Dr John C Carey at the Global Genes / Rare Project 2nd Annual Tribute to Champions of Hope

By Ann Barnes

Wow - what an outstanding evening of celebration...the kind that touches hearts and inspires those fortunate enough to be there. As you will see below, SOFT is hardly alone in the need to educate and seek better outcomes. Global Genes / Rare Project is an advocacy organization for rare diseases and genetic conditions. Their mission is to unify rare disorder/disease groups globally to stand together in hope for treatments and cures for the estimated 7,000 rare diseases and genetic conditions impacting more than 350 million people globally. 10% are Americans; 95% have no treatment. For more information see http://globalgenes.org/

On September 21, 2013 in Newport Beach, CA, SOFT’s beloved medical advisor, Dr John C Carey, was honored as the Global Genes 2013 Rare Champion of Hope Medical Caregiver. SOFT is so grateful for John Carey and delighted that he has been recognized by Global Genes / Rare Project. Founded in 2010, Global Genes raises public awareness and funds, with spectacular events and is organized and operated by R.A.R.E. Project (Rare disease, Advocacy, Research, Education). Biotech and pharmaceutical companies and the sponsorship of Walgreens supported this celebration. The fundraising goal for this event was $200,000. One week after, they reported already being half-way there.

Social media was used to advertise the search for the 2013 Champions of Hope and Global Genes received over 200 nominations from all over the world for advocacy and science. Experts, advocates and those affected by a disorder were nominated for their efforts on behalf of their cause. Nicole Boice, Founder and President of Global Genes said “the competition was awe-inspiring, decisions were difficult, but those honored rose to the top.” She also communicated that John was awarded “because of

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Eleven years ago, I was on a flight from Phoenix to Salt Lake City. About the time we would be flying over the Grand Canyon, the pilot speaking from the cockpit, alerted us to the spectacular view out the left side of the aircraft. I looked up from my book expecting to see the Grand Canyon from 30,000 feet, which is truly an amazing sight! Instead, I saw something I had never seen before! Just below the aircraft and above the canyon’s Colorado River, there was a circular rainbow! Not just an arch from horizon to horizon, but a complete circle with all the colors vibrant and stunning! I sat mesmerized and would not allow myself to blink for fear it would be gone if I closed my eyes if even for a moment. I stared for what felt like hours, but only a few seconds had passed. I studied each band of color and with awe, realized that a rainbow in its truest form is actually a full circle!

I was flying to Utah for a special occasion. Our oldest daughter was expecting her first child and she invited me to go with her and her husband to their first ultrasound. I remember how incredible it was to witness those first pictures of our soon to be born grand-daughter! When the doctor came into the room, he cordially introduced himself. As required, he asked Tricia all the preliminary questions about her health and habits. Then he asked the innocent and yet emotionally charged question, “Do you have any family member that has a genetic disorder?” The room was quiet as she answered, “Yes, my younger sister was born with Trisomy 18. Oh, and she lived to be almost 11.” Not wanting him to misunderstand, I added, “Almost 11 YEARS!” He kindly looked at me and asked if I was Tricia’s mother. I smiled and responded that I was indeed the proud mother of six children and soon to be grandmother of one.

In talking to the doctor about Trisomy 18, I stated there was an organization for families with..... and just as I started to finish my sentence, he interrupted and said, “Oh, you mean SOFT?” With some shock, we all nodded yes, surprised that he knew what I was about to say. I asked him what he knew about the SOFT organization. He then told us that some years ago while working in the Midwest, a nurse from the genetics clinic would bring him every issue of the newsletter. He said he read them with great interest and was touched by the stories and the lives he came to know through the newsletter.

The next sentence he spoke will stay with me forever. He said, “The SOFT newsletter changed my life! It changed the way I talk to families because of the stories I read.” I asked him what he had learned. His response was profound. He said, “I realize that every family needs hope and every family needs one piece of good news. No matter what I find on an ultrasound, I will always give some hope and some good news. Families need at least that much from us.” He then asked how I came to know about SOFT. Tricia giggled and said, “Go ahead, Mom, tell him.” I briefly told him about Kari and Dr. Carey and our ties to Salt Lake City and the University of Utah and how our lives had changed for the better in the many years since her birth. I was proud to share with him that Kari’s legacy of love and hope was the Support Organization for Trisomy 18, 13, and Related Disorders.

Like a circular rainbow, this moment was a rare sight. In this brief appointment, I saw the future in a granddaughter’s ultrasound image; I heard the past in Kari’s message of hope; I felt the immediate love between my daughter and her husband; so the past, present, and future were brought together in a sweet moment in time. As we left the ultrasound room, I embraced my beautiful daughter knowing my life had truly come full circle!

Hugs...Kris
The Storytellers:
Defining, Binding and Enriching Our Community

By Pam Healey

We ask for your stories. We need your stories to make the newsletter the best it can be. We offer to help you write your stories, when you need support by asking questions that will get you started or editing to smooth things out. We promise we will read your stories and carry your love, memories and wisdom into our own days. What each of you writes about your child’s life, whether counted in minutes or decades, is important, not just to you and your family but to those in our trisomy family. When one parent writes about the joys of an older child or adult, those with younger children are given hope. When that parent writes of challenges faced, and creatively and persistently addressed and overcome, others are given guidance. When parents write of their strong love for a child that others see as imperfect, their determination to gain supports they see as necessary to the child’s growth and quality of life, and their trust that difficult decisions have been the right ones, then other parents recognize themselves and are affirmed in their own efforts. When a parent writes poignantly of a child who visited earth briefly, others know they are not alone in their love and loss. When a parent writes of the everyday interactions of a child with trisomy, those whose children did not survive will have a glimpse into what might have been, and this will help the healing and expand their own story. Writing the story of the joys, blessings, challenges, hopes and losses related to your child with the unexpected diagnosis and uncertain future is important for the writer and the reader.

Together the stories of our community form a metaphoric quilt that will keep us warm, enrich us, and bind us together. I share the following, because I believe thoughtfully writing the story of your child can be difficult, freeing and essential. You need to capture these days, or those earlier days, before time and demands blur memory. It will help you gain perspective and help you to notice what in the busyness of your days has been beneath your radar. It will be a gift you give to your future self.

Writing is important. It is an essential human skill that serves us well. Story telling is important and freeing. It occurs in many cultures from the oral tradition of the Irish seanchai traipsing the hedgerows to the Navajo storyteller now depicted in pottery as a seated woman, her mouth open, her lap crowded with listening children. As a writing people we began to capture those stories and preserve them, then created our own.

In a world of tweets, texting and emails, a place for the well-considered story remains. SOFT has recognized this since its inception. The newsletter will hold your stories; the readers will embrace them. We will come to know some of your children through what you write, and when we meet at a conference, you and your child will be familiar. We will learn more about those we have met, when more of the story is shared in writing and pictures.

It is time to enlarge our writing community; it is time for us to archive the stories that define us. Write your story in your own words, capture what your family has become after our shared experience of facing a frightening diagnosis and loving the child that is so much more than that diagnosis. Give words to your experiences, emotions and hopes. Help expand the knowledge of what it means to have a child with a trisomy diagnosis. Give voice to what you have lived and help others on their similar journey.

Writing has always been important to me. From the time I could easily put crayon, then pencil, then a fountain pen to paper, I have written. Before I was twelve I had pen pals: a roommate from the hospital when I was ten, and an age mate in Hawaii and another in England. I kept a diary before I had anything interesting to include in its locked pages. It was black silk with bright embroidered flowers, a Christmas gift from my mother. I went to boarding school at 14 and wrote home infrequently, but I wrote both to friends from home and to boys at our brother school, the letters taken by faculty members who taught on both campuses. We had no access to telephone, so writing was a lifeline. I kept a journal when I was on bed rest.

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before Conor was born. I wrote after his death, because I needed to organize, examine, come to terms with or rid my brain of what I was thinking. Two years later through Penparents I began a decades-long writing relationship with a woman in California, whose daughter with trisomy 18 lived only days. I never met her, but that did not stop a friendship from growing.

By the time I was writing about Conor in the mid-1980s I had come to understand the value of writing. I share the following experience, because there seem to be valuable parallels between using writing to grasp one’s own adolescence and using writing to grasp the unplanned direction a child has given a family. We learn to pull out and come to understand formidable experiences that define us by giving them words. The process is paradoxical. It holds us and frees us. It causes pain as we focus on what was painful, but it helps us reframe that pain and find gifts. It starts as a personal story and becomes a community’s story. We look back to move forward. The process matters; the final product matters.

In 1982 I took a unique course, Adolescent Counseling. There were 15 women in the course, ranging in age from early twenties to late fifties. Our backgrounds varied: rural, city, village, mostly suburban, one who spent her childhood in hotels and on cruise ships, another who lived marginally but had escaped her poverty through education. What we had in common is that either we were currently working with adolescents or that was the career plan. What we also had in common was that we had left adolescence, but in important ways that defining time in our lives had not left us. We all needed to address those difficult years, no matter how distant. It was the best course I ever took. It may also have been the most difficult and emotionally demanding.

The teacher was a therapist at an urban clinic with a caseload of young teens challenged by poverty, abuse, their own and others’ drinking and drugs, and lack of supports and opportunities. Many were pregnant, some barely out of childhood. She knew first hand not just the challenges of reaching a youngster who might be highly defended, unable to consider options or living in the moment, a difficult moment, but also what such work raised in the counselor from her own past. She believed acknowledging and examining one’s personal past was critical to success in understanding and reaching troubled teens. I consider that examining what has happened personally does help others.

