By Pam Healey

The large number 26 on the back of all conference sports themed tee shirts reminded us it was the 26th annual SOFT conference. In 1990 SOFT members met in St. Louis, and this year brought back a good number from that original group, along with many who joined SOFT later and some first time families both from the area and from a considerable distance. With the requisite agenda and plenty of lobby and pool time for spontaneous connections, the time was well spent and flew by. The motto this year was “Another Championship Cause in St. Louis” with the Cardinals’ World Series win the inspiration for the theme carried throughout the conference. We were reminded that, “The St. Louis Cardinals won an amazing 11th World Series last year, but that’s nothing compared to our children who are World Champs every day. We applaud every accomplishment, as if it were a game winning home run.” A special thank you and congratulations to the conference committee, which consisted of Steve and Peggy Cantrell, Scott and Sheryl Crosier, Mark and Jayne Wright and Michelle Wilson (some doing double duty, having worked on last year’s Chicago conference). Also helping were Andy Knef for photography and public relations, the Rochester group: Jack and Judie Laird and Barb VanHerreweghe for registration and fielding questions, and Dr. Stephen Braddock of SSM Cardinal.

Warm greetings from the St. Louis Conference Committee
We Miss You!

Our motto this year was, “Another Championship Cause in St. Louis”, and we know for a little while the Cardinals took a back seat to SOFT.

Our committee can’t begin to express our enormous gratitude to the families who attended and also the many people who were unable to travel but shared both emotionally and financially in our success. The army of volunteers from all walks of life, who appeared out of nowhere, to lend a hand, deserve a hearty thank you.

To the conference sponsors who so generously financed most every aspect and allowed us to focus on enhancing the SOFT experience, we thank you. Thanks to YOU our conference this year has begun a new model for success, which will allow us to meet long into the future.

A special ‘shout out’ to Dr. Carey’s good friend Dr. Stephen Braddock who tirelessly gave his all to the conference. Dr. Braddock organized the clinics but also had a hand in so many other areas. He truly is one of the “Good Guys”.

And finally, thanks to Corey Hodge and the staff of the Frontenac Hilton. Their attention to detail and desire to host our conference was amazing. Corey said: “Let’s make it happen” and we did.

So many memories will last a lifetime and we will never forget what happened here in St. Louis.
Thanks so much again to everyone.

With Warm Best Wishes,
The St. Louis Conference Committee

- Steve and Peggy Cantrell
- Scott and Sheryl Crosier
- Mark and Jayne Wright
- Michelle Wilson

A special thank you to:
- Andy Knef (conference photographer and PR)
- Jack and Judie Laird (registration and many questions)
- Barb Van Herreweghe (El Presidente)
- Dr. Stephen Braddock, M.D. (Cardinal Glennon Children’s Medical Center)
- Dr. Debbie Bruns (workshop coordination)
Lyndsay Stockman turns 12 years old- 
"Living with full Trisomy 18"

We are totally amazed that our little girl is now 12 years old! When we brought her home at 4 months of age we knew she belonged home with us and her brother and sister--Drew and Jordan. We were not sure how long we would have her but knew we had decided we would do everything we could to help her have a better quality of life. 

Lyndsay came through a nine hour surgery on her back for her severe scoliosis in early June. Even though we were in the hospital 8 days, 5 in intensive care we thank God that she came through hopefully the last surgery she will ever have to have. She is now 4 inches taller after the scoliosis correction and sits up so tall and straight. To see her sitting on the pew next to Buster and I by herself so tall and straight this past Sunday was truly amazing as before we would just hold her to keep her supported. We want to thank everyone who offered up prayers for Lyndsay while she was in the hospital and through her recovery. Prayer is powerful!

Lyndsay healed from her surgery enough for us to attend the SOFT Conference in St. Louis this summer. She did real well traveling by van to St. Louis from Virginia. How fun it was to see her name in lights on Friday night, July 20th at the St. Louis Cardinals vs Chicago Cubs game. As you can see they recognized her 12th birthday at the ballpark. We were able to celebrate her birthday on Monday at my cousin’s home in St. Louis with ice cream cake which she really enjoyed as you can see. We then again celebrated on her official day at Hilton Frontenac hotel on Friday afternoon before the ball game. It was a big week of celebrating and lots of mylar balloons which are her favorite toy.

We look forward now to September, the starting of a new chapter with Lyndsay going into 6th grade--middle school. Our girl is becoming a big girl, a survivor living with Trisomy 18--enjoying life with lots of love from her family, friends, church and our SOFT family.

Lynne Stockman 
Mother of Lyndsay, full Trisomy 18
President’s Corner
with the VanHerreweghe Family

Dear SOFT Families:

The conference is over and done for another year! It is always such a let down when we return home and we cannot see our friends every day. We so miss seeing all the beautiful children, those that are able to attend and the pictures of the beautiful angels that left us too soon. Great times were had by all of us! The meet and greet on Wednesday evening was such a great addition. Getting to know every one the very first day was great. It is hard to believe that this event was made possible in honor of Morghan Kubena’s sixteenth birthday! The kids keep getting older but I am moving the other way, down in age!

The SOFT Stroll for Hope was a success again this year. We raised close to $8,000! We rolled around the ballroom, took great pictures of the group and later there it was on a billboard! How amazing and a great way to gather awareness in the St. Louis area.

Families attended the clinics at Cardinal Glennon Hospital on Thursday. That evening we had our dinner with a special presentation by Ironman himself. What advocates we have with him and his wife. We then presented the children in attendance at the conference in the Zion Lint Walk of Fame. They rolled, they walked, they smiled from ear to ear, as each and every child heard their name, received flowers, a pennant and cheers from their SOFT family. What a joy to see. Then it was time to dance through the night.

Friday was the day to learn and gain the knowledge to go home and work hard for our children for another year. The workshops were great. Next it was time to go to the ballgame to have a little fun and see the World Series Champ’s show their stuff! Well I guess there were Cardinal fans but I think I also saw a few brave souls wearing Cubs shirts, wonder who that could have been? We had a great time.

Saturday brought us to sharing with families, the business meeting and of course the wonderful video of all our children. Hal and Kris took each and every picture they received and specially placed them in their video to special tunes. They cherish this time every year getting to know each and every one of your children, whether they are still here on earth or if they are in heaven, each one has a special place in this video.

Then it was time to go off to the picnic. The barbecue was delicious and the sweltering heat gave us a little bit of a break to be able to enjoy good food and great company. The highlight of the day was the Ryan Cantrell Memorial Balloon Release. Tags were attached to a rainbow of balloons with special care. We knew each balloon tag had a story and a family that endured pain but had received unconditional love for minutes, hours, days or years. They all floated into the sky to that special child whose life we were celebrating. There were tears, kisses and hugs as they each floated high. The beautiful rainbow of colors was hard to miss. Butterflies were released and fluttered around, then gone too soon. Just like this conference over and gone too soon.

We headed back to the hotel and enjoyed a night at the auction and our last night to be together as a SOFT family.

After a service in the morning we all went our separate ways home. We left for Sweden, Canada, Puerto Rico or the each end of the United States all hoping to return next year. Love and health to each of your families and we hope to see you and new friends next year. Details will be coming soon of the date and place for next year so you can start making your plans soon.

SOFTly,
The VanHerreweghes

Nurse Judie

After being notified by Foudress, Kris Holladay, that the room was cold and could she please fetch a blanket for her comfort, Nurse Judie busied herself with the task. Your attention is directed to the left as she began the task of wrapping Madam Holladay in a blue blanket, which proved to be insufficient during the course of the meeting.
Summary by Pam Healey

Dr. Carey began by saying questions were welcomed. He also noted most participants were familiar with the basics of trisomy, so he would emphasize new information. The result was he competed about 10% of his forty prepared slides. The order of information that follows reflects that questions that interrupted the prepared presentation.

John began by showing and explaining a karyotype, the diagnostic tool that dates back to the mid 1950s. He explained the reversed banding of the karyotype brings out the differences better. Chromosomes are paired and arranged by size, each pair numbered. Karyotypes are not as widely used as previously with the advent of new techniques, which give more specific information and can measure specific changes in DNA. With karyotypes cells are taken from blood lymphocytes, and a stimulant is given which makes the cells grow for two days, then additives are given to stop cell growth during metaphase, one of four stages of cell division. The cell is stopped just as it is about to split during mitosis. What is obtained is a picture of chromosomes stopped but often curved, overlapped and not lined up. Previously, individual chromosomes were cut and pasted by students and physically lined up in pairs by size and count. They were then photographed. The result was a karyotype. Many of us received this picture at our child’s diagnosis. Now a mouse pulls and drags the individual chromosomes and puts them in order, a much more efficient method.

There are more modern techniques to determine number and structure of chromosomes, in order to, make a diagnosis. With the CGH microarray, we now look at DNA and measure it to test for smaller, missing or extra pieces. The karyotype will never be a technique of the past, but it is not done as often.

An understanding of the structure of chromosomes is helpful. There is a centromere, the middle section or constriction with an arm on either side. The smaller arm is the p arm, named for small in French, petite. The longer is the q arm, the next letter in the alphabet. This terminology came from a meeting in Paris in 1960, the same year that Patau and Smith in Wisconsin and Edwards in England identified trisomy 13 and trisomy 18.

From the Human Genome Project we have learned about specific locations for specific disorders. We know the gene for cystic fibrosis is located at the top of the long arm of chromosome 7. BRCA 1, a gene for breast cancer is located on chromosome 17 near the neurofibrosis type 1 indicator. We know with adults with Down syndrome that memory and attention decrease in adulthood, and we now know the amyloid protein is on chromosome 21 and relates to memory loss and the development of Alzheimer’s disease. We have identified 18 genes on the 18th chromosome, now on a data base, but that does not help in understanding the findings of trisomy 18. We know colon cancer is on long arm of 18. It is not certain if this is related to the Wilms tumor prevalence in individuals with trisomy 18. There must be a gene on 18 that causes a heart defect, specifically a VSD, affecting the pumping chamber. Of those with trisomy 18, 90% have a heart defect, usually a VSD, with polyvalvar heart disease, but more serious defects, truncus arteriosus or hypoplastic left heart syndrome occurs in about 10% of those born with heart defects. The most common malformations must relate to a specific but still unidentified gene. It is not as clear what the effects of three copies of a chromosome are. Scientists use two mouse models for Down syndrome, actually creating a mouse with trisomy 16, the closest to Down syndrome. We need a T-18 mouse model. There is a macaque monkey identified as having offspring with T-18, but primate labs are not as well tolerated by the public as rodent labs.

There is a specific technique for determining the extent of mosaicism. The protocol is to count 20 cells and look for mosaicism, some cells with an extra chromosome. This is the standard. This gives a 95% chance of picking up a cell with a different cell line. If one is found, then 50 more are counted, or 100. The number found then gives some idea of the percent of mosaicism: 15 of 100 cells with trisomy means 15% mosaicism. This was the best way of picking up cell lines of DNA before microarrays.

There is also the deletion syndrome, which means some genetic material is missing from a specific chromosome. This leads to manifestations more specifically than is the case with extra DNA. For instance, a missing segment on chromosome 13 puts one at risk for retinoblastoma. In contrast three copies of the same chromosome, thus the same segment, does not put one at risk.

Only some chromosomal trisomies are seen in live born infants. Chromosomes number 7, 8, 9 are seen in mosaic form in live born infants. In contrast, chromosome 11 and 14 in mosaic form are conceived but not live born. A few with mosaic 22 are live born, but rarely. There are fewer developmental genes in 13, 18, 21, so all three are live born with a full third chromosome. However, there is substantial fetal loss. Half of those identified with having trisomy 13 before 20 weeks are still born. Fetal loss is not so great with Down syndrome. The genes in chromosomes number 1, 2, 3 and 4 do not allow survival, which perhaps may be related to the placenta. Smaller chromosomes generally are more likely to result in a viable fetus, when there is an extra chromosome. There are exceptions which must relate to what genes are present. The 21st chromosome is bigger than the 19th, but 19 must include more developmental

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THE CHRONICLES OF JOEY

Part 5
"Happy Birthday I'm 5, and I'm still alive,
I've been a blessing to my family,
Since the day I arrived"

I'm back to school and doing well and I'm happy. But on April 5th, I woke up in the wee hours of the morning with a distended belly. I remember that day well because it would have been my brother, Tucker's, 10th birthday.

At first Mommy thought she over filled me with the feed pump so she stopped it. Realizing that she hadn't, she thought in time my belly would go down. By 4am, my belly was progressing in the wrong direction. While on "eternal" hold to the doctor, Daddy woke up and saw my big belly and made a command decision to call an ambulance. I'm glad he did 'cause I was feeling awful.

It was "Deja-vu" for Mommy and Daddy. One year ago on Tucker's birthday I had a big seizure and was taken to the hospital by ambulance. And since I like making this special day for my parents a memorable one, I decided to do it again.

The ambulance couldn't take me to to the big hospital in Sacramento that better handles kids like me, so they took me to a smaller, closer one. This hospital didn't quite know what to do with me. And as we waited for another ambulance to take me to the bigger hospital, Mommy anxiously watched my belly grow bigger and bigger, fearing I might pop!

