented Isabella with a new outfit and a cute stuffed monkey for her sixth birthday, which happened to be that day!



**Isabella and Peggy Misita**

We are so very fortunate to have such wonderful youth in our community who have embraced Isabella and our family. I would like to thank Isabella's babysitter, Rachel Congrove and all the other Junior Leaders for coordinating this event and thinking of CFC International. Several other 4-H groups donated money also to bring the total raised to \$300.00. I could not think of a better way to spend a birthday!

Peggy Misita  
Chillicothe, Ohio

## Photo Gallery



Chris, Harley (8) (on the bipap machine), Justin (6), Renee and Brandon (4) Melvin



Meg young with her baby sister Ella Grace and younger brother Jackson in front of the Christmas tree



Meg young (9) the queen on halloween



Nana Conger, Greek Peak Ski Penguin & Clifford Conger (14) enjoying the wonderful NY winter snow



Kyle, Jared (10), Jordan (2), Jason (12) Stowell in the snow



Nathaniel (7) playing in the tube at the playground



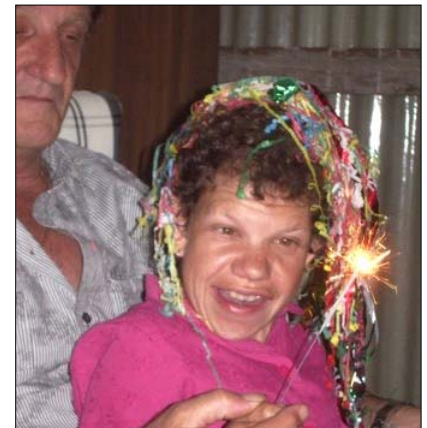
Brenan (5) and little brother Landen (3) in front of the Christmas tree



Isabella Misita (6) on halloween dressed as a ghost



Marcus Weston (3) as Santa Claus



Nancy Newton (21) holding a sparkler at new year



## Coming to Terms with Being 'Chosen'

by *Linda Miyahira, M.S.*  
*TCRC Service Coordinator II*

As a service coordinator serving families of children with disabilities, I have an upfront view of many things. I get to see what occurs when a frightening question turns into a more frightening confirmation. I get to see the grief process and how some parents never stop grieving or stay stuck in a stage of grief like denial or anger. I get to see babies with disabilities grow up or pass away. There are so many things that I see, but there are not many things that I am allowed to reveal because of my position. So, let me take this time to tell you what else I see...

I get to see little souls, little spirits, who come into families to shake up their very foundations. I see a child whose eyes convey so much more that can be expressed verbally. I see families totally oblivious to the answer to their prayers, the "guru" that they have been asking for in that prayer for a "perfect" life. I see parents so focused on finding a cure that they fail to be natural mothers or fathers to their children. I see families forget that they have a beautiful child and not a disability. I see parents grieve over a disability that they do not own. And, I see parents' faces light up with the realization that they were chosen to be the caregivers to an incredible little being...

As much as I see these things, I also feel them acutely. For I have also been graced with an incredible little being who is the guru for my own family. He is a gift who was not initially appreciated despite my many years of working with special children. I have seen through the tearful eyes of a parent receiving confirmation that their baby has a disability. I have raged at the very people who entered my child's life to help him reach his potential because they were grim reminders of a lost dream. I have blamed myself for possible karma from some possible bad deed that created his cross. I have seen my child surprise me and sadden me. I have seen the beauty that is my child.

Being 'chosen' is about choice. It is about choosing to pull that sword out of the stone of grief and former expectations and doing wonders with it or letting the sword remain in place and dreaming of what might have been if it had never been put there. The sword can either

cut down barriers or hurt others, as well. It is an opportunity given to few, but its potential for good is boundless...

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## The Doyle Family Story

It is always hard for me to know where to start the story of our family and our lives with Jack. I used to say, "when I was 16 weeks pregnant with my third child . . ." but now that seems so distant, so different from the life we live today. It has turned into that, just the story of how we got to be who we are today and what will lead to who we will become as a result of where we have been.