Our instructor, my contemporary, believed we could not help today’s adolescents find their way, until we had truly negotiated our own adolescence. Our teacher promised we would have no assigned reading, but we might be embarking on the most challenging course we would ever take. Our only assignment was to write our own adolescent autobiographies, one chronological year at a time, each written over a two week span, over a semester. It was time to examine those years, revisit the pain and uncertainty, and remember and address what sometimes seemed insurmountable obstacles. She assured us it would not be an easy task, but it would be an important one. She was also a poet and an aspiring playwright, had a master’s degree in English, and believed in the power of the written and spoken word. She believed only through writing would we wring out the essentials of our adolescence and be freed from its pain and missteps. In sharing what we had written we would move from private thoughts to public discourse, risk feeling vulnerable and invite comment. This would allow us to get to the other side.

Language was her game and our assignment. We would find our voices, so that we could work with a population that was often voiceless, unable to name what absorbed and troubled them. We would revisit the past, write what we remembered, interpret as necessary, and share with the other women in the group.

For each year of our lives, starting at twelve, she set the stage, went over developmental milestones, typical conflicts and concerns, expected cognitive and social gains, then gave a guided visualization exercise in which she tried to bring us back to the year we would explore in the coming two weeks. Reading would be recommended but not required, serving to present and explain developmental themes, grounding our writing in theory. She then sent us home to write, armed with Piaget, Erickson and Gilligan, who a few pages into the writing process would leave us to our own memories, insecurities, and insights.

The work was difficult, exhilarating, enlightening and painful. Thirty years later it is daunting to read. Much of what I wrote in my 30s has been forgotten in the demands of the intervening decades, so having this “book” is a gift from my younger self.
to my older self. With support and introspection I wrested tales of escapades, hopeful romances, fragile and soon dashed dreams and worries that with the passage of time seemed inconsequential. The teacher looked for themes in what we wrote. I had a strong sense of justice and fought for what I believed to be right. My friends were important, as was poetry, dance and nature. I remembered moments: placing a walnut shell holding a candle in a pond during a closing ceremony at camp, looking out an open window on a cold late autumn night, hurrying to dinner on a snowy campus but stopping to gaze at Venus rising in a still pink but darkening sky, sitting with a classmate on a Saturday afternoon, hearing of her life in Alabama before civil rights legislation, walking under dogwoods with a blue-eyed boy who would fade from my life but had left me challenged and changed. What occurred was interior work that prepared us for exterior work. Both mattered. With some developmental supports and brief guiding into our past, we sat at our typewriters and tried to make sense of and maybe begin to embrace our younger selves.

We were forced to find words for feelings and situations that had piqued us, confused us, challenged us and held us. Often as teens we had walked away from both feelings and situations, despite their draw. Sometimes we flung ourselves headlong into what we should have walked from. We were spectators and participants, and both roles formed us. Finding words for the past was a struggle, but with each phrase, each description, each sentence wrought from turmoil and uncertainty, both understanding and acceptance grew. Many of us examined situations we had hidden away. From that came a freedom from the storms of our younger selves, allowing us in our maturity to reach out to others. The monsters were acknowledged and placated, when we could both name and describe them.

We recognized, began to understand, and when necessary forgave our younger selves. Those who could, shared their stories by reading them aloud. For some even writing was too difficult, and their accounts were short and not to be shared. The youngest struggled the most. For those of us with some distance of years or decades, memories had to be excavated from layers of experience, but we were better protected. The memories and the emotions we older writers carried had sometimes been dulled.

We became better counselors and teachers for the experience of writing our story. We became better at our life’s work, because we learned to find the right words for our past and understand its implications in the present. In sharing our stories we came out from any shadows there might have been. We explored and defined our adolescent selves, allowing us to move on as adults, unfettered, or at least less fettered. Writing freed us, sharpened us and opened us to others. Writing made us examine ourselves and our situations in ways that just thinking does not. Writing gave permanence to our thoughts. Writing allowed us to connect with others, share our experience, enlighten others with realizations or even wisdom borne of challenges and blessings.

Now it is your turn. You have a story that also carries pain and understanding. You have found blessings where none seemed to be. You have had fears you named, challenges faced and hopes, maybe dashed, maybe realized with necessary revisions. Write your story. It is important. You have a ready audience. You may believe what you have to say has already been written. You will present your experience through a different lens. You may find visiting feelings from the past is difficult and something you prefer to avoid right now. It may be the difficulty that makes the experience cathartic and welcome. You may find you discover something forgotten and wonderful when you stand back a bit, examine a moment and write. You may leave the moment, remember, tie together moments, and gain understanding, as you write. You will make meaning. What you write will be a gift to yourself, your child with trisomy, your other children, and to all those in the trisomy community waiting to read what you share.

When Words are not Enough

The Hmong are the preliterate tribal hill people of Laos, who had no written language. Many thousands of refugees were kept for years in Thai camps following the conflict in Viet Nam. During their stay they had time to create their traditional paj ndau or pan dau, reverse applique’ and embroidered story cloths, which record their experiences. The art form had developed over centuries in a minority culture forced to migrate to less desirable areas by the Chinese. The embroidery depicted their personal and cultural history, and it decorated courtship skirts, baby quilts, and baby carriers. In the hills as subsistence farmers and soldiers, there was little time to exercise their fine craft, but in the camps women had time to produce the cloths and men had time to draw patterns for them to use. The Hmong had been CIA operatives in the mountains, and many were eventually brought to the United States. Once settled in their new land, many continued to embroider their stories, and they sold their story cloths to support themselves.

We are a literate people but sometimes words are not enough. Pictures and visual representation are important in SOFT. We have enjoyed Kris’ video for years, and each year she adds new artistic vision. We have a SOFT logo, and every year a logo is designed for the conference, and we wear it on shirts and hats and carry it on bags. Our website carries hundreds of pictures of SOFT kids, along with many family members enjoying their time at the conferences. More recently, we have enjoyed collages or slide shows to celebrate special days. The annual auction is always a celebration of the visual, as the artists among us tell our story in fabric, wood and stone. We marvel at the talent and persistence necessary for the craft. Even the siblings have joined in. Quemby designed the 2012 sib shirts. Gabriella designed a quilt. We are also a visual people, and our pictures carry our stories. We have created our own story cloths, and like the Hmong, our visual stories are noteworthy and unique. –Pam Healey
his exceptional care, focus on the patient and going above and beyond for this (rare) community. He is raising the bar and setting an example for others”.

Winners were from the USA and a number of European countries. Not everyone was able to be there but all were honored in literature provided at the dinner and that information has helped with telling about some who spoke at the event. Every presenter and winner had a unique rare story or connection. John Carey and the following honorees, entertainers and presenters were each given 10 minutes on stage throughout the 2.5 hour Tribute.

Parent advocates and engaging presenters Cristy Spooner and Global Genes board member Caroline Loewy told their stories separately about their undiagnosed children. One of these mothers finally learned that two of her three children have an inheritable rare genetic disorder. The other mother’s child, who was at the event with her, is still undiagnosed. These mothers have begun a Global Genes / Undiagnosed Patient Program - a fundraising campaign to fund gene sequence testing to help undiagnosed patients find answers.

Presenter Eileen Grubba, beautiful actress, writer, and producer overcame polio as a child and later cancer but a few years ago was diagnosed with Lynch Syndrome, a genetic defect putting her at high risk for a number of cancers. She is an advocate for employment of people with physical differences in film.

Rare Champion of Hope Science winner is Josh Sommer. He was diagnosed with chordoma, a rare cancer of the spine and skull in 2006. He and his mother began the Chordoma Foundation in 2007 to advance a search for a cure and Josh is personally involved in the finding of a genetic variant and several therapeutic targets for chordoma. He was the ABC News Person of the Year in 2008 and named one of Forbes’ 30 under 30 transforming science and healthcare.

Rare Champion of Hope Advocacy recipient 6 year old Dylan Siegel authored and illustrated Chocolate Bar, a 10 page book that has raised $400,000 for Jonah’s research fund at the University of Florida to seek a cure for Jonah, his 6 year old friend with a rare genetic liver disease, Glycogen Storage Disease type 1b (GSD). Sales of this little book began November 2012 at a school; his efforts caught the attention of local,
then national media. His goal is $1 million!  

Rare Champion of Hope Advocacy was awarded to the advocacy organization *Positive Exposure* & Rick Guidotti for the use of visual arts to impact genetics, mental health and human rights. Some of you might remember Rick from the 2005 & 2006 SOFT conferences when he attended and photographed our SOFT children. *Positive Exposure’s GENOME ZONE* is currently at the Smithsonian’s National Museum of Natural History in DC.

The **Henri Termeer Lifetime Achievement Award** was received by Dr Steven Groft, Pharm D., and Director of the Office of Rare Disease Research at the National Institute of Health. He has spent over 30 years stimulating research and developing information about rare diseases. Dr Groft was obviously loved by so many that were in that room and it was a touching happy close to the evening. *(Henri Termeer is a life science legend, biotech pioneer, entrepreneur and former Genzyme CEO, a company that makes drugs for rare diseases. He supports new entrepreneurs working to make a difference for those with rare diseases and was a part of the selection committee for this lifetime achievement award.)*

The Tribute began Saturday evening with an outdoor reception, followed indoors by a welcoming toast, outstanding dinner and passionate presentations. Entertainment was provided by Emmy nomi-
nee singer/songwriter Andrew Mahon (leukemia survivor) on piano during the meal and later in the evening by the Cimorellis’, a six sister harmony group; one sister has Turner syndrome. There was not time for all honorees present to speak at the banquet so a number of them were filmed in the early afternoon and these brief clips were shown during the evening. The event sold out and the room was filled to capacity with everyone, even children, dressed-up for this formal “blue tie” affair. Dr Carey was one of the honorees chosen to speak during the dinner and he used this special honor to talk about hope, families and SOFT. His acceptance speech is in this newsletter.