After our rushed trip to Sacramento I was admitted in the PICU where doctors looked over my x-rays. I soon became quite popular as the illuminated, black and white picture of my belly was on display for all to see. I heard one doctor say, "That is the BIGGEST colon I've EVER seeeeeen!" Now, I was quite proud of that diagnosis and apparently the envy of some doctor because I was quickly wheeled into surgery, knocked out, and when I came to, this doctor had taken 2/3 of my colon from me. And while at it, he grabbed my appendix too.

They tried to pass it off by giving me an illiostomy hoping I wouldn't notice the difference, but that didn't work so well. Ten days later I went back into surgery and the doctor reversed it while fixing another blockage caused from an adhesion from the first surgery. Before I left the hospital, I ended up with a case of pancreatitis which prolonged my stay. I finally left 5 1/2 weeks later. I had several scars from the PICC lines, a scar from the illiostomy, and a scar that looked like a zipper running down my abdomen. Add these to the scars from previous surgeries and I thought I was look'n pretty ma-

cho! That is until Mom drew a caterpillar head at the top of my "zipper"............with a smiley face......so unmacho!

When Summer school was out, Dad rented a car and we headed east to the SOFT conference. (Support Organization for Trisomy). Our first stop was in Reno to visit my new baby niece. Yes, I am an uncle named Taylor Kristine. Then off to Chicago, which is known as the "windy city". But this year it was the "hottest city". Little did we know, we were headed into a record breaking heat wave with temperature soaring to 108° and with 85% humidity, the heat index was 128°! It was miserable! At night we would wake up to tornado warning sirens blaring. My big Sissy would sleep through it all. I guess she's used to it living in Maryland. But my California Daddy was watching for funnel clouds searching for shelter.

We took a drive to the Field Museum where Daddy said we were going to see the "Man-eater" lions of Tsavo. This was one of those times I was glad I'm still a boy. Then Daddy assured me they had long been stuffed. "Whew!" I was sweat'n it and it had nothing to do with the heat!

We didn't waste time hanging around Chicago once the Conference was over. Daddy had enough of the heat, tornado warnings and toll roads. He said the toll roads were highway robbery even though I never actually saw a masked man on the side of the road. We headed south to visit long time family friends in southern Illinois and then over to St. Louis were I was born. We had lunch with Cindy the attorney who helped with my adoption and Sue, the woman form Family Christian Services who also helped. Then that night we had dinner at my foster families house where I spent the second month of my life. The next morning, the judge who finalized my adoption made a hole in his docket to see us.

With visiting out of the way, we headed west for home and cooler weather. Dad decided to give a little history lesson along the way. He said, "You know, the pioneers didn't really head west in droves to look for gold. They just wanted to get out of this

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What is round and really violent? A vicious circle!

(Continued from page 5)

dang heat!".....Made sense to me.

Driving across Kansas we kept seeing signs for "Prairie Dog Town", "home of the largest prairie dog!". Now to me, a prairie dog is just a glorified ground squirrel that is more varmint than dog. But, being the hunters my parents are they couldn't resist a peak. So, we pulled in for a "look see". We saw hundreds of prairie dogs overtaking the grounds with their mounds. But what really interested me was the 6 legged steer and his 5 legged cow cousin. This place was home to many miss fit animals. On our way out we passed by a huge box and I heard what sounded like sizzling bacon in a hot pan. When we looked inside, there were dozens of rattlesnake of all different types and sizes.

We then headed for the Colorado Rockies to spend a few days with my Dad's cousins at their condo. The dry cool air was a real welcome! Then it was home.

In September, Mom and Dad entered me in the Georgetown Founders Day parade. The theme was logging days so Mommy and Daddy worked for two days transforming my adapted bicycle and radio flyer wagon into a bright red log truck. Instead of being "Peter Built" it was "Dad Built". Complete with a "Road Kill" license plate and a raccoon hanging off the bumper.

In the fall, my doctor started making some seizure med adjustments, which made me very, very sleepy. More adjustments, and I started having more seizures. Christmas day Mom could tell something just wasn't right with me but she couldn't quite pin point it. While she was waiting for the doctor to return her call, the "south bound" end of me let loose, and I had the worst case of diarrhea ever. When the doctor called back Mom gave her the latest, embarrassing details that led to this event. Her advise was get to the hospital as soon as you can. By the time we got to the E.R, I was now throwing up. Green water was coming out both ends of me and my seizures were out of control! I was admitted.

Now remembering the "colon conspiracy", I was a little guarded with my entrails. Thank goodness no surgeries were needed but I did have a bad case of Cdiff and pancreatitis from one of my medications. And since they had to take me off that medication and try new ones, I was on a video monitored EEG for over a week. It took a couple weeks but they finally found some medications that seemed to keep my seizures under control. So, I was moved out of the PICU and on to the pediatric floor. Mom and Dad felt comfortable enough to leave me for one night to go on a preplanned duck hunt with our church, which was actually closer to the hospital than home. Ruthanne, my respite caregiver came to the hospital to spend the night with me. Which was a good thing because during the night, when nobody would have been in my room, I had a bad seizure and stopped breathing. Not being in the PICU, I wasn't hooked up to any monitors. So nobody would have known. I was taken back to the PICU and Mom and Dad's duck hunt was cut short. After 3 1/2 weeks, I was well enough to come home.

Three weeks later I ended up back in the hospital with pneumonia. It's not unusual for me to go into the hospital with one thing and come out with two or three. But Mom assured me that this was a very "giving" hospital. And true to form, before I left, the Doctor said I had the human metopneumo virus. I guess compared to my others, this was a short stay. Only 1 1/2 weeks.

This year my friend Lillian and I shared our birthdays together again. She always has the greatest parties. And she is always a "hit" at mine.

Well this about sums up this past year. I am praying for a healthier next year!

Your Friend,
Joey


Cooking SOFTly with Cindy Cook

Recently I was at church purchasing something from one of the teenagers. When I went to hand her my check, she said “You’re Jonathan’s mom”. I stopped in my tracks and just started at her. “Jonathan’s mom”. I have not heard someone say that, just that, in a long time. That was who I was for a long time. I know I am STILL Jonathan’s mom, but that is what everyone used to call me. It was something I did not realize I missed hearing so much until she said it.

These days, I am Jacob’s mom, Evan’s mom, Nathan’s mom, the twins mom, the Cook boys mom, but rarely do I hear Jonathan’s mom. It melted my heart. It is a strange thing that happens when your child is longer here with you. That is your world. Everything revolves around the needs of your Trisomy child. Is the weather too hot, is the building accessible, is there air conditioning, are there outlets for my suction machine to charge, where can I change my 10 year old son in private, where is the local hospital, what is the air quality like today, “No sir, this is NOT a stroller, it is a wheelchair and yes it can be brought in”.....the list goes on.

Then suddenly, it all stops. You flounder for awhile or maybe a long time. Maybe some of us never stop. I think that is more the case. That pain never goes away. You just become skilled at suppressing it when you need to. Or there comes a time, for some, when you start thinking about your child, not with as pain and heartache per say, but more of a longing to just show him this new tech toy, or cool museum you found. I still find myself thinking, Jonathan would have liked this; this is really accessible if only Jonathan were here; I wish Jonathan could have seen this. Or as you watch another mom with a child who has special needs, and your heart starts to sink and you remember just how much you miss your angel.

However, there are times, when you think, that you need to keep this to yourself. After all, it has been 5 years, almost 6 (can’t believe that) since your precious baby went to heaven. You need to not be thinking about your heartache so much. So you carry on, smile, stay strong and sometimes feel like those around you, those you don’t see often, may have forgotten.

Then, as you’re standing there, doing some random act, like writing a check, a thoughtful, wonderful young woman, calls you “Jonathan’s mom”. It is then that you realize (again, because you forgot), yes they all do remember him. Yes, I am “Jonathan’s mom”!! Yes, my Jonathan touched more lives and lives in the hearts of more people than I will ever know!

With more pride than words can express........Jonathan's mom.

Moms Only Workshop with Cindy Cook

Put 50 plus Trisomy moms, grandmas, aunties, nurses and friends in the same room; add some sweet and salty snacks; sprinkle with some beverages and you have a recipe for a magical afternoon! This was the third year for the SOFT moms group at the annual conference. What started out as a side conversation with some moms in a restaurant several years ago has turned into one of the most sought after workshops in the past 3 years!

What makes the group so successful, in my opinion, is the open, honest, heart-felt sharing that each of the women feel they can participate in, without the fear of judgment. We all get it. We are either living it, have lived or will live it. If none of those apply, we are there as your Trisomy sister to offer you our words, our hearts, and a shoulder to lean on or arms to hold you with.

The “theme” this year was coping. Whether you are still able to physically hold your child or they are being held in your heart, we all need to learn coping skills to keep ourselves healthy on this Trisomy journey. Many women shared stories of coping with humor, cleaning (to get some control in their lives), exercise, eating healthy, reading, working outside the home, talking to friends and especially other Trisomy moms, using social media, educating others about their child, getting away for a day or weekend with friends, the list goes on.

We all have our own way of coping. Sometimes when you have a child who has special needs you feel like you are on an island. Even if you have the most amazing supportive family and friends imaginable, they can never really relate to everything you are going through. That is one of the many experiences that comes out of this particular workshop. We are a family of moms that learn, share, cry and gain strength from one another. We walk away feeling, I am not alone, I can do this and when I feel like I am hanging on by my fingernails.........I have 50 plus sisters that I can call, text, email or write who will be there for me in an instant.

That is the power of Trisomy moms.

Until next year sisters.

Jonathan’s Mom

PS-I need to give another HUGE shout out to Sara Hayes and family for the beverage and snack donation! We love you Sara!

“Jonathan’s Mom”
Giuliana Lynn
Trisomy 18

This is the story of Giuliana Lynn.

She was born in August of 2010, weighing only 4lbs 2.5oz. Pregnancy with Giuliana was relatively normal. Aside from her small size, there were no concerns because she was growing consistently. No anomalies or other conditions had been found. The doctors decided to induce labor at 37 wks 4 days. The only reason we were given was they wanted to make sure nothing went wrong.

Of course there was concern because we knew that her small size alone could result in a longer hospital stay and potentially even a stay in the NICU. We do not believe in genetic screening so there was also the possibility that G could have other issues related to her small size as well.

Giuliana did not tolerate labor. There were problems with her heart rate and oxygen levels. About 20 hours later, it was decided that an emergency c-section was necessary. The neonatologists planned to be in delivery just in case they were needed. When Giuliana arrived, she had a lusty cry, but she was nonetheless in respiratory distress. They examined her and found some anomalies that appeared to be consistent with trisomy 18, something we had never heard of before. My husband accompanied G as she was whisked to the NICU where the doctors said they could help her breathe more comfortably. Giuliana was intubated.

While we waited on blood work, it was discovered that Giuliana had a large VSD. She also had an ASD and PDA which were the obvious reason she experienced difficulties in natural birth.

Within 48 hours the FISH blood results were completed and the suspicions that Giuliana had full trisomy 18 were confirmed. Prior to this we were promised “time” with G, yet upon diagnosis, the staff arrived to extubate almost immediately. We asked for one more day with our sweet girl that was reluctantly granted, however at the same time we were advised to make her funeral arrangements.

Incredibly, G began to breathe on her own and 10 days later she came home from NICU. The joy of arriving home was quickly crushed as we were greeted by the Hospice people and the Do Not Resuscitate Order. G was now on stand by to die.

If her heart remained sick, we knew that death was inevitable. Our local doctors made it clear G was not a candidate for any type of surgical intervention.

Nothing felt right. Someone must be able to help this baby. Determined to exhaust every option, I began calling facilities to find a surgeon who would look at her case and repair her heart. My husband obtained and copied all her records and faxed them to the facilities that we were applying to. After looking at six different hospitals, we finally found a surgeon who was willing to help our precious daughter. We packed up the whole family, including our other three small children and drove 23 hours by car to avoid the risks of air travel with our fragile girl.

Giuliana’s heart was fully repaired at only 2.5 months and 6lbs 13oz. At 10 months, G had an appointment with a new genetics doctor. At this visit, we were informed that Giuliana actually had mosaic trisomy 18. This had been her diagnosis from the start but we were led to believe that she had full trisomy 18.

About the same time, G got sick with a major kidney infection and it was discovered that she had multiple kidney stones. We were told that a primary cause of the stones were her Lasix that had been administered in the early months when she was in heart failure. A ureteral stent was placed for three months to prevent obstruction of urine flow, only to find out it was too large and incorrectly placed and was doing more harm than good. After removal, a Ureteroscopy was done to crush and remove the stones and she has remained stone free!!!

At 10 months, Giuliana also began to have constipation issues. We thought they were normal at first, as we knew many trisomy children also experienced difficulty in this area.

In August of 2011, G would celebrate a major milestone of making it to her 1st birthday!

The next year would prove to be more challenging than the first. Giuliana would be in/out of hospitals due to her constipation. Laxative after laxative was prescribed and almost cost G her life.

Giuliana developed extreme side effects to every laxative available. She underwent another surgery called a Mini Pena. The surgery would help reposition her anus and situate it distally to the rectum. Unfortunately, the procedure made little difference in the underlying constipation issue.