Our family of five lives in Medina, Ohio. Tim and I met while working our way through college. We got married and started our lives together. We loved working on our old house, hiking, riding bikes and spending time with our extended families. All three of our children were surprises, not planned or carefully thought out. Our first, Madison, who is now 14 years old was a very easy pregnancy and baby. It never even occurred to me that she would be anything but perfect (as they say). Sally followed 2 years later. Other than being a giant baby, one ounce shy of ten pounds, she was also an easy baby. I did have a few complications that gave me a hint that there could be problems, but we overcame them all. Three years later, while helping care for my mother who was dying of cancer, I learned I was pregnant with my third child. I remember so clearly, standing in my mom's kitchen, only a few weeks along saying to her "I think there is something wrong with the baby." Thinking back, I am sure I really didn't even know what I meant by that, I had no idea what it would mean for the baby or for our family. My mom passed away when I was 3 months pregnant. We were very close and I so missed having her to call each day. I wonder how different things would have been if she had been there through my pregnancy and when Jack was so sick. I do know now that she was there with me, it was just hard to realize it at the time. I know that she already met Jack and continues to watch over us all.

So back to when I was 16 weeks pregnant with my third child. . . I had an amino because of my age. The test showed normal chromosomes, but the level II ultrasound showed an abnormality with his spine. Other than too many doctor's appointments and way too much amniotic fluid the rest of the pregnancy was good. Jack was born on June 1, 1998. Other than looking a little red and few fused vertebra he was perfect too.

Now comes the other start to my stories. . . "when he was six weeks old he stopped breathing while in the car with me." Luckily I was able to revive him without CPR. Our little guy was admitted to our children's hospital. It seemed that every doctor who walked into our room had something to add to the list of things that were wrong although none of them could come up with a reason why he had so many problems. We were told it was probably something genetic but they didn't know what it was. We eventually took him home. Caring for Jack was so different than the girls. I am sure the addition of a third child would have been a challenge, health problems or not. I think the first year was so hard. It seemed Jack was an infant forever. Now I know what developmental delay is all about.



**Sally, Jack and Madison Doyle**

Jack was diagnosed with CFC when he was 2 1/2 years old. On a hunch, I sent a letter and photos to Dr. John Opitz in Utah. He called us within one week saying he thought he knew what our son had and could we fly out to Utah to see him. We quickly made the arrangements. Meeting Dr. Opitz and finally having a diagnosis was like reaching a summit on a climb that seemed to lead to nowhere. I'll never forget looking at the CFC web page and looking into Josh Schrock's eyes and knowing we had found others who have made it to the top too.

Today, Jack is nine years old. He is in 1st grade and loves school. This is the first year he is in school all day long. Our school system has been great with Jack. They followed our wishes and allowed Jack to spend three years in kindergarten. They always say you learn everything you need to know in kindergarten, we just wanted to make sure he got it. He is in a regular classroom with an aide, Mrs. P. She is a wonderful person in our life, meant to be where she is, doing what she is doing. He is taken out for therapies. I think he has just about all that are available, OT, PT, speech, vision and mobility. Jack's health has been good. Our main problem is dealing with daily headaches. Though he has been through many tests we haven't been able to find a cause and make him as comfortable as possible.

I think our family is comfortable being who we are. The way I look at it is, this is who we are supposed to be and our experiences are what have gotten us here. We are all perfectly the way we are meant to be doing what we were meant to do.