Fortunate is the parent who has or had Dr Carey as a caregiver for their child. In early September, the managing editor at Global Genes asked about Dr Carey’s work with patients and how his patients perceived him. She included some of the words from the following comments, in John’s introduction.

**By Kris Holladay**

In the summer of 1979 our daughter, Kari (trisomy 18) was not quite two years old. She had already lived longer than expected and was a delightful little girl! However, I had expressed numerous times to our doctors and medical specialist, how alone my husband and I felt and how much we hoped to meet other families who were experiencing similar challenges that come with having a child born with trisomy 18.

At that time, our geneticist, Dr. Bruce Buehler, mentioned that a new, young and very handsome doctor had just accepted a position at the University of Utah Medical Center. This doctor had just completed his work in San Francisco. Dr. Buehler explained to me this new geneticist had shared his con- cern for families whose children were born with trisomy 18 and trisomy 13. As I recall, Dr. Buehler said that this young doctor expressed the predicament for these families was much like being “caught be- tween a rock and a hard place.” That young doctor was Dr. John Carey. The day we met Dr. John Carey was memorable. His compassionate blue eyes and warm conversation were exactly what we needed! In September 1979, Dr. John Carey, Pam Watson and I legally formed the first official parent support group for families with children born with trisomy 18 and trisomy 13, known as S.O.F.T. (Support Organization for Trisomy 18, 13, & related disorders).

Through the years, Dr. John Carey has touched the lives of countless families! I have watched and witnessed his “magic” as he meets families at our SOFT conferences. His warm blue eyes and gentle conversations continue to help parents and heal hearts through his ability to listen and respond with honesty and clarity and compassion. Our precious Kari lived a wonderful 10 years and 9 months. I often share that two of my greatest “teachers” were our darling daughter, Kari, and our dear friend, Dr. John Carey! *(Continued on page 8)*
Dr John C Carey at the Global Genes / Rare Project 2nd Annual Tribute to Champions of Hope

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By Pat Farmer

I have been thinking back on the first time I talked to Dr. Carey on the phone in 1979. Joey was over 2 years old and I remembered being stunned that someone in the world knew what Trisomy 13 was. After many tears and much joy - the first SOFT gathering took place later that summer. When we took Joey there - I know that Dr. Carey fell in love all over again. Joey was the only little boy with several beautiful little girls. What delight we all had with the pictures - of all the girls falling over on Joey! At that moment - meeting Kris and John and the others - we were in the presence of God and angels. John was our hero! He was kind - loving - supportive - and hopeful! He gave us hope when others said there was none. He was everything a new parent needed. And best of all - he loved our children! And he has loved each and every one of the "SOFT" children since that day! He is known around the world for his knowledge and support for our kids. How did we and Joey perceive him? With a great big hug! Joey gave him one of his big wet kisses! We knew we had found hope and love for our son. There are not enough words to describe Dr. Carey. He is without a doubt - the very BEST caretaker we ever found for Joey. He is well deserving of this wonderful recognition. I appreciate the opportunity to share!

By Raquel and Steve Wagner

It is very hard to sum up a thirteen year relationship with such an extraordinary man in only a few lines, but I will try my best. Our family first met Dr. Carey less than twelve hours after our daughter Ashton was born and given a pre diagnosis of Full Trisomy 18. As a professional with a vast knowledge of Trisomy 18 he quickly became one of our daughter's biggest advocates. Ashton has survived viral pneumonia, several bouts of RSV, g-tube placement, coil placement for a PDA, VSD and ASD repair, and a tonsillectomy. She recently began her 8th grade year of school, and we will celebrate her fourteenth birthday in early October with a good quality of life. She is also a very loved big sister to our daughter, Chevelle (age 8) and our son Gavin (age 5.) Dr. Carey has always been honest regarding our daughter's diagnosis and health issues. We never felt that he over exaggerated any hope, but did give us the information and statistics needed to help us make the type of medical decisions that no parent should ever have to make for their children. Our respect and admiration for this man has not wavered. Over the years, our professional connection with Dr. Carey has grown into a long lasting friendship. We are lifetime active members of SOFT- we are in the process of planning our third SOFT conference in Salt Lake City, Utah for 2015, we are active in several social media groups relating to trisomy 18 and 13, and our family speaks to first year genetic counselors every spring at the University of Utah. We do all of these things because of John Carey and his immense compassion for the children and families connected in the world of trisomy. He is certainly a Champion of Hope and an asset to the medical community.

By Debbi Dye

If I could sum up John in one word it would be ADVOCATE-- which was always amazing to me how much of an interest he’s always had in our kids and with SOFT and never had a family member or a personal connection with a trisomy disorder. I met John the day after Morganne was born. He came in to our hospital room on a Sunday – and gave us the facts, but also was very caring and gave us a little hope. It’s difficult to understand how some doctors think he gives false hope, but how can any kind of hope be false – when that’s all you’ve got. I know as an example of him being an advocate for my child, our cardiologist was always second guessing me when I would want something for Morganne – such as an pulse ox or something like that – because “why would you want to do that if she’s going to die anyway”. She was also against Morganne having heart surgery, and we went and talked to Dr. Carey to see what he thought and the next time we saw the cardiologist, she was asking when we wanted to schedule her heart surgery and how fast we could do it. I have no idea what he said to her, but she ended up being a great advocate for our kids as well, and she was Ashton Wagner's cardiologist and Ashton was able to have lifesaving heart surgery. She also taught a workshop and did a clinic at the 2003 conference, so besides being an advocate for my daughter, John turned others into being an advocate for her as well. Unfortunately Morganne passed away before she was able to have her surgery, but the fact that they had agreed to do it at all was totally because of John. So in summary - John Carey is an advocate for our children and gives us that little bit of hope that we so desperately need. Hope cannot be false as far as I am concerned and just having that little bit of hope got us through it all. He will forever be considered an angel in our lives when we most needed it.

The 2013 Tribute to Champions of Hope will always be remembered… as a jubilant introduction to the world’s rare communities and the advocates who are making a difference. We were “dazzled” by the evening and it was so meaningful to be there to see Dr Carey receive this well-deserved award. Thank you Global Genes. See all 2013 Gala speeches at:

2013 Rare Patient Advocacy Summit

It is a true honor and incredible privilege for me to receive this recognition in the name of hope and advocacy — especially as a “medical care giver.” I am particularly touched in that SOFT - an organization with whom I have worked with for more than 30 years, an organization that changed me as a physician more than any other influence in my career — nominated me for this honor.

I am humbled to be here – humbled at several levels. Let me name a few: I am sharing the spotlight with three of my heroes: Francis Collins, who has truly been a champion for patient advocacy long before his NIH directorship; Rick Giodetti, who has done more for removing stigma in persons with visible differences than anyone I know; and Steve Groft, who has led a remarkable effort for years to create a medical and scientific agenda at the national level for rare diseases. Again, I am humbled to be on the podium with these fellow advocates.

I am humbled, as well, because I am being honored today by my mentors, my teachers – the Support Organization For Trisomy 18/13 and Related Disorders. SOFT represents for me the ultimate metaphor for something I consider sacred — the relationship we, as caregivers, have with our patients. While in all humility I may not always succeed in honoring that connection, I strive to achieve it. I have had the privilege to help care for children and families with genetic conditions since the beginning of my training as a pediatrician in the early 1970s. I have also had the opportunity to work not only with SOFT, but also with the Genetic Alliance and numerous support groups. I must say – no one, no professor, no scientist, no doctor in my 45 years, since beginning medical school, has inspired me, moved me as much as the parents of my patients and, in particular, the families and kids of SOFT.

Families of children with trisomy 18 and 13 and related rare conditions have a particularly unique plight. They have to unite the care of a person with a disability and chronic medical condition with the high prospect of infant death. Their ability to accomplish this union – this marriage if you will – represents a role model for me as a person and as a physician.

I became involved with SOFT at its beginning: I met Kris Holladay, the founder of the organization, when Kari, her 2-year-old daughter with trisomy 18, became “my patient” a few weeks after I joined the faculty of the University of Utah in 1979. Kris recognized that there was a need for families with children with these serious medical conditions to have a support network to provide up-to-date information and connections with fellow travelers. This was a time when the development of patient advocacy groups for genetic conditions was barely at its beginning stages. There was no Internet. Some of my colleagues at the time were skeptical of the rise of “these groups” during the late 1970s and even into the 1980s. Kris and I agreed that I would refer families to her with infants I would encounter in my role as an attending physician at Primary Children’s Hospital. I met the first such family in 1979. I can recall the events vividly: At first, I had some hesitation to refer the parents to Kris, (thinking naively) that meeting with the parent of an older child would give them “false hope.” I have realized over the 34 years of my connection with SOFT and with many parents that there is, in fact, no such thing as “false hope” — those two words do not go together. Hope is never false. To my other medical colleagues: there is no such thing. Once I connected Kris with the family of this young lady named Sarah, I began to experience a kind of magic that I had not encountered before as a doctor.

I have witnessed that particular magic, that change in experience of isolation, that family-like connection between two parents of a child with the same rare condition, over and over again, and I never lose my awe of its beauty. SOFT grew from that early referral and 8 years later, the first conference occurred in Salt Lake City. Now there are thousands of families around the world who are connected and in the recent years, even more by the Internet and social networks. What little I knew at that time in 1979? I repeat what I said in the beginning: I am grateful to my mentors.