After a year of testing, a final consult with a renal motility specialist revealed that G had nothing wrong with her from a GI standpoint. We were told a colostomy was our final option.

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Since that appointment, on our own, we switched G to a gluten-free diet even though she has never tested positive for Celiac Disease. She is now having regular bowel movements and is almost completely potty trained. She says two words, “poop” and “yeah”. She is working on crawling, standing/walking and eating larger “pieces” of food. Overall, she is doing very well.

As we near Giuliana’s 2nd birthday, raising awareness remains an important and high priority for us. This year, our birthday announcement was much bigger than the small card we sent out last year. It would better reflect the amazing girl Giuliana has become and at the same time, advocate for other children who are diagnosed with trisomy 13/18. Working with an agency, I arranged to display three large billboards with a bold message.

We believe that genetic discrimination is the main reason providers are failing to offer unbiased information to parents. Realistically, death will always be a part of trisomy 13/18 but newer families deserve to know that surgical intervention may also be available and can lead to longevity for some children.

I personally plan to continue the billboard project as part of my ambition for public awareness and education.

Giving hope – the hope that we were not given, is a gift we can offer to other families. It is the gift that Giuliana was born to share. We will continue to celebrate Giuliana’s life and use her accomplishments to advocate for others with trisomy 13/18 with the vision of eventually helping to erode the stereotypes attached to this diagnosis.

We are so proud of Giuliana and all she has accomplished and endured. She is the light of our lives and the best little “big” girl we know!

Please follow G at:

www.g-giftoflife.blogspot.com

Every child can help make a difference!! For more information regarding the billboard project please contact:

Jill DelSignore

tris18info@ymail.com

or find me on Face Book at:

Jill DelSignore (Ohio)

Hi Barb,

I hope you and your family are doing well. I graduated from the genetic counseling program at Brandeis a few weeks ago, and have taken my first position as a prenatal and cancer counselor in Reno, NV. So far it has been a smooth transition even though I am far from home and trying to keep up with the demands of a busy clinic!

I have benefitted so much from receiving the SOFT newsletter throughout my training, and volunteering with SOFT gave me valuable personal and professional perspectives.

I have been meaning to write and give you my updated address, but today seemed an appropriate time since I just gave my first diagnosis of Trisomy 18.

I referred the couple to the SOFT website for some more information as they contemplate next steps, and I hope I can continue to use SOFT as a resource during my practice. The books that you gave me when I left Rochester “to start my practice” have a place on my bookshelf here in my office. Back then being a full-fledged genetic counselor felt so far away.

Thanks again for the opportunity to be a part of SOFT and to learn about your important work. My new address is below. I would love to continue receiving the newsletter.

Erica J. Wellington, MS
Genetic Counselor
Perinatal Associates of Northern Nevada
1500 E. 2nd Street, Suite 108
Reno, NV 89502
The Chin Kiss King was reviewed in The SOFT Times many years ago. The novel was discovered by Chris Hassan, mom to Joanna, now well into her fourth decade of life. This is simply the story of a baby with trisomy 18 and the women who love him. With Sheryl Crosier nearing publication of her book on Simon’s almost three months of life with his family, I thought this would be an appropriate companion piece. Both the novel and the memoir cover the same ground, express the same strong emotions and celebrate a child not expected to be celebrated. If you have the time I highly recommend reading the book. If not, enjoy the details provided below. The author, a syndicated columnist for the Miami Herald gives a realistic picture of the medical demands and powerful emotional responses to caring for a child with trisomy 18. For your additional reading pleasure, her recent columns are available online. Also, be sure to check out I’m not a Syndrome -- My Name is Simon by Sheryl Crosier, available as an e-book in the coming months. Go to Simonismyname.com for more information.


The Chin Kiss King is a poignant, often humorous, although devastatingly sad story of three generations of Cuban American women living in Miami in the 1990s, who, as all of us have been, are shocked by the unexpected birth of a child with a chromosomal diagnosis. This is the story of this beloved child’s short life, beginning hours before his birth and ending as he dies. Each woman carries her own story, weaving the past with the new challenges of the present, and clinging to some sense of hope for the future. Alone and together, they face and try to make some sense of the grief and the joy that Victor Eduardo brings them. Each also changes as he embraces this dying child who captures each generation.

Book Review
by Pam Healey

Cuca is the 77 year old matriarch, who has seen seven of her own infants die within hours or months of birth. After the death of her third baby, Cuca vows to the Virgin Mary never to cut her hair, if she can have one child survive. Her next child, Adela, lives. Cuca wears her hair in a long braid, her vow kept. She greets each day with her 46 bangle bracelets, her house dress and great resolve. She is superstitious, spiritual, philosophical, and emotional. She is funny. She makes lists because “her memory was not what it used to be; actually never had been, but now she had a believable excuse.” She sees life as a garden, and her tasks to pick the roses with the fewest thorns. She is observant, able to step back and study others. She misses little. From the time she was a child, when she was visited by the spirit of her dead brother, she has communicated easily with the spirit world, especially in the quiet time just before and after sleep. She also visits with spirits at the bus stop. She grows herbs, and she keeps a kitchen filled with pharmaceutical supplies, that “keep the surface of her life polished just so.” She knows herbal remedies for much of what ails family members. She prides herself on “being ready for the apocalypse.”

When she is told her granddaughter’s water has broken, she manages a few mambo steps across her well swept kitchen floor, but still for some unexplained reason she feels “the weight of a thousand sorrows on her soul.”

Cuca awakens that morning to a heavy mist and the thick smell of honeysuckle, and she searches for meaning. She wonders what is being presented: melancholy, peace, joy, evolution, or deep sadness. She believes traces are being left of what is to come. When she is unable to order the mist and heavy fragrance to leave, she pulls up her covers and thinks, “Accept that which is unacceptable, what is inexplicable, what no one can find.” She believes she “glimpsed the blinking essences that were the faithful spirits of her lost loved ones in the vast darkness of infinity, so many of them, so many.”

Cuca, who knows more dead people than living people soon welcomes her frail grandson. She, who believes she is given a different script than she plans time and time again, is open to all the possibilities. She is then visited by the spirit of her dead husband, who warns her to tread gently, because things are not as they seem.

Adela, Cuca’s sole surviving child, is a hairdresser, until a fall puts her on disability. She spends her mornings scratching lottery tickets and playing the numbers. She spends her nights with her friend’s husband. She is described as “Tinkerbell nearing retirement, aging in fits and spurts and not always in good sense.” Adela is passionate, cunning, and in her own way loyal. Cuca blames Adela’s sloppiness, her piles of books on making quick money, mounds of clothes and the crumpled paper left about, on the need for order of Adela’s child, Maribel. Cuca considers her only grandchild to be “an uptight know it all.” Adela, upon learning that her daughter Maribel’s water has broken, realizes it is leap year day and plays number 29, certain this can only be a wonderful sign.

Adela is cautioned by her boyfriend about a boy being brought into a world of so many women. Adela proclaims, “I will love him no matter what….even if he looks like a cooked cauliflower. Even if he walks like a clown.” They laugh at the immeasurable love of a grandmother. She believes being a grandmother means affirmation, and she welcomes the joy without the responsibilities of a parent. She embraces her new role. She believes a baby will teach her daughter that life is random, which will force her to relax and not take herself so seriously.

Maribel, who has her great grandfather’s Chinese features, was never young. She thrives on stability and order, never takes risks, and avoids ad-

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“The heart of another is a dark forest, always, no matter how close it has been to one’s own.” - Willa Cather

(Continued from page 10)

venture. Her mother despairs when, given her first coloring book, Maribel instinctively colors within the lines. That is the chasm between Adela, who knows no boundaries, and the confinement that drives Maribel, who harnesses her thoughts and knows neither impulse nor curiosity. This curtails her joy. Adela is pained by Maribel’s constraint and her inability to believe in dreams. Maribel is proper, correct to a fault and pathologically organized. She is college educated and has a good corporate job working for a boss, who appreciates her.

Cuca believes life to be “an ordeal of balancing opposing forces,” and she believes the next two generations have failed to learn that. Adela worries, because she knows, “even the most careful plans fell victim to fate.” Maribel is pregnant with her first child and alone because her drug dealing husband is hiding somewhere to avoid arrest. In the months to come Maribel has to reconcile her mother’s recklessness, made more appalling by the daily demands and emotions related to the baby, her husband’s disregard for both his son and her feelings as a mother, and her boss’s consideration, understanding and unspoken desire.

Nothing is simple in the lives of these three women, but the book in its complexity is realistic and the several story lines compelling.

During her long and painful labor Maribel thinks back to her own childhood and her father who makes weekly visits, until he just stops and presumably dies. She remembers their favorite game of kissing with noses, toes, knees, elbow, both soft kisses and bony kisses, always ending with a drum roll and chin kisses. She delivers her son as she remembers chin kisses with her beloved Papi.

She spends Victor Eduardo’s life playing the chin kiss game, creating a connection, ordering her life and carrying on tradition, despite all the limitations imposed by her son’s condition. Victor is the “sequined winged angel,” who begins life as a three pound infant with a quiet mew and a look first as a fish, then a rat, and finally a bird, an exquisite bird. In his frailty he is the most beautiful thing his mother has ever seen.

Maribel is told of the possibility of trisomy and thinks of her first tricycle. She is told of severe mental retardation, organ defects, limited possibilities, but she only wants to see her baby. She tells herself there is something wrong with his blood, because his blood is being tested. She visits her son for the first time and is shocked by all the tubes and the noisy machines. She is disappointed she can only stroke him, when she wants to hold him close. She begins the first of many medical lessons. She learns about apnea, soon about an esophagus that is not attached, then kidney reflux, coarctation of the aorta and holes in his heart. Maribel hears from a kind but honest doctor that her son may die, and she begins to shake and chatter uncontrollably. She has moved from denial after the first news to shock. When she asks what is happening, her physician explains, “It is the quaking of the soul, my dear.”

Maribel asks more questions, knowing the doctor “will choose carefully between truth and merciful lie.” She clings to the possibility that her baby might not die, grateful there is some hope. When she is visited by a cardiologist, then a nephrologist, rage takes over, and she rails at the specialists and their dire news, and they back out of her room. She believes no one knows how she feels and rejects any empathetic gestures. She becomes isolated in her grief and anger.

Maribel leaves the hospital alone. She returns often to her son’s bedside and plays the kissing game. She touches each place on his body and with a drum role ends at his chin. Victor Eduardo opens his eyes and in his pupils “she recognized the infinite black of untamed space.” She rants at God for “doing this to a little kid.”

When Maribel is too heartsick to visit the hospital, her mother and grandmother go and are allowed to take her place because the baby needs love to survive. The older women are shocked by his frailty, impressed by his hearty cry and encouraged when the doctor tells them the baby is a fighter. Maribel stays in bed, trying to grasp the depth of her pain.

The karyotype indicates that Victor has trisomy 18, 75% mosaic with all the characteristics of a child with full trisomy 18. The doctor tries to give hope, explaining a few children with a similar diagnosis were alive at three or four. He cannot tell this mother if her child will smile, walk, or know she is his mother. He offers no road map.

Maribel keeps vigil by her son after his first surgery, learns to use a G-tube, confronts on-going problems such as a leaky G-tube and severe diaper rash. Maribel thrives in the order required to care for her son. She loves bath time, singing and playing with her child. The book rings true to the feelings of SOFT parents, when she thinks, “And when he watched her, she feels she knows more than the doctors’ learned knowledge, more than their passel of theories. Unlike theirs, lifted between the covers of a book, replicated and regurgitated, her knowledge was original and without peer, stored in the heart, not her brain.” She calls Victor her “big heart brave heart boy,” and he holds her gaze and communicates with purrs and moans, communicating without words.

Victor survives pneumonia, has his G tube removed, soon develops seizures. He regresses. Maribel worries.

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Workshop: Transition Points in the Trisomy Journey

By Pam Healey

Transition Points in the Trisomy Journey was a morning workshop led by Joyce Coleman, a Licensed Clinical Social Worker with over 20 years experience in health care. She has provided individual, marriage and family therapy. She has worked at St. Louis Children’s Hospital with families whose children have acute or chronic illnesses. Her focus in her therapy is to help both individuals and families manage life changing events and transitions. This workshop was an opportunity for parents to talk about their experiences soon after the diagnosis of their child and at other transition points in their child’s and therefore their own life. Topics were skillfully guided by questions and the introduction of specific topics. With many in the group eager to share their own experiences, little prompting was necessary for group participation. Most comments that follow came from parent participants reacting to questions posed. They spoke from personal experience and conviction.

Parents were asked when they first learned of their child’s diagnosis. Some receiving prenatal diagnosis were told face-to-face, but others learned such difficult news by telephone, with no regard for whether they might be alone. Often there was a limited opportunity to process what they had been told. The best scenario was a physician sitting down with the family giving the diagnosis, explaining the implications and prognosis and supporting the parents as they absorbed and tried to understand such devastating news. For many a difficult situation was made more difficult by health care professionals who may be focusing on expediency and not care. Some parents reported that after the diagnosis less care was available, as if the diagnosis had sealed the child’s fate.