Judy Doyle  
Medina, Ohio

## Special Needs Estate Planning for Persons with Disabilities

*By Edward V. Wilcenski, Esq.  
Jones & Wilcenski PLLC Attorneys at Law*

One of the greatest fears that parents and other caregivers have is the possibility that they will die without having arranged for the care of a disabled son, daughter, relative or friend. Most families only have to be concerned about this issue until a child reaches an age when he or she is self-supporting. However, many individuals with disabilities will never be fully capable of self-support, and their parents and caregivers will have to plan for the day when they will not be available to provide assistance and oversight. For these families, the failure to properly plan can cause tremendous hardship for the person with the disability at precisely the time when he or she most needs help: when the primary source of support, often a family member or close friend, is no longer available for companionship, assistance, and help.



“Special Needs Estate Planning” is the practice of ensuring that services and support will continue for the life of the person with the disability when the caregivers are no longer able to help.

The type and level of assistance that will be needed vary according to the nature of the disability, the disabled person's age and family circumstances, and many other factors. For example, parents of a minor with a severe developmental disability are often most concerned with identifying a Guardian who is willing to undertake the task of caring for a special needs child. Caregivers dealing with mental illness understand that the illness can bring loneliness and isolation, and they want to ensure that there will always be an advocate willing to step in and assist in a time of crisis. On the other hand, many people with disabilities live very independent lives, and need nothing more than some basic assistance in their day to day affairs.

Comprehensive Special Needs Estate Planning ensures that the question, “Who will take care of my loved one when I am gone” is answered in the most cost-effective and efficient manner possible, and in a fashion that considers not only the needs of the disabled individual, but also the ongoing financial and health care needs of the caregivers themselves.

### **Begin With a Comprehensive and Honest Assessment**

Special Needs Estate Planning requires a working knowledge of a broad range of issues: government benefit eligibility, trust and estate law, estate and income tax rules, guardianship, and others. In all cases, the planner must understand the nature of the particular disability and must have a sense of what the future care and oversight requirements will be. In turn, the care needs will determine the resources that will be required to support a comprehensive care plan.

This last consideration, identifying the level and cost of the services that will be required to provide support to a loved one, is often the most difficult. Indeed, families and caregivers seldom add up the costs of the various forms of support they give to an individual with a disability. Those who contend that a disabled individual's financial needs are minimal often forget to add up the cash value of the many services they provide. These can include serving as advocate, social service coordinator, companion, guardian, chauffeur, money manager, and recreation director. These services enhance the quality of the disabled individual's life. If a parent or caregiver dies without planning for the

continuation of these services, the quality of life that the person with a disability previously enjoyed is likely to be reduced substantially.

Some of these “quality of life” services are available through government funded programs designed for individuals for disabilities. These programs are generally designed to provide only a basic level of support, and the items and activities that make our lives enjoyable, those that truly provide “quality of life,” are simply unavailable. Moreover, the eligibility thresholds for most of these programs are quite low, and living within these thresholds can be quite difficult. As a result, families and caregivers often seek to “supplement” the goods and services available through these public benefit programs with their own funds, but without jeopardizing benefit eligibility. This is where competent Special Needs Estate Planning becomes critical.

### **The Elements of a Comprehensive Special Needs Estate Plan**

Each Special Needs Estate Plan is unique, and it should maximize the formal and informal supports that the individual with the disability receives from government funded programs, family caregivers, community supports, and others. However, all Special Needs Estate Plans contain three basic components: a legal plan, a financial plan, and a life care plan.

#### **Legal Planning**

The legal planning component of a Special Needs Estate Plan will address many traditional Estate and Long Term Care Planning issues. Has the client considered how the estate will be divided among his or her intended heirs? What is the family's current estate and income tax exposure? Is there a Will in place, and if so, has it been updated since the onset of the son's or daughter's disability? Will the appointment of a Guardian be necessary, and if so, who will be the Guardian?

What if the caregiver needs assistance? Does he or she have a properly drafted Power of Attorney and Health Care Proxy? If aging parents are serving as the primary caregivers for the person with the disability, have they considered how they will pay for their own long term care needs without jeopardizing the inheritance of their children? Does the parent's Will or Living Trust include a properly drafted Supplemental Needs Trust, which is a trust instrument designed especially for individuals with disabilities? Who will serve as Trustee of the



Supplemental Needs Trust? Does the Trustee understand how these types of trusts are to be administered?