I would like to close with some words that resonate for me in this context of discussing advocacy, inspiring hope, and developing strategies for rare diseases. As the eminent physician, Francis Peabody, stated to a class of Harvard medical students almost 100 years ago, “The secret of the care of the patient is...in caring for the patient.”

And, finally, a few words written by the Haiku poet of the 18th century, Buson. Please forgive my overly-simplistic metaphor – but our patients who die at a young age are like cherry blossoms...they come...give off singular beauty...and go...-

The end of spring

lingers

in the cherry blossoms.

The above text is the acceptance speech given by Dr. John Carey
Thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, 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:**
- Ioannis Karmis
- Frank and Lisa Hollowell
- Elliott and Patty Lawson
- BP Employee Fund, matching Elliott Lawson’s donation
- Families and friends who raised money for the Stroll For Hope held during the annual SOFT Conference
  - Jennifer Rose
  - Karl Spindler
  - Bryan D Sibthorp
  - Joseph Cannizzo
  - Michelle Benedict
  - Deborah Knisley
  - Kimberly Minear
- Debbie Phillips and Paw Prints by Deb
- Pradeep Kumar
- Lisa Fisher
- Anonymous
- Karl Spindler

**Donations to the Joey Watson Fund,** established to help families attend the annual SOFT conference
- Pradeep Kumar
- Laremont School, Gages Lake, Illinois in Memory of Frank Joseph Jorgenson

**In Memory of Jillian Walker**
- Mark J. Galvin

**In Memory of “Super Corbin” Alfred McHenry,** given with notes saying “Corbin sent us”
- Victoria Watterson
- Nancy Matherly
- Angela Howard
- Tim and Kristen Keeley
- Jose Quiroz
- Richard Giunta
- Kate, Dave, Deacon and Dryden Read-Maney
- Zachary Glen Carlson
- Vahe Kocharyan and Inga Tadevosyan
- Victoria Watterson, “In memory of Corbin and in celebration of a wonderful life, though short. He touched many peoples’ hearts and taught many about Trisomy 13. He had very strong and loving parents who did all they could do to give Corbin a wonderful life here on earth.”
- Chester Bowman, Jr
- William and Angela Harlow
- Kori Stolzman
- Gigianna Fiorese
- Richard and Shari Morales
- Daniel and Cindi Svoboda
- Sharon Stroh
- Frank and Lisa Rushlow
- Marcia M Eggleston
- Kaitlyn Read-Maney, in memory of Super Corbin

**In Memory of Lilly Hollowell**
- Frank and Lisa Hollowell

**In Memory of Grace Anne Cooper**
- Baptist Foundation of South Carolina

**In Memory of Keira Faith Salom**
- Amie Wojtech

**In Memory of Aiden Dryden**
- Michelle Benedict

**In Memory of Michael Bernard Javidi**
- Susan, Seth and Elsa Conaway

**In Memory of Noah Idan Stein**
- Doni Ernst

**In Memory of Elizabeth Ann Carson**
- Steven and Patricia Warren

**In Memory of Faith Anne Sewell**
- Timothy and Susan Sewell, “This is in honor of our precious granddaughter, Faith Anne Sewell, born April 30, 2013 with Trisomy 18. She went to be with her Heavenly Father on September 30, 2013 and took a piece of our hearts with her.”
- Don and Dee Dee Sewell, “Faith is a Trisomy 18 angel who went to heaven on her 5 month birthday. Every day was a gift. She was loved by her parents, two brothers, Christian and Caleb, one sister, Anna, family and friends. We were all so blessed to share her life journey.”
- Capt. and Mrs. Edward C. Wallace
- The Salty Dogs, VX-23 Officers’ Mess
- Kyle and Michaela Ackerman
- The Coffey Family
- Fred Henderson and Family
- Mike and Jen Kingen
- John and Jennifer Alex
- Rebekah Kunz
- The Drivers Family: Joe, Khristi, Steven and Sophia
- Kelly Tousignant and Derek Palm
- Shawn and Ashley Hall
- The VanHouten Family
- Al Hullopeter
- The Rusnok Family
- Alyson Miller
- The Gronberg Family
- Tammy and Kurt Totten
- Angela Dean

**In Memory of Caitlin Rose Bringhurst**
- Michael, Kimberly and Andrew Minear

**In Memory of Sloane Ramsey Remaly**
- Hilary Blackburn
President’s Corner by Barb VanHerreweghe

Dear SOFT Families:

This is the first time the newsletter will be online only. We hope that you have been able to view the newsletter online and you are happy with the changes we are making. We want to build the newsletter so you all enjoy it. We want your stories. You do not need to be asked to have your story included. Write it up, send it to the Thompsons for The SOFT Times newsletter at jmgthompson@att.net. Remember to send it in with pictures and then send it on to the website so your story is there for all the newcomers that come to the website. The more information and help we can give new families the better as they are waiting for their baby to be born. What are you looking for in the newsletter? Let us know. Does your child have a birthday picture or school picture that is special? Send it in.

We hope you are all updating your membership if you haven't already. Membership is free. Membership will still need a yearly renewal. There is a short form available on the website if you have no changes. Keep us up to date with surgeries for your child. On a weekly basis we share this information with families that are trying to make informed decisions for their child. Your information may be the key to help them make the decision of what surgery is best for their child.

Dr. Carey received his award and the recognition he deserves. He certainly is a Rare Champion for all our children. Send your congratulations to him and look for his summary of the evening in this issue.

The books are all on sale at this time for $6 each and that includes postage. Now is the time to buy them for presents for your family and your Doctors. Those interested can shop on the SOFT website or you can just put your check in the mail and let us know which book(s) you want. Send your request to: SOFT, 2982 South Union Street, Rochester, New York 14624. There is postage added to those mailed out of the United States.

The conference committee is working hard to make next year in Norfolk, Virginia the best it can be. Make sure you get your room reservations in as there are a limited number of rooms available. If you have ideas for the 2014 conference, let the committee know. Look for more information in this issue to plan your extended vacation in the Virginia Beach area. Start getting your pictures together for the upcoming holidays. We will be putting together slide shows. We want your children and families involved. Look for more information coming soon.

SOFT is always looking for volunteers and new and interesting ideas. Share with us. What is on your mind? What would be helpful to your family? Let us know.

SOFTly,
The VanHerreweghes

“Anyway, I keep picturing all these little kids playing some game in this big field of rye and all. Thousands of little kids, and nobody's around - nobody big, I mean - except me. And I'm standing on the edge of some crazy cliff. What I have to do, I have to catch everybody if they start to go over the cliff - I mean if they're running and they don't look where they're going I have to come out from somewhere and catch them. That's all I do all day. I'd just be the catcher in the rye and all. I know it's crazy, but that's the only thing I'd really like to be.”
— J.D. Salinger, The Catcher in the Rye

SOFT Mission Statement

SOFT is a network of families and professionals dedicated to providing support and understanding to families involved in the issues and decisions surrounding the diagnosis and care in trisomy 18, 13 and other related chromosomal disorders. Support can be provided during prenatal diagnosis, the child's life and after the child's passing. SOFT is committed to respect a family's personal decision and to the notion of parent-professional relationships.

For a list of Resources, Related Disorders Contacts and International Contacts see the SOFT website: www.trisomy.org

The SOFT Times is published by SOFT, Inc. Editors for the 2013-2014 fiscal year: Margaret & Jim Thompson 1232 Seminole Drive Richardson, TX 75080 jmgthompson@att.net 972-234-8788

Please submit all stories, pictures, info, etc. to the above address. If you wish to have items returned, please include a self addressed, stamped envelope.

2014 Conference Planning Committee Report

Conference Planning Committee by Ann Barnes

The 2nd meeting of the conference planners was held on Oct 5th at the home of Mary and Rick Steele. In attendance were Lynne & Buster Stockman, Mary & Rick Steele, Yolanda & Tony Myrick and Ann & Frank Barnes. Two other committee members sent their input by email. Plans are moving along for the 28th International SOFT conference in Norfolk, VA. Eighteen topics were on the agenda and Lynne, a very organized conference chairman, covered it all in 2 hours’ time! The conference committee is so excited to bring SOFT to Norfolk in 2014. They have chosen the Waterside area of Norfolk along the Elizabeth River for hotel accommodations and the picnic site. A paved walkway along the river, a designated city park, will be easy access for “strolling on the river”. Ships, tug boats and other craft are all within view as well as the shipyards of the US Navy on the other side of the river.

Logo:

Thanks to Mary Steele the 2014 conference logo design is completed. Conference t-shirts will have this logo on the back with the SOFT logo on the front pocket.

Budget:

Attendance numbers were estimated and food costs (the biggest expense for a SOFT conference) were calculated/considered but not yet finalized. A preliminary budget is in place. Conference fees will be $125 per adult this year (up $15) as conference registration fees do not cover all food costs and have not for a number of years. This necessary change is still not likely to cover the food completely but will defray these expenses.

Childcare:

Tony and Yolanda Myrick own a childcare facility and will handle the childcare arrangements and needs for all children during the conference. Their 3 year old daughter, Milan with t18, is known by the NICU nurses who will help with caring for our SOFT children/adults during the conference.

Transportation:

Two of the conference events are within walking distance, thus bus needs will be less in 2014. Medical clinics, older sibling outing and the grief outing will require buses or vans and Tony Myrick is knowledgeable about those costs and arrangements.

Fundraising/Donations/Wish List:

Donations and fundraising have begun. SOFT conferences are awesome events for families that could not happen without the generosity and help of SOFT families and friends. A Wish List has been generated for view on the website-find it from the conference page. Check it out and see if there is a special event or wished for item that you might be able to make happen! Conference booklets with schedules, presenter biographies, attendee lists, maps, local information will come together with time and registrations. Medical clinics, workshops, and keynote speaker are under construction and will be advertised on the web site in the near future.