Next, those attending this workshop were asked their initial thoughts and feelings upon hearing the diagnosis. Older parents shared that after getting a prenatal diagnosis, or even after birth, they wanted to learn more and as quickly as possible. Before it was possible to google a few terms and receive information instantly, parents went to the library and hoped there were some medical books available. Unfortunately, the medical books that might be available were not filled with beautiful pictures of smiling children. Trisomy 18 and trisomy 13 were represented by clinical pictures of children showing no affect with an emphasis on any physical anomalies that might be present. Even fifteen years ago the face of trisomy, what parents would see to understand their unborn child or newborn, represented the worst, not the best of what children looked like. Finally, there was an easily available internet with some search capacity, but there was more limited information than is easily available today. There were bulletin boards, but no list serve; social networking was limited. In the early years of this century SOFT families had a list serve so they could give and receive information. Rainbows Down Under, established by

Book Review by Pam Healey

The Chin Kiss King

whether he is in pain and clings to every day he lives. She watches him weaken. She keeps vigil but still retreats home. Finally, she can take no more, and this programmed woman of order creates chaos to stay sane. The others understand. Cuca particularly watches her granddaughter to see her progress. She who has had so much grief in her long life believes everyone “travels through pain at a pace right for them”. She believes that interference does nothing but prolong the heartbreaking progress. She is heartened by glimpses of Maribel moving on with her life, despite months of her life revolving around the hospital routine, medical tests and procedures and her child who fights for his life. There is hope for her, even if there is little hope for her infant son.

When Victor is five months old Maribel is told the holes in his heart have closed on their own. The good news is short lived, as he faces a fourth bout of pneumonia. Adela wants to help her daughter but feels powerless. She tries to pray but realizes she does not know what to pray for. As Victor weakens, and his death seems inevitable, Maribel leaves him with her mother and grandmother and goes from the hospital to the shore and cries. In the darkness she yells, “What do you want from me?” She returns to the hospital and takes Victor home to die surrounded by the women who love him, each stronger and more wise from knowing such love.

This is a wonderful vibrant story with rich, engaging characters, poignancy, deep spirituality in the midst of mundane life and passion. It is both a story of the Cuban-American experience and the human story of what it means to be family, to love and to go on bravely when the script is not the one expected and too tragic to comprehend. It is the story of being the gardener and finding the blooms despite the many thorns.

In The Chin Kiss King there are many memorable, perfectly expressed lines, passages that need to be reread and both characters and truths that remain long after the book is finished. This well written first novel is true to the experiences of many in SOFT. The characters ask the questions we asked, react with the same emotions and grow despite everything devastating that they face. The author affirms many of our own hopes, fears and joys and gives language to what we cannot.

-Pam Healey
Our Journey with Angela and Trisomy 13

By David Ricker

The day of Angela’s birth found us up early. Contractions had begun at 2:30 am, and the calls to friends and family and the midwife went out around six. The morning dawned in softness, the horizon clothed in lavender and mist but the day soon became sharp, bright and clear. It was going to be a great day to be born on our little hill in northern New Mexico, the foliage was full, and having gone apple picking earlier in the week, baskets and bowls of apples were all about the house. The place smelled like a cider mill and the room where Angela was going to be born was suffused with a gentle autumnal light. We had been preparing for this day for weeks and all was in readiness. By nine, family and friends had arrived, and our two children, Karina (age 4) and Dylan (age 2) arose from bed excited to see their new sibling come into the world, but in particular at the sight of the large birthing tub assembled and partially filled in the living room. Melinda was anxious to get outside and enjoy her labor in the open air, so she went out alone for a walk.

When the midwife arrived, Melinda was nowhere to be found. This somewhat alarmed the midwife, but I assured her that all was probably well. This was Melinda’s way. We had walked for a long time around our little hill in rural New Mexico before Karina was born and labored in the Dirt Cowboy Cafe over smoothies in Hanover before Dylan’s birth. When she did arrive back at the house, the midwife checked on her and the baby and determined that the labor was progressing nicely. It was not our first home birth, nor would it be our last. Karina had been born in a small adobe house in Albuquerque, Dylan, in campus housing at Dartmouth College, and Erin later in the same room where Angela was about to be born. But of course, Angela’s birth turned out to be something a little different.

Soon after the midwife arrived, Melinda had her first urge to push. Within a half an hour she was on her hands and knees in the living room (the tub only half full) and in the final stages of labor. I was kneeling at her side and the first hint that there was a problem came as the midwife took out her amniohook and then set it down, her face suddenly becoming very serious. I felt the first twinge in the pit of my stomach that something was wrong. That which the midwife had first thought was the bag-of-waters was instead the membranes of my daughter’s brain. The midwife kept this information to herself and Melinda birthed Angela beautifully and gently.

The next words I remember were the midwife’s, saying that “there was an issue with the baby.” When I was handed the baby, I looked at her head in near terror, noticed her feet were not quite right as well, and could feel my life changing before me. I wanted to remain calm, for my wife, the kids and their grandparents, and that was made easier by one look at my baby daughter’s face. Her eyes were bright and without sign of distress. Her face was in fact serene, and I said to myself, “Well, if she is not going to get all worked up about this, then neither am I.”

Moments like these had hitherto remained in unusual ways. There was still a lot of joy in the room, although obviously somewhat darkened with concern. There was no panic. We even waited for our four year old to come downstairs to cut the umbilical cord. The midwife called down to the hospital. The other midwife, an apprentice, had arrived so there were plenty of hands on deck. I converted our van into a kind of ambulance, warmed it up to a nice temperature, and soon, Melinda, the midwife, Angela and I were heading down to Dartmouth-Hitchcock Medical Center in Lebanon.

There is levity in these moments as well. I remember my wife and I joking about Angela’s nose, that it certainly did not come from either of our families. Little did we know at the time that her nose would be one of the signatures of her rare and severe syndrome. During a brief moment of near panic I had on l-91, I looked at the speedometer of our Honda Odyssey, and wondered if it really could do a hundred and forty miles per hour. But there was no need. All seemed well in the back of the van.

We hit Hanover, and of course the red light at Main Street, and I had a moment of profound realization. There everybody was, going about their everyday business, carrying coffees from Lou’s, or packages from the Dartmouth Bookstore, talking happily in the morning sunshine. It was just another day in Hanover. No bombs had exploded, the sky had not fallen; yes, the Baker tower bells were tolling, but they were tolling for us alone. How oblivious was everyone to the tragedy that was unfolding just a few feet away in the sky blue minivan. It made me wonder, while still waiting for the light, how oblivious I was to the everyday tragedies that were probably unfolding around me.

We arrived at the hospital with little fanfare. There was simply a woman waiting for us at the emergency entrance with a wheelchair. No ambulances or doctors rushing about like you would see on television, just a simple wheelchair and a guide to take us where we needed to go. Melinda got into the chair holding Angela, and we were led through a seemingly endless subterranean-feeling labyrinth of dimly lit corridors and closed doors to a very large elevator, and finally up into the Neonatal Intensive-Care Unit (NICU).

What happened over the next five days in terms of the information that had to be absorbed, the lack of sleep, the logistics of dealing with two patients (Angela and parturient Melinda), two small children, a growing coterie of well-meaning friends and relatives, and the difficult decisions made under extreme duress would have befuddled the most seasoned staff of the White House West Wing. I started taking notes in a little brown notebook to keep track of everything. The situation was further exacerbated by the fact that they would not admit Melinda into the birthing pavilion, because she had not given birth there. She was exhausted, and obviously distressed, with no place to lie down or rest, and the focus was still very much on the little baby with the large encephalocele, clenched thumbs, rocker-bottom feet, and I should also mention, bewitching tear drop shaped pupils in the pools of her clear blue eyes.

The first doctor who examined Angela was a young resident who gave us a rundown of the family-centered care approach of the unit. The next person we saw was the most senior physician of the unit, a man a bit grave in manner, but kind and forthright. When one is in a situation like this, one looks for authority, a captain to guide the ship past dangers yet to be even imagined. I knew right away, this was the guy. He examined Angela and voiced his suspicion of some kind of syndrome. “It is not just the head. I see the feet and the hands. There is something else going on here.” This was followed by a neurologist who took one look at Angela’s head and said, “I have to be honest, I’m not sure what I am looking at here.” It was at this point that I was getting a sense we had strayed into a kind of Terra incognita, with all the attendant terrors, real or imagined, that inhabit these nother regions of the human experience. The neurologist left say-
Our Journey with Angela and Trisomy 13

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We found we would have “plastics” come up and take a look.

At some point the senior physician arrives with a resident and an intern. He is laying out his thoughts, and his philosophy of total transparency. He assures us that nothing that we did has caused this to happen. “It’s not because you didn’t take your vitamins (Melinda did), or that you smoke (we don’t) or drank. Everybody produces sperm and eggs that have extra chromosomes. It is just that they rarely meet, and even when they do, the result rarely makes it to term.” What we are seeing is simply the result of an unlucky roll of the cosmic dice, he insists. It is here that he first mentions the word “Trisomy”, a word that is new to me. “As she grows, things will just get worse. Babies are programmed to grow. Malformations could be found anywhere.” It was a parent’s worst nightmare: Your child has some rare and incurable condition that you have never heard of. It is as if a hole has been punched in your universe, and dark matter is rushing in. It starts to sink in that all this is adding up to the fact that this child is not going to make it. Looking at her feet and hands over the course of this ordeal, my mind had been flashing forward to scenes painful and poignant of a child, my child, in a wheelchair, by a soccer field watching her siblings or peers play. Now even these simple scenes were feeling too much to hope for.

You bring in a child like this, where a number of systems are affected, and it is as if all the lights on the control panel are flashing red and all the sirens are blaring. People start coming and going at a dizzying rate from various specialties: neurology, plastics, gastroenterology, genetics, cardiology, and not only doctors, but residents, interns and students as well. After a while, they are all just white coats. Residency, cardiology, and not only doctors, but residents, interns and students as well. After a while, they are all just white coats. The medical staff are the only ones who are wearing white. People start coming and going at a dizzying rate from various specialties: neurology, plastics, gastroenterology, genetics, cardiology, and not only doctors, but residents, interns and students as well. After a while, they are all just white coats. Residency, cardiology, and not only doctors, but residents, interns and students as well. After a while, they are all just white coats. People start coming and going at a dizzying rate from various specialties: neurology, plastics, gastroenterology, genetics, cardiology, and not only doctors, but residents, interns and students as well. After a while, they are all just white coats. Residency, cardiology, and not only doctors, but residents, interns and students as well. After a while, they are all just white coats.

By evening, the diagnoses started coming in. The SOFT times, August/September/October 2012
cries of these poor child tragedians rising in plaintive chorus to the deaf ears of some lesser god.

Day two had almost come and gone, with more doctors, more tests, more decisions, and more tears and still we had not given the child a name. The yellow card on the side of the bed simply read “Baby Girl Ricker.” A friend had fashioned us a woolen angel that we hung from the IV stand above her bed. Angela? It was a good start. I had been thinking of my paternal Grandmother, and the child she lost back in the thirties, a so-called “blue baby.” Once while visiting a graveyard in Ohio with my grandfather I watched him pour a cup of water on the child’s grave. “I never found out if he was baptized or not,” he said by way of explanation with tears in his eyes. After my grandfather died, I found a little box with a ribbon tied around it at the back of a linen closet. Inside were notes of congratulations on the birth of the child. The postmarks were from 1934. My grandmother’s name was Frances, like the saint. She would look out for the child. Angela? It was a valid name, a favorite book. These can be highly emotional moments for a parent. How do you present to your children, ages 2 and 4, their new baby sister, head swaddled in gauze, and explain to them that she is going to die? When we finally reunited with them after sweeping their new baby sister away and saying to each other, “Where’s the new baby! Where’s the new baby!” insisting on seeing her. What about our other children? How are they going to handle this? There is no joy for a parent like that of experiencing the world through their children’s eyes, first snowflakes, first live concert, a frog, a dragon-fly, a favorite book. These can be highly emotional moments for a parent. How do you present to your children, ages 2 and 4, their new baby sister, head swaddled in gauze, and explain to them that she is going to die?
Our Journey with Angela and Trisomy 13, continued

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after a flood of four-year-old tears. Then it gets broken. Karina is once again inconsolable. She says in full hysteria to a room full of teary-eyed friends while protesting how much she loves the doll that, “It’s broken and can’t be fixed. Just throw it away. It can’t be fixed.” Is it the doll, or the baby of which she speaks? Her grandmother has her draw a picture of the doll, whole again, and this she carries around as a kind of totem to the doll/baby that “can’t be fixed.”

By day four in the hospital, people wanted to come. A lot of people. It soon became overwhelming. Friends we have known for years told us for the first time of their childhood bearing loss. We never knew. These things are kept secret, or rarely spoken of. I guess we were earning the right to know now. We had the pass-key to that other world of sorrows that people keep to themselves. We had a friend take over the coordination of our personal affairs. Anything outside the hospital room was simply too much to handle.

At one point I was told that I need to get out for a bit. An old friend was coming up from Boston to help. I remember sitting at the bus station watching the people disembark, one by one, people of all ages, colors, and sizes. “Survivors”, I remember thinking, “survivors all.” I realized that I was never going to look at the world the same way again. The old friend arrived, and I was told that I looked ashen. I had forgotten to eat again. My cheeks were feeling bruised from so much crying.