What is the functional level of the individual with the disability? Is he or she capable of executing his or her own Power of Attorney and Health Care Proxy so as to preclude the need for a formal guardianship at some future time? What are the federal and state benefit programs that support the person in the community, and have the eligibility requirements for those programs been factored into the Special Needs Estate Plan?

A sound legal plan will address these and other issues, and as with any type of planning, it is best developed early and comprehensively, considering the needs and intentions of all members of the disabled individual's circle of support.

### **Financial Planning**

A sound financial plan complements the legal component of a Special Needs Estate Plan. Whereas legal planning primarily involves the preservation and transmission of wealth, financial planning is primarily concerned with the enhancement of wealth and the selection of assets to ensure growth, diversification, liquidity and availability to meet a client's goals and objectives. The two areas are closely intertwined, and a comprehensive Special Needs Estate Plan will contain components of both disciplines.

Consider, for example, a family whose primary asset is the family home. Many families hope that the value of the home will be available as an inheritance for a disabled son or daughter and other heirs. Indeed, many parents and other caregivers contemplate that the disabled son or daughter will be able to continue to reside in the home after they are gone. But have they considered what will happen if they themselves reach an age when they will no longer be able to reside in the home and need assistance with their own health care needs? If the caregivers have not considered how their own long term care costs will be met, there is a risk that the home would need to be sold to satisfy these obligations, and may never be available for the son or daughter. One solution may be to use other assets to generate the income that would be necessary to pay these costs. Another possibility may be the purchase of a long term care insurance policy. In the end, the most appropriate planning route may be to restructure assets so that long term care costs would be paid for through the Medicaid system. Legal and financial professionals participating in the development of a Special Needs Estate

Plan should expect to share their ideas on the pros and cons of each strategy, and arrive at the most appropriate solution for the family.

More traditional financial planning considerations include planning to ensure that a family will have sufficient funds for a comfortable retirement, investing in assets that will minimize income tax liability, and consolidating assets to minimize the cost and effort of overseeing a diverse portfolio. These issues are best addressed with a competent and knowledgeable financial professional who understands the heightened importance of proper planning for individuals with disabilities and their families.

### **Life Care Planning**

The final step in developing a Special Needs Estate Plan is often the most overlooked. At least in theory, people appreciate the need to address the legal and financial issues discussed above. But once the parents and caregivers are gone and the assets have been protected for the benefit of the individual with the disability, many questions still remain. "How should the funds that the family has worked so hard to protect be used to truly enhance the life of the person with the disability?" "To whom should I, as Trustee or Guardian, look to for advice and suggestion when the person with the disability cannot speak on his or her own behalf?"

"Life Care" planning is the process of providing answers to these and similar questions for the family members, friends and advocates who will provide assistance and oversight after the primary caregivers are gone. It begins with ensuring that as much personal, financial, and other pertinent information concerning the person with the disability is stored in a single place and accessible for future reference. Many advocates use workbooks designed specifically for this purpose. The workbooks usually request background medical information, financial information, family history, community contacts, and recreational preferences of the person with the disability. The workbooks also often request that the caregivers provide similar information about their own finances and family supports.

This information can prove to be especially crucial for those who must step in and assist when the caregiver is seriously injured or dies unexpectedly.

It is difficult to overemphasize the importance of this step in the Special Needs Estate Planning process.



Consider this. If you were to get up and leave town today, right this minute, completely unexpectedly and without advance notice to anyone, including your disabled family member or friend, who would step in to handle your affairs? Does this person know where all of your pertinent financial information is stored? Have you provided him or her with the legal authority to access your funds and act on your behalf? Who breaks the news to the person with the disability? Who will step in to do what you have been doing all these years? Who stays in contact with the service coordinator or social worker? Who double checks to be sure that medication is being taken as prescribed? Who will make those calls when no one has heard from your son or daughter in days, and who will they call? And if you have someone in mind, have you provided this person with the information he or she needs to carry out your wishes? Does this person know what you know about your son or daughter's needs, preferences and dislikes?