Hotel Registration is Open!

You can reserve a room now. Make your reservations early and start saving to come to the conference. You will be so glad you did!

If a wheelchair accessible room is needed, it must be requested at the time a room is booked. There are a limited number of these rooms and those with larger children in wheelchairs ought to register early. If you want/need a refrigerator, microwave, crib or cot, ask for these at the time of registration

The 2014 SOFT Conference will be held July 9-13, 2014, at the Sheraton Waterside Hotel, Norfolk, VA, 23510. The board meets Wednesday, July 9th and there will be a Welcome Reception Wednesday evening for all arrivals. The conference begins Thursday, July 10th. Hotel reservations can be made by calling 757-622-6664. Our special SOFT rate is $115.00 plus tax, per night, including complimentary in-room internet service. The rate for a suite, if desired, is $250.00 per night, for SOFT attendees. Here is the link for attendees to register for a hotel room. The SOFT special rate code is built into this link: https://www.starwoodmeeting.com/StarGroupsWeb/res?id=1309093441&key=B82B6

If registering by phone, be sure to ask for the SOFT Group Rate when making a reservation. The special SOFT rate for the room & and room block ends June 8, 2014. Self-parking is $7.00 per day. There are no laundry facilities at the hotel but they offer 8 am laundry pick-up with pm return, for a charge. Individual hotel guest accounts are payable at check-out by cash or credit card. The cancellation policy is no penalty if a person cancels by 6 pm EST on Tuesday July 8th. If they cancel after this time then they will be billed one night’s room expense of $115.00.

If you have any questions, contact Lynne-lynne.stockman@verizon.net.
2014 Conference Planning Committee Report

Frank Barnes, left and Buster Stockman planning your conference.

Your Conference Committee hard at work at their 2nd meeting!

Below: the Waterside walkway along the Elizabeth River.

The meeting was held in the home of Rick and Mary Steele (Ryan, mosaic t18).

Below, Lynne Stockman gives us a sneak peek of the 2014 logo!
Courage is like love; it must have hope for nourishment.-Napoleon Bonaparte

On the Elizabeth River

SOFT hotel-
The Sheraton Norfolk

Restaurants along the Elizabeth River Waterside Walkway are an easy stroll from the hotel.

Older Sibling Outing

The older SOFT Siblings will be bussed to Virginia Beach, VA for a fun outing at Ocean Breeze Water Park.

849 General Booth Blvd.,
Virginia Beach, VA 23451
Phone: 757-422-4444

Bring Your Swimsuits!

OCEAN BREEZE WATERPARK
Where there is no vision, there is no hope. - George Washington Carver

The site of the 2014 Grief Outing will be Norfolk Botanical Garden

Norfolk Botanical Garden
The Gardens are open from 9 am to 7 pm
6700 Azalea Garden Rd.,
Norfolk, VA 23518

Located next to the Norfolk International Airport, and minutes from Downtown Norfolk and Virginia Beach.

From Williamsburg, follow I-64 to Exit 279 (Norview Avenue), turn left on Azalea Garden Road from Norview Avenue. The Garden Entrance is on the right.

From Virginia Beach, take I-264 to I-64 (Richmond) to Exit 279 B (Norview Avenue). Turn left on Azalea Garden Road from Norview Avenue. The Garden entrance is on the right.

The Elizabeth River Ferry

Younger Sibling Outing

The younger SOFT siblings will take a short ride on the famed Elizabeth River Ferry to Portsmouth for their outing and lunch at Virginia's largest interactive museum, The Children's Museum.

ww.childrensmuseumva.com/
And
http://vshfm.com/
Things to Do In and Around Norfolk

There are myriad things to do, see, and experience in Norfolk. Enjoy a harbor cruise on the river or a leisurely walk alongside Waterside Market Place. World-class museums, galleries, performing arts, and other attractions dot the city's downtown waterfront, just minutes away. Or head to one of many nearby sandy beaches.

From the majesty and detail of a battleship to the wild and wondrous fun of a children’s garden, Norfolk is filled with attractions to please every age. From specialty shops and antique stores dotted along residential streets to national retailers such as Nordstrom and Dillard's anchoring major shopping centers, Norfolk has a treasure trove of spots for the serious shopper to explore.

Dining and Nightlife
Norfolk knows its stuff when it comes to the culinary arts! With scores of chef-owned restaurants about town, you are sure to find the food experience that will make this visit memorable.

When the sun sets, one-of-a-kind places become eclectic spaces for dancing and nightlife. Many of the city's trendiest establishments are a short walk from the downtown hotel area.

Arts and Entertainment
Home to the Virginia Symphony, Virginia Ballet Theatre, Virginia Opera, Virginia Stage Company, Virginia Chorale and the Commonwealth Theatre Company, Norfolk is your place for cultural arts and activities.

The nationally acclaimed Chrysler Museum of Art is a must-see while you're here, and the annual Virginia Arts Festival always has plenty to offer in the spring.

Conveniently located along the mid-Atlantic coast, Norfolk is home to a cruise port even the most well-traveled visitor hasn’t experienced. In the heart of downtown, the Half Moone Cruise and Celebration Center is a debarking point steps from hotels, attractions and a shopping center with over half a million square feet of surprises. Stay before at Sheraton Norfolk Waterside Hotel before your cruise, and come back and stay after. Just don’t miss all Norfolk has to offer.

Arts & Culture

MacArthur Memorial 0.2 km/0.1 miles
USS Wisconsin Museum 0.3 km/0.2 miles
Nauticus, the National Maritime Center 0.3 km/0.2 miles
The Chrysler Museum of Art 0.8 km/0.5 miles
Mile Marker 0 1.6 km/1.0 miles
Childrens Museum of Virginia 8.0 km/5.0 miles
Fort Story First Landing 27.3 km/17.0 miles
Cape Henry Lighthouse 29.0 km/18.0 miles
Virginia Marine Science Museum 32.2 km/20.0 miles
Virginia Air And Space Museum 48.3 km/30.0 miles
Living Museum 48.3 km/30.0 miles
Jamestown Settlement 83.6 km/52.0 miles

Nearby Destinations

Waterside Marina 1.6 km/1.0 miles

Recreation

Colonial Williamsburg 83.6 km/52.0 miles

Shopping

Harbor Park (Norfolk Tides) 0.3 km/0.2 miles
Town Point Park 0.5 km/0.3 miles
Harrison Opera House 0.9 km/0.6 miles
Virginia Opera House 3.2 km/2.0 miles
Virginia Beach Oceanfront 25.7 km/16.0 miles
Farm Bureau Live at Virginia Beach 25.7 km/16.0 miles
Seashore State Park 27.3 km/17.0 miles
Virginia Beach, Virginia 32.2 km/20.0 miles
Busch Gardens 80.4 km/50.0 miles
Water Country 80.4 km/50.0 miles

Local Attractions

Spirit of Norfolk Cruises 0.2 km/0.1 miles

Community

Norfolk Convention Center 0.2 km/0.1 miles
Norfolk Scope/Chrysler Hall 0.6 km/0.4 miles
Norfolk State University 3.2 km/2.0 miles
Eastern Virginia Medical School 8.0 km/5.0 miles
Old Dominion University 8.0 km/5.0 miles
College of William and Mary 83.6 km/52.0 miles

Waterside Marketplace 0.1 km/0.1 miles
MacArthur Center Mall 0.3 km/0.2 miles
Nordstrom 0.3 km/0.2 miles
Williamsburg Pottery Factory 83.6 km/52.0 miles
All human wisdom is summed up in two words; wait and hope. - Alexandre Dumas

Above, Nana Vivian and Grandaddy Scott Showalter, and son Uncle Stephen, welcome their new grandson, Ellis Holmes Dusenbury. Ellis was born September 2, 2013 at 11:32 am. He weighed in at 8 pounds, 6.4 ounces.

Sarah and Gabe Dusenbury introduce baby Ellis to the world. Sarah is the daughter of Scott and Vivian Showalter, longtime SOFT members.

Kelsey Smith, and Grandaddy Scott play smiling games with Baby Ellis.
Andrew Solomon, a lecturer in psychiatry at Cornell University, begins his book by explaining that reproduction is anything but reproduction. We produce the next generation, and there is no guarantee our children will be like us. “Although parents may imagine they will see themselves in their offspring, they are deluding themselves. Each child is an individual, and parents face not themselves but a stranger whose needs they must meet. Children often carry throwback genes and recessive traits and are subjected right from the start to environmental insults beyond our control.” (1) He explains there are vertical identities in children who share some parental traits through DNA and values through cultural identity: eye, skin and hair color, religion, and language. Some children have inherited or acquired traits that differ in important ways from their parents, and they also may gain identity from a peer group. This is a case of horizontal identity. Horizontal identities include being deaf, gay, physically or intellectually disabled, and having disabling psychopathology. This book explores a range of horizontal identities through interviews with family members, who are in important ways strangers who must come to know and understand each other. In each long section he presents what he has learned from observation and interviews with a number of people whose lives have been touched by certain conditions or identities. He focuses on children who are dwarves, have Down syndrome, autism, schizophrenia or severe disabilities that preclude language, mobility and the understanding of even toddlers. Horizontal children are also gay or transgendered, are the result of a rape, are criminals and are prodigies. Each child in important ways does not reflect the identity of either parent. He finds the difference, even differences that would seem to overwhelm, does not preclude love. Solomon acts as a guide through each condition, learning himself as he goes, changing his own perceptions, asking questions the reader might also ask. He brings humor, sensitivity, even awe, as he reports what he has been told and what he has observed.