The morning rounds during the final couple of days took on the utmost of importance. We waited patiently for them, putting off food, visits, even bathroom breaks. Then the room would be full of white coats going through the growing laundry list of all that was wrong with our daughter. What they had to say did not describe the child who we were getting to know, the child she was and is, bright-eyed and full of wonder.

At one point, I interrupted the chief resident saying “you know, all we have been talking about is all the things wrong with this child,” then, holding her up in my hands to show them, “well, there are a lot of things right about this child as well. Look at her. She’s beautiful.” This caused one of the interns to weep.

There was a final meeting before the floor chief left for vacation and handed the baton to a new doctor. The entire team was assembled around a large conference room table. There were a lot of tears, even among the younger staff. We discussed what would be next for Angela. Various options were proffered including leaving her at the hospital. Melinda and I were of one mind: This child was born at home and she will die at home. In the meantime, we will give her the best life we possibly can. A plan was discussed for what needed to occur before they would release her. She needed dressings, prescriptions filled, hospice care arranged and what seemed like a hundred other things. Milliliter syringes of breast milk needed to turn into tiny bottles. Of course, the prospect of leaving the hospital was scary. How would we do? How would the end come about? Whom should we call? I had a rather uncomfortable conversation with one of the doctors about how quickly we would need to deal with my daughter’s body. Does nature allow for an unhurried goodbye? I had had some experience with this, having taken care of my grandfather at his home until he died. Answer: We’d have more time with Angela.

On the fifth day, the afternoon before check out, I filled out Form F-1005, the “New Hampshire Protocol – Do Not Resuscitate Order (DNR).” I could hardly read the form, my eyes swimming with emotion, the words “terminal medical illness,” “no resuscitation,” “signature of patient or holder of power of attorney” sticking in my throat. I remember scoffing about the “power of attorney” part. It felt more like playing the part of judge and jury, with fate waiting as executioner in the wings. At 2:37 pm on the afternoon of October 12th, 2004, I signed my daughter’s life away. At least that is what it felt like. The last image I have in my head of the hospital is of our family moving down the long corridors of the hospital, a motley procession of gifts, flowers, luggage and left-over food, finally venturing out alone into the great unknown with our little bundle of hope, fear, uncertainty and wonder.

On the road home, heading north on New Hampshire Route 10, through Lyme, was like driving through a kaleidoscope of fall colors. I was driving on egg-shells. Anybody who has ever put a newborn child in an automobile for the first time knows the feeling, driving like there is Waterford crystal loose in the back seat, uninsured, with the house payment overdue. But there was little traffic to worry about and the day was beautiful. Angela was happy and so were we.

The homecoming was joyous. We were finally home and together as a family again, come what may. Her life would begin anew, however short or long it would be as. It happened, days and weeks turned into months, and months into years. Six years of final days, and each day the story continues. It has been a bumpy ride full of many joys, pains, fears and challenges. In short, six years of the stuff of life, a life lived in the immediacy of the prospect of the absence of life. Angela has pushed us in ways that no other child could have possibly pushed us and we are stronger and better people because of it. It has often been extremely difficult and not always been pretty, but she has also been the raison d’être of our finest hours as parents, and as human beings. Through her we have met some of the most amazing people, meeting immense challenges, and living extraordinary lives. Her impact on the lives of her siblings and on the lives of those who know her in our little community is immeasurable.

Angela started school full time in the fall. This Christmas we watched as she sat in her wheelchair up on stage with her kindergarten class at the school holiday concert smiling and laughing. This child is truly special, and it has been one the great privileges of my life to raise this child, to be part of her life, and to be able to say, and say proudly, that I am her father.

“The homecoming was joyous. We were finally home and together as a family again, come what may.”

-David Ricker

Nurse Judie, continued

On Page 3, Nurse Judie was shown beginning to meet the comfort needs of Madam Foundress. Above, kindly direct your gaze, to the finished accomplishment that apparently pleased Madam. She was finally warm. Nurse Judie was dismissed with a smile.
“No dream comes true until you wake up and go to work.” - Anonymous

SOFT Conference 2012
July 18-22 St. Louis, MO

SOFT Medical Clinics at Cardinal Glennon Children’s Medical Center

Teams for SOFT

Stroll for Hope

HOPE
“Sanity may be madness but the maddest of all is to see life as it is & not as it should be” - Don Quixote

Start 'em young
“The dedicated life is worth living. You must give with your whole heart” - Annie Dillard

May I Have This Dance?

DANCE LESSONS WITH GERRI

Shake it!
“I still believe in hope, mostly because there’s no such place as Fingers Crossed, Arkansas” - Molly Ivins
“Hope is the only universal liar who never loses his reputation for veracity” - Robert G. Ingersoll
New Families

Photo Left: Fred Bird!

Take Me Out To The Ballgame!

SOFT members attended a baseball game at Busch Stadium: Cardinals & Cubs!
FAMILIES COME EACH YEAR AND REMEMBER THEIR CHILD BY RELEASING A BALLOON

Releasing the bunch of balloons at end of service to remember all the children lost, whose names are unknown to us.

Siblings reverently release balloons in memory of their brothers and sisters.

Butterflies were released following the balloons.

SOFT’s Sacred Ritual - Balloon Release

AUCTION RAFFLE
If two is a couple, and three is a crowd, what is four & five? Nine
Another Championship Cause: 26th Conference Wrap-up: St. Louis

Glennon Children’s Medical Center for stepping in when John could not be present until Thursday by educating the board, supporting families and coordinating the clinics.

A new addition to the conference this year was the sponsorship initiative. The registration area, later the ballroom, the picnic area and the auction hall were adorned with large signs, each announcing a donor and what was sponsored. Sponsorships included items, such as daisies, centerpieces, building space, snacks, sib tee shirts, awards, binders, welcome bags, balloons and sound system, and butterflies at the balloon release, angels magnets for our cars, a highway billboard sign, pre-game activity, and photography sessions. Other donations paid for food and drink during specific activities, a large picnic tent, fans, tables and chairs, childcare supplies and activities, the DJ at the banquet, workshop refreshments, and the general conference coffers. Noah’s Never Ending Rainbow sponsored both the picnic food and helped bring 23 families to the conference. The Joey Watson Fund also helped families attend. This model of extensive sponsorships immensely helps the conference committee members, so they can turn their attention from the drudgery of fund raising to the creative endeavor of enlisting volunteers, finding speakers and entertainment and planning menus and special activities. The conference fee, which is kept to a minimum, only covers some of the hotel meals, nothing else. All these individual sponsorships, the proceeds from the auction and from the SOFT Stroll for Hope defray costs substantially. Keeping costs down means more families can afford to attend the conference. With the success of the sponsorship model this year, it has been decided it will continue. This may mean more members will consider bringing the annual SOFT conference to their cities.

We were busy this year and had fun. The conference always starts with the board meeting, which is not fun, but necessary. It ran all day, even with several conference calls during the year to address on-going concerns. Committeees reported on their activities and listened to recommendations. The budget was reviewed. Research funding, conference support to families, and a presence at genetic conferences were considered. Recommendations were made. Discussion ensued on the expense and thus viability, as well as, format and content of the newsletter. We discussed the needs of the website to bring more information more quickly, expand family content and promote special features such as the Trisomy Awareness daily stories in March.

There was discussion of the concerns about the Facebook link when the philosophy, legal mandates and professionalism of the organization and the privacy of individual families are not always respected, jeopardizing what so many have worked hard over many years to establish. Non medical people giving medical advice, even based on what has worked for them, can have negative ramifications, putting children at risk and raising legal issues. Photos shared without permission can be an invasion of privacy. The rapid expansion of social networking in our lives means the need for making sure it is the positive tool we want and believe it can be. Behind so many board discussions is the reality of our mandate as a support organization and the legal and financial constraints under which we operate. Once again, older members reminded us of the times when there was only loose change to fund our organization. We have realized both longevity and growth, because we have acted responsibly and stayed consistent with legal demands, as well as member needs. Every member must represent SOFT well and not jeopardize what is both important and hard won.

During the board meeting Dr. Stephen Braddock presented a review of recent journal articles, getting board members up to speed on research findings. Board members also enjoyed hospitality, caught up with each other and had time for some frivolity. Kris found the air conditioning a bit extreme and jerry-rigged a cape from a blanket held together with paper clips.

Wednesday evening there was an opportunity for those arriving early to gather for light refreshments. Many later wandered into the hotel restaurants or crossed the street to the local mall restaurants. We comfortably eased into the twenty-sixth annual SOFT conference on the banks of the Mississippi.

Thursday morning after breakfast, the second annual SOFT Stroll for Hope took place in one of the hotel ballrooms. Children and their wheelchairs and strollers were colorfully and thematically decked out. Family members wore matching tee shirts. Both surviving children and those held in hearts were celebrated in this intimate community and through donations in the larger community. The money raised is split between SOFT National and the conference. With some teams bringing in over a thousand dollars and many families participating, an impressive amount of money was raised. There was music, laughter, group and individual pictures and awards. This event, sponsored and coordinated by the Cook family in memory of Jonathan will continue in future years.

The clinics followed the Stroll and busses made continuous loops carrying families through the St. Louis University (for all the Catholic families in SOFT, that is where so much wonderful modern liturgical music originated) to the SSM Cardinal Glennon Children’s Medical Center. Families reported clinics were helpful and well organized. Each child was able to be seen by three clinicians, and questions were answered. Physicians welcomed the opportunity to meet so many children who had survived the trisomy
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odds. Steve outfitted children in small fashionable sunglasses that fit on low set ears to help with photosensitivity. Waiting time was fine, since families could visit and get to know each other better. During the afternoon clinic time workshops were given on sharing memories, one to adults and another to siblings who are grieving. Other families did some sightseeing Thursday afternoon or arrived during that time.

Following the clinics was the annual Welcome Dinner, which encompasses other events. Each SOFT child entered the room individually: walking, in wheel chairs or strollers, or carried. Names were announced and Craig and Marie Donaldson, whose beloved Carey Ann had passed away only a month earlier, handed each child a bouquet of daisies in memory of a child who lived well into her third decade of life and captured the hearts of many of us. Each child and family member then moved forward and was given a team pennant by members of Zion Lint’s family. The parade of stars was initiated in Roanoke by the Lints and has since been renamed the Zion Lint Walk of Fame. The Hennessey “Iron” children gave each child a trisomy a tri-be tee shirt, which stands for: Battle against pain, death, fear, anger and ignorance; Breathe, since no trisomy parent takes a breath for granted. Believe that life is precious, each day is a gift and faith that the strength needed will be there.

The Keynote speakers were the Hennessey’s. Michael Hennessey has taken up the cause for trisomy by raising money and awareness by breaking the Guinness record and completing 15 Ironman races in a year. He ran his first Ironman, in fact, The Ironman, when he was eighteen, raising money to help fight hunger. Years later he saw the competition as a means of raising awareness of trisomy 18 and 13, often dismissed disorders that needed a good publicity campaign. He competes to change minds and hearts about the sanctity of life through one population of children and to celebrate the courage of these families, who run their own Ironman every day. Hennessey and his wife, Janelle, who perhaps has the more daunting task of caring for their children, while her husband covers the world competing, have embraced this cause. While he ran, she cared for their six children ages seven and younger at the time of the fifteen races. As a runner and a mom I would just like to ask, “Who is the true Ironman here?” Since the record breaking year, they have used fundraising in many ways and awareness to support families and provide recreational equipment for children. In the future they would like to establish a retreat/respite home for families in Comfort, Texas. This is a driven couple, inspired by the many families with children with trisomy they have met. They have lived their faith and held strong in the commitment they made to uphold their belief in the sanctity of life by supporting those who live that belief as parents. They and their children were a welcome addition to the SOFT family.

The many Hennessey children joined the many SOFT sibs in dancing the night away to the music provided by the DJ, “Over the Top.” Adults joined in, including the provision of some dance lessons for adults and kids by Gerri Meggett, but the kids ruled. There was perpetual motion, many smiles and laughter.

On Friday after a SOFT hearty breakfast, and the introduction of first time families, there were workshops for adults and outings for the kids. The SOFT sibs divided into two age groups and wearing their bright blue designer tee shirts designed by Quenby and sponsored by Leilani, they boarded busses to the City Museum, an eclectic collection of found architectural and other materials from the city that makes a unique playground or the highly acclaimed St. Louis Zoo.

The adults attended a variety of workshops, some of which are summarized in this newsletter. The first session included John Carey’s presentation on trisomy, 18, 13 and related disorders. Barbara Braddock shared her results from the study of communication in children with trisomy 18 and 13, that she undertook at a previous conference. There was a workshop on assistive technologies, a rapidly changing landscape of possibilities for our kids, and a workshop on advocating for your child presented by a panel of SOFT parents of young children. The next session of workshops included one on chiropractic interventions for parent and child, a trisomy 9 update from the TRIS project, advice on insurance and accessing governmental programs and a look at transition points during the trisomy journey. During lunch the chapter chairs met and discussed business, while other members attended their own luncheon. In the afternoon, at the request of last year’s attendees, moms and dads met separately for an extended workshop. This provided an opportunity for getting to know the larger group and sharing common experiences, joys and concerns. What was said was confidential, so all that can be reported is that there was laughter and tears, hugs, increased understanding and appreciation of our shared and individual journeys. Although side chit chat was discouraged, and even Morghan complied, there was some distraction in such a large group. There was an atmosphere of respect for what was shared. It was an important way to welcome new members, who we suspect will return, because they too feel as if they have come home.