To those people who will step in and assist your disabled family member or friend when you are no longer able to do so, a well written Life Care Plan will be worth its weight in gold. And as uncomfortable as it is for many parents and other caregivers to face the subject, completing this piece of the Special Needs Estate Planning process often provides the most satisfaction and relief. Certainly the legal and financial components are equally as critical, but in most circumstances, competent counsel will be able to preserve some of the family's funds for the person with the disability, even if no planning whatsoever has been completed prior to the disability or death of the caregiver. This "crisis intervention planning" is always more expensive, time consuming, and will be conducted before a court as a matter of public record, but it can be done.

Once the parents or primary caregivers are gone, however, the ability to prepare a comprehensive and detailed Life Care Plan becomes quite limited. There may be an Individualized Service Plan to use as a reference, a dedicated service coordinator who might have some additional personal information, or some other family member or friend who could assist in compiling pertinent information, but none of these fallback references will ever replace the Life Care Plan prepared by the person who has taken care of the person with the disability all of his or her life.

## Conclusion

"Special Needs Estate Planning" is by necessity a dynamic process. It is common to hear financial professionals talk about the need to periodically "review a plan" to be sure that it still meets a family's needs. This admonition is equally as important, if not more so, in the context of planning for an individual with the disability, as many people with disabilities are unable to actively advocate on their own behalf once their primary caregivers are gone. Laws governing taxes, property rights, and government benefit programs that support a disabled individual in the community are changing constantly. And the resources, needs and preferences of the person with the disability as documented in the Life Care Plan will change with time.

The most important thing is to begin the process. Once you have built the foundation, small changes are easy to accommodate. Legal documents can be modified, assets can be restructured, and new information can be added to the Life Care Planning workbook with minimal effort. But if you wait too long to begin the process, you may never have the opportunity to answer the question, "Who will take care of my loved one when I am gone?"

Mr. Wilcenski, Esq., is a co-owner and co-manager of the law firm of Jones & Wilcenski PPLC. He practices in the area of Special Needs Estate Planning, Elder Law and Trust Estate Administration. Mr. Wilcenski is Vice Chair of the Medicaid Committee of the New York State Bar Association's Elder Law Section. He is Trustee of the NYSARC Pooled Trust, serves as a Trustee of the Wildwood Programs Third Party Pooled Supplemental Needs Trust, and serves on the Board of Directors of the Living Resources Home Health Agency, an organization which provides home care services for the elderly and disabled. His professional affiliations include membership in the National Academy of Elder Law Attorneys, the New York State Bar Association's Elder Law and Trusts and Estates Sections, and its Committee on Issues Affecting Persons Under a Disability. He is a member and past President of the Special Needs Alliance, an invitation-only, national network of leading disability attorneys who practice in the areas of Special Needs Trusts and public benefits. The Alliance provides support for individuals with disabilities and their families, for personal injury attorneys representing disabled plaintiffs, insurance companies that finance litigation settlements, and for Trustees of Special Needs Trusts.



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## **The Boy in the Moon**

For 11 years, writer Ian Brown and his family have dealt with an unexpected presence – his son, Walker, born with a rare and complex genetic disorder, CFC which makes life very disorderly indeed. Unable to communicate or even to eat on his own, mentally delayed, fragile, sickly, sometimes destructive, sometimes joyful.

Walker is a mystery made possible by modern medicine.



In this remarkable frank and intimate story, Brown describes his struggle to care for and to understand his son – and through him, the value of any human life.

To read this story and listen to the video links please visit the Internet at:

**<http://www.theglobeandmail.com/boyinthemoon>**