In the chapter on Down Syndrome Solomon writes about “Welcome to Holland” and tells the story of its author and her son with Down syndrome, and we begin to see not only the similarities but also what makes the children individuals. He also writes of Adam and his mother who wrote the classic, Expecting Adam. We learn what has happened in the intervening years. In between he introduces many other families and their children with Down syndrome. He is not surprised by the challenges inherent in raising a child with Down syndrome, but he writes also of the joy. Having a child with a horizontal identity does not preclude love, delight and feeling blessed.

Children with autism bring other challenges, along with exhaustion, isolation and many unanswered questions. Parents are in diverse camps with activists decrying vaccines, others fighting to champion the child’s neurodiversity, and most hoping that science and social policy can help their child reach his or her potential. In speaking of autism, Simon Baron-Cohen notes, it “is both a disability and a difference. We need to find ways of alleviating the disability while respecting and valuing the difference” (282). The same can be said of other biologically based disorders in which the child’s identity is closely related to his genetic make-up. Solomon understands the belief by those who love the horizontal children that their identity is their disorder, but he also sees schizophrenia as a disorder in need of a cure to free those afflicted.

In the chapter entitled “Disability” he explores the world of families with multiple severe disabilities. He lists what these children cannot do, will never be able to do, then proclaims they “are human, and often they are loved.” He speaks of the purity of parental engagement with a child who will make little progress. Such a child simply is and that is enough. As with other chapters, Solomon gives the history of how people with severe disabilities have been treated and how family involvement has changed over the years. He also writes of parents who make controversial decisions, which raise important questions. He tries to put the experiences of parents whose children are at genetic or environmental extremes in the context of typical parenting experiences and reactions. He examines the ambivalence of all mothers which in normally developing children allows the child to individuate and become independent of the parent. It is necessary for parents to feel negatively at times and help push the child out of the proverbial nest. It is illogical to think that parents of children who will never leave them, for they will always be dependent, do not also have ambivalent feelings at times. It is not the child’s limitations that creates the ambivalence, it is a normal part of parenting, and the negative feelings that may arise should not be judged or seen as more than a normal reaction of a tired or stressed parent, or one wired to let go at an age appropriate time, even when that time can never occur.

One of the most interesting chapters is on prodigies and how they, like those with debilitating or isolating conditions,
Albuterol Sulfate Inhalation Solution, 0.083 percent (Nephon Pharmaceuticals): Recall - Aseptic Processing Simulation Results

NOTICE-NOTICE -NOTICE
SOFT Announcement:
Notice of recall of Albuterol Sulfate Inhalation Solution.
Many of our children use this.
10/17/2013

ISSUE: Nephon Pharmaceuticals initiated a voluntary recall, at the retail level, of ten lots of product due to results from an internal monitoring process. NPC performs aseptic process simulation as part of an internal processes to assure product quality. All of the lots listed above met and passed NPC’s quality specifications at the time of manufacture. In accordance with published guidance regarding aseptic processing simulation from the FDA, NPC has initiated this recall as a precautionary measure.


RECOMMENDATION: NPC is asking retailers to remove the affected lots from store shelves and is asking consumers to discontinue use and dispose of any product they may have that is included in this recall.

Book Review by Pam Healey

Far From the Tree: Parents, Children, and the Search for Identity

(Continued from page 18)

present challenges to their parents. Financial sacrifices, moving, and intense scheduling are necessary to help the child realize his dizzying potential. What these children can do is amazing, and Solomon enters the journey of finding the right teachers and opportunities to foster the gifts. These are extraordinary children of parents with ordinary phenotypes, somehow passing on rare and unimagined potential.

Solomon writes, “Rumi said that the light enters you at the bandaged place. Most of the families I met ended up grateful for experiences they would have done anything to avoid.” Solomon captures that parents rise to meet the demands and special requirements of their child with an unexpected identity and are profoundly and positively changed in the process. Solomon acknowledges the bewilderment, isolation and pain that can follow a diagnosis. He is cognizant of prejudice and misunderstanding that activists fight. He also becomes increasingly aware, family by family, of what it means to embrace a child who is different, and emerge stronger and wiser. He is touched by the gifts of horizontal children, outwardly so different from their parents, yet as much a part of their lives as vertical children. He writes of the diversity within families and the humanity of all children.

Solomon drew from 40,000 pages of interview transcripts of over 300 families to write his book. In these families he finds eloquence, honesty, and inspiration. He reflects on what he has learned by talking at length with many families, entering their homes and experiencing their day-to-day lives. He says, “Families rise to the occasion of various difficulties, struggle to love across those divides and find in almost any challenge a message of hope and occasion for growth or wisdom.” (353)

He considers his own family situation. He is gay; his parents have a heterosexual relationship. He has a horizontal identity, and he reaches out to his peers who understand him and share his challenges. He becomes a father, knowing he will continue the horizontal identity, for chances are his child will be heterosexual. Solomon interviews, lives with, and embraces many families for each situation. He comes away admire them. He gains a heightened awareness of the complexities of the parent-child relationship and its importance. He sees how much good comes when the identity of the child is “far from the tree,” and parents must work and grow to achieve the best relationship possible with offspring who do not reflect them. Solomon tells of the enrichment found when children are not like their parents in essential ways. He comes away from his years of interviews realizing that the diversity found in families unites people more than it alienates them.

I highly recommend this book. It won the National Book Critics Circle Award, and was deemed by the New York Times Book Review one of the best ten books of 2012.

Check out the website and enjoy the slide show: http://www.farfromthetree.com
Committee Reports

SOFT Website, Surgery and Membership Committee Reports - Ann & Frank Barnes

Website:
We continue to expand the number of pages, links and information that are available on the web site. It has grown from 58 pages last January to over 250 pages of information, articles and other content now. We are getting about 55 requests per month for information. Monthly traffic runs in the 6,500 – 7,500 visits range.

There were about 70 usable Family Stories last January and this has been increased to about 130 now. We invite you to submit your Family Story if you have not already done so.

Professional articles have been increased fourfold and there is much more helpful information for families. If you have not done so recently, we suggest you carefully explore the site.

An automated, passworded Conference Registration System has been developed and will be used for the 2014 conference. Book sales have also been automated and a reporting system added, as have donations.

A substantial effort is being expended by SOFT’s Facebook managers (mostly Therese Siegle) to coordinate and link content between the website and the SOFT Facebook pages. Similarly, linkages between www.trisomy.org and Terre Krotzer’s “Trisomy Talk” website (http://trisomytalk.com/) are utilized whenever events are scheduled.

The passworded website newsletter library continues to grow as each quarterly newsletter is produced and it receives quite a few hits each month. All newsletters are readable there and can be printed as .pdf documents, by current SOFT members. (Newsletters will no longer be printed and mailed. Barb will print an issue and mail it to those members who do not have computer access if they send a request.)

A system of “blast” emails is used to send information about upcoming events to members and you will receive about one per month, providing updates on the progress of the 2014 conference.

Surgery System:
Increased registrations have brought more reports of surgery and we now have nearly 1900 surgery reports logged, with Cardiac surgeries remaining the primary concern. With increased numbers of reports of cardiac surgery for our children, Dr Carey is working on IRB approval for a new cardiac study. There is a short form on the site for members to update surgery information without a need to submit the entire membership form. Please keep SOFT informed of your child’s surgery data. A beta version of a passworded automated surgery system is now running on the website. When completed the entire system will reside there. This provides dynamic data and a number of available reports and is accessible by the specific members who require that access.

Membership:
Membership was converted to a free Registration model in March. This has generated a burst of new registrations, nearly doubling our membership. An automated membership registration system with current, dynamic information and reports has been developed and integrated into the SOFT website. It is, of course, passworded and accessible by only the few members who require such access to do their jobs.

SOFT International Committee Report– Pam Healey

International News:
Memberships continue to come in from other countries. We are not yet the United Nations, but we are getting there. More recently we have added families from Trinidad and Tobago, Brazil, Mexico, Ireland, Australia, Sweden and several from Canada. Their children lived hours, days, weeks and years, with a few now having double digit birthdays. It was interesting that most had a diagnosis of trisomy 13, ordinarily less frequent than trisomy 18. We also welcomed back some “oldtimers” from Canada. One family is awaiting their son in November. Another is remembering a child that lived nearly six months in 1975. Another joined SOFT soon after their child’s birth. We welcome all our international members, long standing and new. We have a shared history, despite geographic and language differences. Be sure to check the websites of SOFT Ireland, SOFT UK and SOFT Italy.

CONGRATULATIONS DAVE RICKER

Congratulations to Dave Ricker on his essay, “Bariolage” being accepted for publication by the literary magazine, The Hamilton Stone Review. It is a first person account of lambing in 2009, the fight for survival, the need to help nature, and the raising of heartfelt, crucial questions that surround our trisomy children and their siblings. He describes the rocky hillside of New Hampshire he and his family call home, the everyday life of his family, and the music, challenges and special moments that are counterpoints to what is difficult. This is a reflection, not just because he reflects on events and makes meaning of them, but because some events reflect others and make a connectedness that matters.

-Pam Healey
Family Story: The Crosier Family and Their Journey with Simon

by Sheryl Crosier

Simon Dominic Crosier was born on September 7, 2010, in St. Louis, Missouri. He was diagnosed with trisomy 18, and lived for three memorable months before passing away on December 3, 2010. Despite his disabilities, Simon had a huge impact on all who came into contact with him. Trisomy 18, also known as Edward’s syndrome, involves an extra chromosome in the sequence of 18 — just as trisomy 21 affects the 21st chromosome for people with Down syndrome.