Many families attended the Cardinals-Cubs game at Bush Stadium, within view of the magnificent arch. We were not disappointed with our own good company, a home run by Matt Holliday, a cool enough clear evening, a win by the Cardinals, and baseball food and drink, including hotdogs, nachos, cotton candy, soda and beer. We wore our own team shirts, moved about during the game, and enjoyed...
who return every year, so many of the names are now familiar, and we picture each child as the name is read. It seems such a sacred duty to release the balloons of children whose parents could not be here. Each is sent with love and regret. For each of us standing on the field, wherever it is each year, it is such a poignant time, when we are asked again to let go of our child and watch a simple balloon carry our prayers, memories, however short or long ago, loving wishes and the dreams we once held. We let our balloons go both alone and in community. Craig and Marie released Carey Ann’s first balloon. It was suspended a short while within the canopy of a tree at the field’s edge, but soon eased away and floated upward. She seemed to stay among us a bit longer before joining the other angels who had preceded her. As she always has, she kept our attention, drew us in. Bo and Malin Sander traveled from Sweden and lovingly released Anna’s first balloon. She too had full trisomy 18 and had lived into her twenties. We never met her, but knew her through pictures and her siblings’ and parents’ adoration of her. We were delighted they made their 4,000 mile journey back to their SOFT family. After the balloon bouquet representing all unnamed children was sent skyward, monarch butterflies were released in memory of Simon Crosier. They fluttered about, circled us, and headed across the field. A few lingered. Young fingers gently held a few slow to leave. Butterflies are a traditional symbol of a child lost too soon. They enter our lives fleetingly, and when they are gone, we remember their beauty and smile.

The organizers through the years have tried to separate the joyous, lively picnic with the solemn balloon release, a potentially tricky combination. Those of us, and there are many of us, who return each year with our child in our hearts, are grateful to the many parents who generously share their children, so we can remember our child or imagine what our child might have been like if he or she had survived longer. This is important. We are also grateful to all those parents with children by their sides, who know our journey is just as important as theirs and join us reverently and respectfully during the balloon ceremony and teach their young children the importance of such quiet respect. The games and noise by others during this time are distracting and not consistent with the values of SOFT and the needs of its members and did not go unnoticed. We need to be supportive and unified, sensitive to situations and emotions.

Chris Donahue once said, a bit tearfully, that being with those whose children had died, yet they returned year after year, were engaged in life, laughed, yet held on to memories, reassured her that when her time came, she too would be okay. Most of the time she imagined she would not be fine. She got that reassurance each year at the conference: our gift to her. Mary, now a teenager, is her gift to us. Each year a family or two that we have known and many newly known have their child added to the list of names. We cry anew, wishing we could absorb some of the new pain. We stand and listen to each name, following so many balloons until they fade from sight. Maybe observing the balloon release from within the group, agreeing to let go of a balloon that needs someone to release it, joining in with a ritual so important and essential to SOFT, will help some understand why we gather at a field, on a hill, by a pond or high on a mountain each year. This understanding may unify us more. SOFT has always included geographic, ethnic and social diversity, and now includes more generations, but we can stand together supportively in respecting and providing what we all need.
Saturday night was hearty hors d’oeuvres and many desserts. The auction followed. Both silent and live items drew attention and competition. There was lively bidding for Cardinals signed memorabilia. Many handmade items were appreciated and brought high bids. The highlight was the raffle of Craig’s wooden box. He gave clues (if they build it, they will come, adding, think broadly, and Canadians find comfort). Tickets were sold, bringing in over $1,000. The wooden box was beautiful and several commented they were bidding for the box. There were no correct guesses, even though Craig added that what was inside was not made of wood. The winning ticket was selected from the hundreds sold. Liz Bona-Cohen selected the winning ticket and hugged the winner. Craig presented the key, held by Marie, and the chest was opened, revealing a beautiful red white and blue quilt with embroidered and quilted baseball team patches in a grid on the front. It was magnificent, and we learned that Marie with her needle is as talented as Craig with his saw. We appreciate the time invested in this venture, now joint, and hope such a creative and exciting new tradition continues.

Sunday came and from the earliest hours families began to leave, many with several days drive ahead of them. We reluctantly left behind all the special activities and our friends old and new. Siblings hugged each other and knew they would pick up where they left off in a year. The time had gone so quickly, but we left to Canada, Sweden, Puerto Rico, Washington, New Hampshire, Utah, Texas, Virginia, California, Tennessee, thirty different states in all. There were seventy-eight families. The 45 SOFT children ranged in age from less than one to early 30’s and represented fifteen different diagnoses. There were twenty children and adults with full trisomy 18. Once again, we had made a pilgrimage, gathered in what for many was a distant land and found we had come home.

-Pam Healey

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We’re linked to the internet at http://www.trisomy.org
Perspectives on The Medical And Genetic Aspects of the
Trisomy 18 & 13 Syndromes
John C. Carey MD MPH  University of Utah

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genes, because it cannot survive in a trisomy state. With chromosome 20, there are no live born, but it is a smaller chromosome than 21. The deciding factor in viability is not extra DNA but specific developmental genes.

There are more forms of aneuploidy. Triploid, which means all chromosomes are in triplicate, are live birth only if mosaic. This is the result of the breakdown of the natural mechanism that bars a second sperm from fertilizing an egg. There are 2 sperms, dispermia, each with a full complement of chromosomes. It is believed that 60% of babies miscarried have a trisomy. One third are triploidy. Turner’s syndrome, XO in females, is a large cause of fetal death, but we are not sure why.

There are a range of human conditions involving chromosomal anomalies. There can be an alteration of number, which is an aneuploidy. This includes trisomy, monosomy, mosaicism of trisomy 18, 13 and 21, Turner’s syndrome (XO) and Kleinfelter’s syndrome (XXY).

There are also disabling and lethal conditions resulting from alteration of structure of chromosomes. This includes deletions, duplications and translocations. An example would be 4p- in which a segment of the short arm of chromosome 4 is missing. A missing piece can be related to a rearrangement, translocation or reciprocal attachment, which affects chromosomal separation. With an unbalanced translocation a parent has the right amount of chromosomal material, but the child does not, getting too much of one chromosome and too little of another when chromosome aligned. Another way of dividing the chromosomes is into autosomal: 1-22, and sex chromosomes, X and Y.

Knowledge that has allowed us to identify specific chromosomes and understand the mechanism of specific syndromes has been recent. Only in 1956 was it possible to see the chromosome number. Only in the last 20 years have we been able to identify genes and place them on chromosomes. Progress in this area continues rapidly as more genes become known.

We also know statistics related to specific syndromes. We know 90% of children with trisomy 18 and 80% of children with trisomy 13 have heart defects. We know there is increased neonatal and infant mortality. We know 50% have succumbed by the second week of life. By six months of age, 50% have died. Only 10% will reach a first birthday. In the latest study from 2011 the numbers seem to stand the test of time. SOFT knows about the other 10%, the long time survivors.

The only way we know about survival is through data. A 1968 chromosome lab study says 3/4 of children who survive past a year, die by age 5. We have no new data confirming or denying this statistic. In Utah 10 children have lived past a year. Ashton and one in Idaho, Erin in Utah. Three are still surviving, and seven, many known to SOFT members, have passed away at various ages over the past 20 years.

With trisomy 18 and 13 the ages of deaths spread out over next 18 years. Deaths of infants with trisomy 18 cluster in the first week, with more spread out in six months, then spread out over decades. The pattern holds. Doing more surgeries does not necessarily allow them to live longer. There can be maximum support, including cardiac surgery and immediate survival increases, but by a year survival rates remain the same. Trisomy 18 remains a highly serious condition.

There is data accumulated in Japan now, looking at heart surgery performed at the average age of 3 months. They went from 9% to 25% survival after heart surgery. Intervention did not seem to make much difference to survival. Children would pass away from something else such as pneumonia. There were 120 children and 89% had surgery and left the hospital.

All studies look at frequency of condition and there is the same live born frequency across cultures, and ethnicities. There has been 1: 5,000 to 1: 6,000 live born in Utah. With amnio and other prenatal diagnostic tools, the frequency numbers have changed, with live born dropping 40% as a result of elected terminations. There is greater availability and acceptability of termination. The updated data is in 2004-2009: 1 in 10,000.

Data in the United States from the Center of disease Control indicates there is 70% termination of T-18/13, which is lower than termination of Down syndrome, which is 88%-92% termination rate. In Europe terminations are more frequent. Less common syndromes, such as T-9 mosaicism which is rarer than T-13 have not had figures calculated. There has been a registry of chromosomal syndromes since 1999 in Utah, which will give more information. Not all birth defect registries keep track of all chromosomal syndromes.

We have much to learn of the outcome of survival. Procedures are increasingly available that can effect out come. There are cardiac medications offered to some children which can make a difference. For instance, cardiac meds are available which keep a PDA open, that is, keeps fetal blood circulation going which offsets some cardiac defects until surgery can be performed. When the PDA closes, which will happen naturally, the baby dies.

Time was over, many slides remained, but the session was informative, and participants, whose engagement was seen in questions and comments, wanted more time.
Dear families of SOFT.

Some time has passed since our loss and your loss of Carey Ann. As we type this, our pain is still raw and our tears never seem to stop. So how can an individual who was not our natural child have such an effect? We look for answers in all places, family, friends, experts, but most of all in memories. Please have patience with us as we try to cover some of those precious memories in a tribute to a very special young lady.

First the medical memories and concerns.

Carey Ann entered our lives when we were asked to take in a highly agitated child of three and a half years, who by then had been given up by her birth parents. She had been institutionalized for those years and by the time we met her had had a history of medical crises.

At birth she was grossly underweight for a term baby and found to have congenital heart disease and intrauterine growth retardation common with Trisomy 18. She was transferred from the University hospital in Edmonton Alberta to a long term care institution at the age of 3 months. During this period Carey had surgery for bowel obstruction caused by Meckel’s diverticulum. She also suffered numerous bouts of chest and urinary tract infections.

Diet was a tremendous problem due to feeding difficulties. She was being gavaged 5 times daily and vomited at least 2 times daily. Carey slept only a couple of hours at a time, was irritable, had well developed scoliosis and only weighed 18 pounds.

She came into our house and family on June 26 1987. In July a gastrostomy tube was inserted. Baby food was introduced through the G tube and chloral hydrate at night for sleep. She showed significant improvement. She underwent an inguinal hernia repair in April 1989 and came through like a trooper. Chest and UTI’s still were a concern at this time. She had bilateral heel cord lengthening done in April 1989 and was in a cast for 3 months.

We took her on a holiday to England that summer and had a great time. She remained cheerful throughout the whole trip and really enjoyed the attention she got from friends and often complete strangers. She is a very sociable young lady.

Throughout this period her weight reached 25 pounds but she would still vomit at least once a day with circamoral cyanosis. Tests were done which always came out negative. Carey’s liver was found to be the shape of a ball with the bowel flipping over it every so often. When this occurred we found that Carey had a hard time with her bowel movements and produced excessive vomiting. In October 1990 a fundoplication and cystoscopy were performed. She was in hospital for one week and hasn’t vomited since. In addition her urinary and chest infections also decreased.

The next 4 years her health was very good with only the occasional illness. She became active and aware of her environment, enjoyed play and attempted vocalisation. She attended a structured school program and got great pleasure riding the school bus with her school friends. Her sense of humour was an asset. She enjoyed bouncing on the bed, getting around in a large walker and weight bearing. She was introduced to the swimming pool and bath nights were her best moments of the day.

In August 1994 we were introduced to SOFT at the conference in Toronto. We met many of you and gained insight into some of the potential problems with Trisomy 18. However it gave us encouragement to carry on and advocate in the strongest possible way for the needs of Carey.

Little did we know how soon we would need to advocate for her medical rights.

On returning to Edmonton with Carey we picked up our other foster care child Stephen, from a respite care centre, who had had a temperature of 104 for 24 hours. Six days later Carey woke up with a similar high temperature so we treated her symptoms. Two evenings later she went into respiratory distress so we took her to the ER. Now the question of “resuscitation” came up by the emergency staff, the issue being Trisomy 18 and the general prognosis that goes with it. We demanded treatment as would be given to any normal child in distress.

Carey was admitted for IV antibiotics. There was no improvement and she got worse. Her urine output decreased, respirations were laboured, she was puffy, and exhausted. They refused to give her chloral hydrate at night and 3 days into this as my husband and I were bathing her she stopped breathing. A code was called and CPR done without intubation. She got Lasix and the chloral. She settled down and finally slept.

The question: re Resuscitation and intubation, what should be done? We forcibly informed the interested parties that they again should do what they would do for any other normal child. At
Unable are the loved to die. For love is immortality–Emily Dickinson 1830-1886

Carey Ann Neufeld . . . A Tribute to a Very Special Young Lady

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9 pm that evening she was having problems so at 11pm she was intubated sent to the PICU and hooked up to a respirator. Four days later Carey obligingly extubated herself.

Our girl came home four days later but her lungs had sustained some permanent damage. She was on oxygen full time at 2 litres. She then developed a rapid kyphosis which also impaired her breathing and mobility. Chest and UT infection increased. She had to be catheterized since she tended to hold her urine for as long as 18 hours. A new wheelchair was ordered for her comfort.

She was placed on prednisone for 3 months which resulted in a weight gain to over 100 lbs. The kyphosis progressed rapidly and we couldn't use the brace for the scoliosis. With great trepidation we had Harrington rods inserted on March 1995. She came home on March 31st. We started in earnest in looking at her diet since she had mobility and lifting problems because of her weight gain, in addition to an increase in chest infections. We placed her on a diet of 600 calories.

This worried us. We started looking at alternatives to the diet. A local homeopathist suggested we take Carey off the diet she had been on for years and give her vegetables, fruit, tofu, nutrients supplements, tissue salts, and 1000mg of vitamin C, plus homeopathic remedies for specific problems such as chest and urinary infections. Her pediatrician agreed to keep a vigil on her to make sure we were not slowly starving her. Carey's improvement was tremendous. His statement was "he doesn't know why this change is working, but don't touch anything in regards to "madam's" diet".

Carey now weighed 55 - 65 lbs, stood 4' 6" tall, was alert and had returned to the previous activity level of 1994. Her school attendance was impressive. There were no signs of puberty, she was now 14, but her attitude about getting up and going to bed at a reasonable hour told us she was happy to assert her teenage rights.

Carey's dependence on O2 was for 2 years before we finally weaned her off. Her diet continued to be modified and she moved into a period of good health. In 2010 however a pneumonia meant she was back on the O2 once again.

Now came what was to be her final challenge. Scans showed that her gall bladder needed to be removed, so in March 2011 a successful operation was completed. The gall bladder was small but heavily packed with stones. It has always been our protocol never to leave children in hospital without at least one parent in attendance.

This time after reassurances that any change in Carey's disposition and we would be notified ASAP. We left for a break to go home after 4 days in attendance. On a premonition we called back to the ward to be informed that Carey had been transferred to a recovery ward. We immediately returned only to discover that this young lady with no verbal communication skills and no active monitoring had been placed by herself in a room distant from the nursing station. To our horror she was deathly white, absolutely scared. Calling a nurse in charge, new to her care, that something was desperately wrong.

It turned out that Carey was suffering from a large bleed from the liver, caused by giving her adult doses of heparin (to prevent clotting during the operation). No questions, she was immediately returned to the theatre to seal the bleeds. She had lost 3 pints of blood. Seven days later we brought her home.

Over the past few months Carey began to show evidence of seizures. She went on to seizure medication. It changed her personality somewhat, she was listless at times and subdued. Other times she was her normal cheerful self.

On the afternoon of Saturday June 16th she had what appeared to be a major episode. We nursed her through the night as we had done before. Sunday morning we called the EMS. Carey was not in the ambulance for more than 5 minutes before her heart stopped. Resuscitation revived her but because of the DNR that we had on her for many years, life support was withdrawn. On Monday the 18th she passed away peacefully within 2 hours of her oxygen removal, her family surrounding her.

On reflection... Carey Ann whom many of you met during our conference visits, 8 in all. Toronto, Chicago 3 times, Denver, Salt Lake City, Roanoak and Sioux Falls was the brown haired, blue eyed girl with the wonderful smile. Happy, a sense of humour, mindful of her rights, always working on her abilities, with a spirit to survive no matter what health challenges or adversities that came her way, and yes she was a full Trisomy 18.

Over the years we have passed on through the SOFT magazine many of the precious moments that endeared her to her family. Like the time she snuck the flow pen from dad's shirt pocket and proceeded to apply her version of make up (Jan 2010 ). The time she dressed up as Brave heart, helped this time by dad, (April 2010 ) Her pure pleasure on the Disneyland trip and the multiple rides on the Small World boat trip,(May 2010) In Chicago the shear pleasure she showed being held by her Dad on the boat trip watching the lightning in the distant clouds.

Carey was a well known sight in the Sherwood Park neighbourhood as she rode her special bike on the bike trails in the summer. (October 2009) Often met by RCMP officers also on bikes and given an escort along part of their patrol. She attended a stimulating school environment in a special needs class. She graduated and moved to Robin Hood a wonderful not for profit organisation where each week day she participated in a program designed to meet her needs for socialisation, physical stimulation and skill development.

Throughout the years she travelled
greatly, dipping her feet in 3 oceans. She loved to travel, adapted readily to new locations as long as mum and dad were with her. As her eldest sister said at her funeral, "Carey Ann was the perfect sister, she never borrowed my clothes, she never took my boyfriends, always willing to listen to my troubles and above all never told my secrets".

Over the years many special needs and terminally ill children came into her life here at home. Some died and some went for adoption.

In those days of sadness Carey became our strength. She was aware of the increase in activity at the time of loss and responded to us with a loving smile and a closeness that gave us the strength to continue. Carey became the "glue" that kept the family together. She had become a source of great strength in the home.

So in answer to the question posed at the beginning, why in her passing has Carey had such an effect on those around us? Children such as these ask nothing of you but care and love. They return this love in buckets full.

We attempt to help these children to achieve as much in life as they possibly can. We watch them, nurse them and take pleasure in the smallest of their achievements. Apart from our 4 natural children Carey Ann was the greatest gift given us. We cherished this gift for 26 years. In her passing many people have shared our loss and have expressed great sadness. We now move on comforted in the knowledge that she no longer suffers and is at rest. As my wife and I see it, her enduring legacy here on Earth was to bring people together in love and fellowship. Something she has achieved in great measure.

Many thanks to all of you at SOFT in these difficult days. Your support and best wishes have been greatly treasured never to be forgotten.

all our love,

Marie and Craig Donaldson
Thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you

**SOFT Sincerely Appreciates Your Generosity, And We Recognize The Love That These Donations Represent**

**Donations to SOFT's General Funds**
- Elliott D Lawson
- Anonymous
- Ioannis Karmis

**Donations to the Joey Watson Fund, established to help financially challenged families attend the annual SOFT conference**
- Quay and Tim Wolfe

In Honor of
- Bella Santorum’s 4th Birthday
- Roger Rathburn
- Frank and Gloria Hardman: “You are in our thoughts and prayers”

In Honor of
- Brigid Coyne
- Patrick and Ann Marie Coyne

In Memory of
- Siddhi Shah
- Ajay Shah

In Memory of
- Faye Epping
- Judy Groner and employees of the Circuit Clerk’s office in Callway County, MO
- Christine Carpenter
- Boone County Missouri Circuit Clerk’s office: “From your friends with all our love and support to both of you”

In Memory of
- Nathan Patrick O’Maley
- Jeffrey and Suzanne O’Maley
- Larry O’Maley
- Elizabeth O’Maley
- Grandpa and Grandma O, with love
- Gram and Grandpa Rodal: “Our heartfelt thoughts are with you”
- Stan and Mary Beth Rodal: “Nathan was blessed to have had you both for parents”

Janet Elstro
- Travis and Christy Tollett
- Angela Karch
- Christopher Catalano: “You are in my thoughts and prayers”
- Kevin and Mary Hart
- Kim and Jerry Kramer: “Nathan was on this earth such a short time but will live in our hearts forever”
- Dennis Middle School: “May the blessings of love be upon you, May its peace abide with you, May its essence illuminate your heart, Now and forever more”
- Renee Smith
- Darlene Wendelin
- Staff and Administration at Centerville Indiana Senior High School: “Our thoughts and prayers have been with you and will continue to be for all time.”
- Anna L. Trent
- Cynthia L. Gordon
- Richard and Eleanor Edwards
- Kim and Doug Rawlings

In Memory of
- Rachel Emilia Nelson
- D. Brit Reynolds, from your friends in Undergraduate Admissions

In Memory of
- Eve Luciana Cagna
- Grandfather Joseph and
- Grandmother Marie Cagna
- Uncle Michael and
- Aunt Denise Mandolese

In Memory of
- Bryce Logan Householder
- Keely and Joe Drewnowski
- “Householder’s Honeys”, Mrs. Householder’s kindergarten class of 2012

In Memory of
- Sebastiaan Xavier Keg
- Antonia Keg

Kammie Wolpert
- Jen Swezey

In Honor of
- Natalee Van Landingham for her Grandmother’s 70th Birthday
- Reneau Van Landingham

In Memory of
- Simon Crosier
- Tim and Mollie Lucchesi

In Memory of
- Julia Childress
- Anja Landis
- John Boger

In Memory of
- Nathaniel Troy
- Popielarz
- Sheryl and Scott Crosier: “We love you and miss you, sweet boy!”

In Honor of Kids
- Titiksha Sukhadia

Baptist Foundation of South Carolina
- Grace Anne Cooper

In Memory of
- Jason Seilnacht
- I’m thinking of you, my buddy Jay, on my wedding day. Love from your cousin Therese and my husband Brad Johnson

In Memory of
- Garrett Stephen Twardowski
- Gale Twardowski

In Memory of
- Carey Ann Neufeld Donaldson
- Margaret Krause-Thompson

In Memory of
- Phillip E. Krause
- Margaret Krause-Thompson

In Memory of
- Greta Rose Thompson’s 32nd Birthday
- Margaret Krause-Thompson
Workshop: Transition Points in the Trisomy ...

(Continued from page 12)

Karen Schuler in Australia allowed more interaction and an easy flow of information. Parents living at great geographic distance discovered in each other what they had in common, what they could share with others and how they could be supported in their day to day interactions and concerns about their child with trisomy. Friendships formed and people met live, just as happens today at conferences. Finally, there was a convenient and immediate way to contact other families affected by trisomy through Facebook and other forms of social media. Currently, families have become friends with others with children in their child’s cohort. They seek others at the same stage of the trisomy journey.

Parents emphasized how important it had been for them to gather in with children with a similar diagnosis. They felt isolated and uninformed. They looked for both resources and other families who understood their situation. This was important support.

When asked about social support, the consensus was that there was mixed value to the support. One mother shared that people prayed for her child, which was appreciated, and people were available to help out when the child was an infant, but later the support went away. The diagnosis did not go away, but those who had been attentive and involved began to pull away. One mother shared that people seem to be there to give support when it seems the child might die, but when it appeared the child was thriving, they went away. People see their role as consoling, not supporting. People were fine in a crisis but chronic conditions that needed on-going support were not understood. Getting a babysitter was a problem. It seemed to participants that there was more need for support later, but people had backed off.

Parents expressed that it was very helpful to see thriving children at the conference, and that encouraged them. They came home "with gloves on" ready to fight for their child, because the hopeful possibilities had been presented. They had seen the survivors, and more was now at stake.

Parents were asked who is a great book friends than with family and friends at home. There was just a different connection and many found that important and useful.

Some parents saw they lost support, because their own priorities had changed. They began to focus on their child. Friends drifted away, because they cannot nurture other relationships the same way. One mother explained she might be on a call and had to suddenly hang up to go to her child. Focus on adult friendship was lost when the child’s needs were being met. Families were not always helpful. One family only advised the young parents to do what the doctor said and discouraged questioning. Some family members would not visit, stating they were afraid they would make the child sick. Too often family members were characterized as distant and less than helpful.

Parents saw changes in themselves. They would give pep talks, saying they could do what ever needed to be done themselves. They learned that they were strong.

They learned not to be judgmental about others and their reactions. They learned they had to become an advocate for their child, a squeaky wheel that was noticed. A concrete example was to plan, call ahead at a restaurant and make requests, so what was needed would be provided. Parents learn to become assertive in ways they did not think possible. They learned that it is all right to ask, and if the answer is negative, ask again in a different way.

The parents were asked about their experiences with early intervention services.

One mother emphasized that a social worker is your advocate, the guide for services available and the person who could make things happen. Therapies could be in the home, or in school and that was negotiated through the social worker whose client is the parent. Later, services orchestrated by the social worker could include a preschool program dedicated for disabled children, a social setting with other children to build skills in interaction or a mainstream school, although health issues can interfere with that setting. The social worker both helps the parents determine the right program and facilitate entrance.

The next transition point is the transition to public schools. Parents advised to fight to stay in the building, fight for access. Knowing your rights is essential and even threatening lawyer involvement can move things forward. Educational settings are tricky. Some children are included in general education classes, others are relegated to separate programs. School can be a battle ground. One mother commented that in kindergarten the tone was set by the teacher and that can determine how the child is seen by others. When a teacher says it is a waste of time for the child to be in that class, does that mean the child is disruptive to other students and the teacher’s agenda or that what that child needs is not being provided. This could be positive or negative. Other points made were that the school must provide proper nursing care. Parents should investigate what is available and insist on what their child needs medically.

Models should be considered. The pull out model means the child leaves the mainstream class for individual time in another place with a therapist. The push in model means a therapist joins the child in the classroom and facilitates learning. Circle of Friends is a model in which mainstream children increase their acceptance of children with disabilities through meaningful participation in schools and in the greater communities, breaking down barriers. The emphasis is on understanding differences and building interactions and friendships.