The medical community looks at statistics and too often decides these kids with special needs aren’t worth the effort. Many say: “What’s the point? They’re going to die anyway.” Ninety percent of babies with trisomy 18 have heart defects and 95% aren’t brought to full term. Many are aborted when their conditions are revealed during prenatal testing. Only one in 6,000 comes into the world.

Struggling with the fragility of your child’s life is one thing. Fighting the popular pragmatic culture that measures human life in terms of dollars instead of dignity is quite another. “Our kids are not disposable and deserve every consideration,” said Dr. Steve Cantrell, the father of Ryan, who died of trisomy 18. “The souls and spiritual essence of our children are not disabled. Their physical handicaps exist but their desire to thrive is not diminished.”

Dr. Stephen Braddock, director of medical genetics at Cardinal Glennon Children’s Medical Center in St. Louis, adds: “I always teach new physicians that children with chromosomal conditions haven’t read the statistics. These families deserve an informed and thorough discussion of challenges and options they face.”

Dr. John Carey, a pediatrician and specialist in medical genetics at the University of Utah, believes: “It’s important for those of us who have the privilege of caring for children with complex conditions to stop, listen, contemplate, take off our shoes, and walk with our fellow traveler.”

If only we knew these compassionate healers when our Simon was alive.

It was after six miscarriages that we found we were expecting in early 2010. At the 20-week ultrasound my husband, Scott, and I, along with our sons — Samuel, age 7, and Sean, age 5 — were overjoyed that we were having a boy, but terrified of losing another baby. Prior to this comprehensive ultrasound, I had undergone many tests early in the pregnancy. Each ultrasound indicated our child was developing and healthy.

We were heartbroken to learn the 20-week ultrasound showed markers of trisomy 18. Our son Simon had clenched hands and a cleft lip. Even though the ultrasound doctor encouraged an amniocentesis, we refused. After experiencing the emotional trauma of losing six children to miscarriage and the risk of a miscarriage by an invasive procedure, we would never do anything to harm our little boy. I could never forgive myself if something happened to Simon. We continued to embrace hope. Our faith in the Lord would carry us through the possible storm of another pregnancy.

As we were leaving one of the excruciating long ultrasounds, the doctor and sonographer cornered Scott and me in the doorway. The doctor told us without emotion: “You know there are parents who terminate for cleft lips.” We were saddened and sickened by such a callous remark. It was as if the doctor wanted us to follow his path of destruction for our child. This was our boy — our son — for whom we had waited so long. Our response was: “No, we’ll never have an abortion no matter what. We are proudly pro-life. We have hope and put our faith in God.”

As the pregnancy continued, my doctor became more and more distant and showed no compassion. At one of my check ups, he said, “Sheryl what do you want to hear? There are problems.” We told him it was clear that he did not have hope in our little boy — but we did. We expressed many times to this physician that our faith in God would support us if he was determined not to.

My OB/GYN decided to schedule an induction because of my increasing blood pressure. He said Simon probably was “growth restricted.” Later, I discovered that my medical records stated: “Induction for fetal anomalies and maternal gestational hypertension.” Several hours after being induced, doctors noticed deceleration of Simon’s heart rate. We made it clear that any signs of distress should lead to a C-section.

On September 7, 2010 at 5:40 pm, we heard the first cry of Simon Dominic Crosier as he entered this world. Simon weighed 4 pounds, 3 ounces. He was 17 inches long. Simon was small with a bilateral cleft lip, but he was absolutely perfect to his adoring family!

After delivery, Simon was taken to the level III neo-natal (Continued on page 22)
intensive care unit (NICU) in the hospital. He was put on a continuous positive airway pressure (CPAP) machine to provide breathing therapy, fed total parental nutrition (TPN), and given platelets. He also had bilirubin lights for jaundice. On Day 2 of Simon’s life the echocardiogram revealed that his heart was broken: in more clinical terms he had a ventricular septal defect (VSD; valve doesn’t fully close), coarctation of the aorta (pinched aorta), and a patent ductus arteriosus (PDA; blood bypasses the lungs preventing oxygen from circulating throughout the body). Simon also had pulmonary hypertension. Immediately, caregivers started Simon on medicine called prostaglandins to keep his PDA open. We were told this medication was crucial and in a sense his “lifeline.”

On Simon’s third day of life, he was diagnosed with full trisomy 18, also known as Edward’s syndrome. I’ll never forget how the neonatologist walked in Simon’s room and said matter-of-factly: “The results came in, Simon has full trisomy 18.” She added, “I’m sorry,” and walked out of his room.

Once Simon was diagnosed with trisomy 18, his care changed dramatically. We were told our son was incompatible with life. How dehumanizing! Because of his extra chromosome, medical treatment changed to comfort care and we began to hear doctors say, “not for Simon,” when aggressive treatment options were considered. We weren’t told about relevant research on outcomes or survivors. We continued to pray for the maximum time with Simon.

I would say, “We want Simon special needs and all.” My husband would emphasize, “We’re not here to expedite his demise.” As parents, our wishes were clearly communicated.

A few weeks after Simon started receiving prostaglandins for his heart, the medical team advised us to consider stopping the medicine so “nature could take its course.” We resisted this advice because we believed their approach amounted to pulling the plug on our son. As Simon’s parents, our responsibility was to guard and defend him.

Simon’s nurse, Beth, informed us that if the medical team knew Simon had trisomy 18 before delivery, they would have resisted any life-saving measures and not started the prostaglandins. She asked if we would like a meeting with the hospital’s ethics committee, and here we expressed our passionate desire to offer our son the very best medical care available. We hoped to take him home if possible.

Nurse Lola even recalls walking out to the parking lot after her shift and overhearing another nurse make the comment, “Why don’t they just get it over with?”

After many discussions, Simon’s medical team approved our decision to take Simon home on prostaglandins and stop his treatment at home. We were deeply disappointed to learn doctors didn’t even plan on ordering more than a day or two of medicine for Simon. We expressed our frustration forcefully to the ethics committee. Their best medical opinions about Simon’s future left little hope. They said if we stopped his medicine, his PDA would close and Simon would pass shortly after. If we stopped treatment in the hospital and took him home, he would probably die within 24-48 hours. To us it seemed as though some medical professionals were always planning for Simon’s death, not his life.

One nurse later explained to me, “The atmosphere with some of my colleagues walking into Simon’s room was like walking into a funeral, like his death already happened,” she recalled. “Because of his heart rate and oxygen saturation rates, they acted as if there was not much hope, nothing further they could do. But the child’s eyes opened and I looked into his eyes and told myself, Simon doesn’t need this atmosphere. Give him what he deserves. He was like Prince Charming to me. I connected with Simon through my heart and not as a medical case. He drew me to him with silent eyes.”

I later learned that after Simon was diagnosed with trisomy 18, he wasn’t offered breast milk or formula. Although I was pumping breast milk, the medical team wasn’t using it. Instead they gave our little boy drops of sugar water when he fussed. Looking back it, it pains me to realize our little boy was hungry. Only after Nurse Lola went to bat for us did Simon’s physicians finally agree to give him breast milk via a nose tube. I had to ask if we could instead put breast milk in a syringe to feed Simon when he fussed. Again our supportive nurse Lola got approval.

Medical caregivers informed us of an ominous fact. Some parents of children with similar condition don’t feed their babies. We were shocked!

Despite all the discouraging news, our Simon was living. He carried on in the face of doctor warnings that he wouldn’t make it past the first week. He was proving to everyone that he was not incompatible with life. His life was God at work. We faithfully advocated for our child — and God granted us precious hours and days with Simon to care for him.

Bishop Robert Hermann of St. Louis, a holy man and personal friend of our family, puts it this way: “These parents have received the light of wisdom to realize that they are experiencing the kingdom of heaven within them when they are taking care of this child,” he said. In sincere union with Bishop Hermann and the precepts of our mother Catholic Church, my family believes that the right to life comes from the creator of life.

As Simon continued — with the Lord’s help — his struggle for life, the medical team encouraged us to stop using the bag and mask during our son’s frightening apnea episodes. I was enjoying a rare opportunity to have lunch at the hospital down the hall from the NICU with the mom of a baby with trisomy 21. As I walked back into Simon’s room I
immediately noticed something very wrong. I screamed, "His monitor is off!" A nurse told me that one of his doctors turned it off. This was the same doctor who kept continually advising, "let nature take its course." When I asked him why he did this, he said we should enjoy our son without the bothersome noise of his monitor. Again, I responded angrily, Simon was having apnea. We relied on the monitor to tell us if our son stopped breathing. His doctor was talking casually about a matter of life and death.

During the last week of Simon’s life, his oxygen needs increased while his heart rate dropped. At this point the medical team told us his CPAP mask wouldn’t help and would be uncomfortable. We wondered why; didn’t he need more assistance with his breathing? I felt completely helpless to comfort my precious son.

We asked Simon’s doctors to look at Simon as though he didn’t have the label of trisomy 18. We wanted them to treat Simon with their God-given talent as physicians and leave the rest in God’s hands.

Again, Bishop Hermann explains why children who have special needs have an important role in God’s eternal plan: “When we look at a special needs child, Jesus is asking us directly, ‘Do you see me?’ These children draw out in their parents strength and grace they didn’t even know they possessed. They are a gift from God — to families, communities, and the Body of Christ. Their ability to edify and inspire unconditional love can change our self-image from a culture of death to one that grants all God’s children the dignity they deserve.”

Yes, Bishop Hermann, my Simon inspired me to love more deeply than I ever knew I could.