Another transition for families of children with disabilities is first IEP meeting. Family Service Plans are different. Parents have to do battle in IEP meetings, giving in on some needs so others can be met. The meetings can be difficult and confusing for parents. The process should be understood by all participants, but that is not always the case. Some parents may waive the three year reevaluation if it seems more disruptive than helpful for a child making slow progress. Parents need to know benchmarks are set at 60% or 80% achievement. This means greater than chance in some situations. The child’s ability may be underestimated. Parents should go in with the bar set high and perhaps ask for a higher percent of achievement expected. What the child can do may be masked by skills and cognitive ability the child does not have. Sometime there is a new medical diagnosis such as seizures which must be addressed and the IEP team should reconvene.

Parents were asked if they thought doctors are trying to upgrade their skills to understand conditions better. Parents were not sure about this. There are insurance issues, fear tactics to scare them, and too often little encouragement. Examples were given of medical treatment that might have been less than another child would receive. Sometimes a child is released after surgery too soon and complications arise that compromise recovery and require subsequent medi-
A SOFT Parent’s Perspective

edited and printed from
Giuliana’s Gift of Life - A Trisomy 18 Blog
www.g-giftoflife.blogspot.com
With permission of Jill DelSignore, mother to Giuliana born 8/4/10 with mosaic trisomy 18

Our Community Has a Voice is a collage poster of some of the beautiful faces of Trisomy 13/18 children, created by SOFT parent Barb Farlow, co-author of the study The Experience of Families with Children with Trisomy 13 and 18 in Social Networks.

July 23, 2012 was a monumental day for children and families with trisomy 13 and 18. It was the first day that our many voices would resonate within the medical community. Some history...

Almost two years ago, there was a collaboration between Dr. Annie Javier, Dr. Benjamin S Wilfond and Barbara Farlow, mother of Annie (5/25/05 – 8/12/05) born with trisomy 13. Adverse experiences with her own daughter’s care led this mother to believe that there was research to be done. Together, they created a survey and sought respondents among multiple online support groups that consisted of trisomy 13/18 parents. Many of the 332 families that completed the survey, including me (Jill), are members of SOFT. The first paper that resulted was ultimately published in Pediatrics, one of the most accredited journals in pediatric medicine with the highest impact factor. The Experience of Families with Children with Trisomy 13 and 18 in Social Networks is the name of the study. A copy of the abstract of this study follows below.

So just what makes this publication so significant?

Until 24 hours ago when this paper was published, many doctors were basing their treatment plans on what they had learned from textbooks alone. Most of the information published to date includes only grim statistics and paints a negative outlook for any child who is diagnosed with trisomy 13 or 18. Meanwhile, parents had mostly positive views from other families in support groups they were networking with and the differences led to dilemmas and conflicts about ethics. Parents who were seeking treatment were being accused of not acting in their child’s best interest.

The new study offers a first-hand look at what the true experts (the parents of course!!!) know about trisomy 13/18. The survey reflected that most parents just wanted to trust doctors to treat their children as people. The parents reported that they wanted their doctor to realize that a life, even a short one, had value and meaning. Parents wanted professionals to understand that they deserved to be involved in shared decision-making for their child. They wanted to be involved in exploring alternative options for treatment while still keeping in mind the realistic limitations of their child and the overall diagnosis.

For the first time in medical literature, words like “happy” and “enriched lives” were associated with trisomy 13/18 and will hopefully come to replace the common description currently being used like “lethal” or “incompatible with life.” The broad spectrum of the conditions was emphasized—each child is unique and all are equally special. Some may live for a short time, while others may live longer; some benefit from intervention and others do not.

I believe that this article in Pediatrics will mark the start of a change in the way our trisomy 13/18 children are being perceived. Parents know it is a difficult diagnosis and we know that there are many challenges. We are realistic. What we want and deserve is respect, compassion and honesty with our physicians. We are hoping that now, doctors will see our perspective about our children and care will be improved.

The Abstract of the Pediatrics article:

The Experience of Families With Children With Trisomy 13 and 18 in Social Networks
Ann Marie Janvier, MD, PhD, Barbara Farlow, BEng, MBA, and Benjamin S. Wilfond, MD

Author Affiliations

1University of Montreal, Pediatrics and Clinical Ethics Sainte-Justine Hospital, Montreal, Canada;
2Patients for Patient Safety Canada, Mississauga, Ontario, Canada; and
3Treuman Katz Center for Pediatric Bioethics, Seattle Children’s Research Institute and Department of Pediatrics, University of Washington School of Medicine, Seattle, Washington

Abstract

BACKGROUND: Children with trisomy 13 and trisomy 18 (T13-18) have low survival rates and survivors have significant disabilities. For these reasons, interventions are generally not recommended by providers. After a diagnosis, parents may turn to support groups for additional information.

METHODS: We surveyed parents of children with T13-18 who belong to support groups to describe their experiences and perspectives.

RESULTS: A total of 503 invitations to participate were sent and 332 questionnaires were completed (87% response rate based on site visits, 67% on invitations sent) by parents about 272 children. Parents reported being told that their child was incompatible with life (87%), would live a life of suffering (57%), would be a vegetable (50%), or would (Continued on page 36)
ruin their family (23%). They were also told by some providers that their child might have a short meaningful life (60%), however. Thirty percent of parents requested “full” intervention as a plan of treatment. Seventy-nine of these children with full T13-18 are still living, with a median age of 4 years. Half reported that taking care of a disabled child is/was harder than they expected. Despite their severe disabilities, 97% of parents described their child as a happy child. Parents reported these children enriched their family and their couple irrespective of the length of their lives.

CONCLUSIONS: Parents who engage with parental support groups may discover an alternative positive description about children with T13-18. Disagreements about interventions may be the result of different interpretations between families and providers about the experiences of disabled children and their quality of life.

Accepted April 17, 2012.
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http://pediatrics.aappublications.org/content/early/2012/07/18/peds.2012-0151.abstract

From Dr. Carey and Dr. Barrington about the publication of The Experience of Families with Children with Trisomy

Workshop: Transition Points ...

13 and 18 in Social Networks:

Dr. John C. Carey, medical advisor for SOFT
Barb, Ben and Annie,
Again-Congratulations on your paper and also on its fabulous coverage! I do believe that this work (has already and) will go on to help transform the stereotype of children with trisomy 18 and 13, providing for the pediatric community a more balanced -which in fact is the more “realistic”- view of the conditions.

John

Dr. Keith Barrington, husband of Dr. Annie Janvier
Dr. Keith Barrington, neonatologist and clinical researcher at Sainte Justine University Health Center in Montréal, discusses the need for professionals “to rethink how they present diagnosis of serious conditions to parents” and offers suggested guidelines for his colleagues, in his Neonatal Research blog about the study his wife co-authored. His words, in turn, had an “amazing” number of heartfelt responses from parents. The blog and parent comments can be followed online at http://neonatalresearch.org/2012/07/23/our-children-are-not-a-

Workshop: Transition Points ...

(Continued from page 34)
tical treatment that might be extensive. There could be insurance issues, and the parent is left wondering if the script would have been different if the child had initially stayed longer in the hospital. Doctors need to know that children with certain syndromes take longer to heal, so the usual expectation is wrong. Understanding that can mean a different protocol, longer hospital stay and faster recovery. These children may also overreact to drugs and that should be considered. Parents agreed that doctors need to understand they must look at this child differently if medical care is to be optimal and appropriate.

Next, parents were asked what they were most hopeful about. Parents expressed that they were hopeful because the outcome of kids with trisomy is not seen as being as dire as once thought. There is a movement toward understanding that these kids get better. Parents expressed that it is now possible to get their kids out, to talk to doctors and school personnel and begin to make others as positive as they are about the possibilities. Parents should consider what therapies have helped children with trisomy and request appropriate ones be provided.

Finally, parents were asked what had been the most rewarding part of parenting their child with trisomy. There was much agreement that unconditional love was high on the list. Parents felt the experience had been good for the siblings who developed important values and had their lives directed by their experience with their sibling. Many have chosen medical careers.

This was an important workshop, directed by an experienced social worker who drew out comments from many members of the large audience. Comments made were valuable, and, hopefully, many parents left with new ideas, new energy and confirmation that their experiences at transition points were both important and shared.
Friendship is born at that moment when one person says to another: “What! You, too? Thought I was the only one” - C.S. Lewis
Don’t forget to renew your SOFT membership!

CALL Barb VanHerreweghe at 800-716-SOFT (7638) for U.S. Families Only: We depend on annual memberships to fund the newsletter, but if you cannot afford a membership and still wish to receive the newsletter, please call Barb VanHerreweghe at 800-716-7638 for information about a limited number of membership assistance scholarships.

SOFT SURVEY:

Page 1

1.) How did you learn about SOFT?

2.) Barb VanHerreweghe is the contact person for states that do not have a local chapter chair. Have you been in contact with Barb?

3.) Have you been in contact with someone from your state or nearby state that is your state’s local SOFT chapter chair?

4.) Did your child receive the Synagis series for prevention of RSV?

5.) Does (or did) your child have a reaction to any vaccines/shots, please explain which immunization and reaction: ________________________________

6.) If your child had a reaction to any vaccines/shots, please explain which immunization and reaction: ________________________________

Child Health inquiries: Providing SOFT with information about your child’s growth, immunizations and surgeries is optional. This data might be of help for other families or for medical studies concerning our children. We would appreciate your input.

Growth: (Circle all that apply)

How is (or was) your child fed? Tube Bottle Breast Cup Spoon other

Is (or was) your child able to self-feed? YES NO With Help

Birth weight: ________ (lbs/oz) Birth Length: ________ (inches)

Current/Last Weight: ________ (lbs/oz) Current/Last Length: ________ (inches) Current/Last date: __________

If your child is no longer living please provide last known measurements and at what approximate age: ________

Immunizations: (Circle answer where applies)

1.) Is your child or, if no longer living, was your child up-to-date with your state recommended immunizations? YES NO Don’t Know

2.) Is (or was) your child on a delayed immunization schedule? YES NO

3.) Did you decline (refuse) any immunizations? NO ALL SOME (explain) Declined shot series

4.) Did your child receive the Synagis series for prevention of RSV? YES NO Declined vaccine

5.) Does (or did) your child receive a seasonal flu vaccine every year? YES NO Declined vaccine

6.) If your child had a reaction to any vaccines/shots, please explain which immunization and reaction: ________________________________

Surgical Information: SOFT maintains a surgery database to help families needing information. When reporting surgeries using a mailed paper form, use a separate page if more entries are needed. When reporting by Web, if additional space is needed, use the “add surgery” button to make as many lines as needed.

# Date Name of Surgery Name, City, State of Hospital Name of Doctor Successful?

1

2

SOFT Survey: (Circle answer which applies)

1.) How did you learn about SOFT? Health Care Provider Another SOFT parent WEB site Other (explain)

2.) Barb VanHerreweghe is the contact person for states that do not have a local chapter chair. Have you been in contact with Barb? YES NO

3.) Have you been in contact with someone from your state or nearby state that is your state’s local SOFT chapter chair? YES NO

Circle Card Name: VISA MasterCard Card # ______________ Exp. Date: _____ / ______________

Signature: ______________ Date: ______________

Annual Membership: U.S. = $25; Other Countries = $35 in U.S. Funds. Multiple years are welcome. Enter Amount: ______________

Joey Watson Fund: This fund was established to help financially challenged families attend the annual SOFT Conference.

If you wish to donate to this fund, please add a donation to your membership fee and enter the amount here: ______________

Donations: If you wish to make a donation to SOFT to help with operating costs, please enter the amount here: ______________

TOTAL AMOUNT: ______________

PLEASE SEND THIS FORM, AND PAYMENT (if paying by check or money order) to:

SOFT Membership Committee, c/o Barb VanHerreweghe, 2982 South Union St., Rochester, NY 14624

We assume that your name may be shared with other SOFT members (only) unless you specify otherwise.

For U.S. Families Only: We depend on annual memberships to fund the newsletter, but if you cannot afford a membership and still wish to receive the newsletter, please call Barb VanHerreweghe at 800-716-7638 for information about a limited number of membership assistance scholarships.

Membership Join/Renewal form 

http://www.trisomy.org (800) 716-SOFT (7638)

SEE SOFT’S HOMEPAGE FOR INFORMATION ABOUT SOFT, CONTACTS, MEDICAL AND FAMILY INFORMATION, AND THE NEXT CONFERENCE:

Page 38, The SOFT Times, August/September/October 2012
I thank God upon every remembrance of you.-Philippians 1:3

Remembering SOFT Angel Wings

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<td>June 6, 1983</td>
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<td>Molly Rose Van Blarcom</td>
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<td>Annie Farlow</td>
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<td>Ella Catherine Marohn</td>
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<td>Rachael Kleimola</td>
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Email Jack Laird for family contact info at jlaird@rochester.rr.com
Deadline for Nov/Dec 2012/Jan 2013 SOFT Times Is October 30th!

Welcome to SOFT ST. LOUIS 2012 CONFERENCE

SOFT THANKS ALL THE GENEROUS SPONSORS

SOFT of St. Louis 26th Conference Committee
Thanks You for coming And celebrating With us!