On December 3, 2010, Simon’s oxygen saturation levels began to fall. We were told this is the end — nothing more could be done. At 10:45 a.m. on December 3, 2010, the tears poured from our eyes and others as Simon left this world for his eternal home.

It was absolutely heart-wrenching to look through baby Simon’s medical records after he passed away. To see indifferent clinical phrases like “comfort feeds-only” and DNR (do not resuscitate) in his records was sickening. We never signed a DNR order!

In my struggle to deal with my grief and understand Simon’s purpose during his short life, I decided to write a book to honor him. Simon’s story is being revealed to people all over the world. The name of Simon’s book is I’m Not a Syndrome — My Name Is Simon. If you look closely at the cover photograph of my beautiful son, Simon will tell you "I love you" in sign language.

A friend and fellow trisomy mom, who is a writer and researcher, describes the book this way: “Sheryl Crosier’s memoir, I’m Not a Syndrome — My Name Is Simon, of her journey during her pregnancy and her infant son Simon’s short but important life, is a story of the heart and spirit. It is also a story of the head that explores the capabilities and constraints of modern medicine and policy, parental rights and ethical decision making.” Those kind words come from Pamela Healey, PhD, mother to Conor, who died with trisomy 18.

God did not bless us with a syndrome. God blessed us with a son. His name was Simon. Simon’s story is filled with compassion and outrage. It is a story of a child knit together by the hand of God. Each of his days was written and ordained. Because of our hope in the Lord, we will be reunited with all of our children in heaven again.

Sheryl Crosier, MA, MBA, is the Chapter Chair for SOFT—Support Organization for Trisomy 18, 13, and related disorders. Sheryl and her husband Scott and their two sons live in St. Louis.

Her book, I Am Not a Syndrome — My Name Is Simon, was published in August 2012 by All Star Press—Books That Change Lives. It’s also available on Amazon and Barnes and Noble for download or as paperback. Simon’s website, www.simonismyname.com, has information on the book as well as on trisomy-related conditions. A portion of proceeds from every sale of this book will go to SOFT. See more at: http://www.wf-f.org/133.Crosier.html#sthash.ODHzZGm0.dpuf
Simon’s story -- the power of love in every life

By Sheryl Crosier

Simon Dominic Crosier was born on September 7, 2010, in St. Louis, Missouri. He was diagnosed with trisomy 18, and lived for three memorable months before passing away on Dec. 3, 2010. Despite his disabilities, Simon had a huge impact on all who came into contact with him.

Before Simon’s arrival my husband, Scott, and I lost six children through miscarriage. With each loss the sting of pain was greater. After we lost our daughter Faith in September 2008, we rid our home of most of our baby items. Losing a child is a pain so deep that is difficult for anyone to grasp. It can be like falling down a chasm that seems to have no bottom. The chasm is lined with thorn branches that scrape and pull at your skin when you remember what you have lost.

When we learned we were expecting in early 2010, Scott and I, along with our sons Samuel, at the time age 7, and Sean age 5, were filled with joy and yet terrified at the thought of losing another baby. On the day of Simon’s birth we embraced our son with sheer happiness, despite his cleft lip and clenched fists. Although doctors were concerned, our family felt only hope.

On day two of Simon’s life the echocardiogram revealed that his heart was broken... and so was mine. My son had major heart defects that prevented the efficient oxygenation of his blood, resulting in pulmonary hypertension and severe apnea episodes during which he would stop breathing.

On Simon’s third day of life, he was diagnosed with trisomy 18, also known as Edward’s syndrome. This condition involves an extra chromosome in the sequence of 18 -- just as trisomy 21 affects the 21st chromosome for people with Down syndrome.

I will never forget when the Neonatologist walked into Simon’s room and said, “The results are in. Simon has full trisomy 18. She then said, “I’m sorry,” and walked out of his room.

Our precious son was now labeled “incompatible with life.” The medical community looks at statistics and too often decides special needs kids are not worth the effort. Ninety percent of trisomy 18 babies have heart defects and 95 percent aren’t brought to full term. Many are aborted when their conditions are revealed during prenatal testing. Only one in 6,000 comes into the world.

After Simon was diagnosed with trisomy 18, his care and treatment changed dramatically. We began to hear doctors say “Not for Simon” when aggressive treatment options were considered. Struggling with the fragility of Simon’s life was one thing. Fighting the popular, pragmatic culture that measures human life in terms of dollars rather than dignity, is quite another. As St. Louisan Dr. Steve Cantrell, a parent of Ryan, a deceased trisomy 18 child, stated, “Our kids are not disposable and deserve every consideration. The souls and spiritual essence of our children are not disabled. Their physical handicaps exist, but their desire to thrive is not diminished.”

Physician Dr. Stephen Braddock, Director of Pediatric Genetics at Cardinal Glennon Children’s Medical Center in St. Louis, adds: “I always teach new physicians that children with chromosomal conditions haven’t read the statistics. These families deserve an informed and thorough discussion of challenges and options they face.”

Dr. John Carey, a pediatrician and specialist in medical genetics at University of Utah, believes: “It’s important for those of us who have the privilege of caring for children with complex conditions to stop, listen, contemplate, take off our shoes and walk with our fellow traveler.”

Although we prayed Simon would become strong enough for surgery to repair his damaged heart, he spent the next 88½ days on a roller coaster of good and bad days. In retrospect, every one of those days was a blessed learning and loving opportunity for everyone who knew Simon. That includes his nurses who recognized his special qualities of peace and perseverance, many of his doctors, and our friends and family members who were privileged to meet this remarkable ambassador of love.

At 10:45 a.m. on December 3, 2010, the tears poured from our eyes as Simon left this world for his eternal home. In my struggle to deal with my grief and understand Simon’s purpose during his short life, I decided to write a book to honor him. Simon’s story is being revealed to people all over the world. The name of Simon’s book is I’m Not a Syndrome — My Name is Simon. If you look closely at the cover, Simon says “I Love You” in sign language.

A friend and fellow trisomy mom, writer, and researcher, Pamela Healey, Ph.D., describes the book this way: “Sheryl Crosier’s memoir, I Am Not A Syndrome — My Name is Simon, of her journey during her pregnancy and her infant son Simon’s short but important life, is a story of the heart and spirit. It is also a story of the head that explores the capabilities and constraints of modern medicine and policy, parental rights, and ethical decision making.”

God did not bless us with a syndrome. God blessed us with a son. His name was Simon. Simon’s story is filled with compassion and outrage. It is a story of a child knit together by the hand of God. Each of his days was written and ordained. I Am Not a Syndrome - My Name is Simon is available at All StarPress - Books that Change Lives. It’s also available at Amazon and Barnes & Noble. Simon’s website, www.simonismynname.com has information on the book and on trisomy conditions. A portion of proceeds from sale of this book will go to SOFT, Support Organization for Trisomy 18, 13, and Related Disorders. (The above was printed in the September Issue of Missouri Right to Life & reprinted with permission)
I thank God upon every remembrance of you.-Philippians 1:3

**Remembering SOFT Angel Wings**

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Hello SOFT Families,

I really enjoy receiving the SOFT newsletter and keeping up with what is happening with our families. I have not contributed a story for quite a while and would like to give you an update on Ella.

Overall, Ella has been doing well. She will turn 13 on March 19th – WOW! She weighs about 85 lbs. and is 55 ½ inches long. She has a G-J tube which was placed when she was about 5 years old. This type of feeding has allowed for Ella to grow nicely and become healthier and stronger. This spring, April 22nd to be exact, Ella underwent a full fusion back surgery after a culmination of 16 prior surgeries. Ella had the first surgery to place the rod in her back in January of 2005 and continued to undergo surgeries to lengthen the rod every 6 months up to April of this year. She had also worn a back brace since was 3 years old. The April surgery put an end to all back surgeries and to wearing the back brace; this is such a big relief for us. The surgery, itself, went well but the recovery was very difficult for Ella. A 7-10 day hospital stay turned into 28 days. She got very sick with a suspected pneumonia setting in and her feeding tube had to be pulled and a pic line placed due to an ileus. Through it all she was such a brave little girl who barely fussed or complained.

Fall is definitely starting to arrive in Wisconsin, but it is hard to let go of all the nice summer memories. My husband is a teacher and I stay home with Ella so we have the whole summer together. We started out in June with my nephew’s wedding. Since it was a bit of a drive we stayed overnight in the hotel where the reception was held. Ella stayed up late that night hanging out in her gait trainer by the dance floor – she loves her music. We had the opportunity to visit two of Ella’s trisomy 18 friends this summer. We went to see sweet little Leila Adamson (who is almost 2 years old) whose family was staying at one of the handicapped accessible cabins in WI. There are 7 state parks in WI that have these wonderful cabins totally built to be used by anyone with a disability for only $30 a night. It was so nice of Kari and James to invite us for a visit; we had a nice afternoon. A few weeks later Joe, Ella and I were able to stay at the same cabin for a few nights. In August my mom, my sister, Ella and I traveled to Minnesota to visit Rosemary Valentine and her daughter Mary who is 25 years old. We spent a day at their house and had a great time. We also took in the Mall of America and the Minnesota State Fair. Some of our summer days were spent at our mall where Ella could walk around in her gait trainer; what girl doesn’t like to shop? Most of all this summer we enjoyed being out and about a lot (restaurants, church, family and friends gatherings) without the fear of Ella getting sick.

Joe went back to teaching in September, but we had to make a very difficult decision to take Ella out of school this year. Over the last few years her school program has greatly changed. It has went from one of self -containment (this was working well for Ella) to a resource room (many students coming in and out during the day) to that of total inclusion. Ella was getting sick too often and ending up in the hospital. We cannot afford to let her lungs become more compromised. Two years ago Ella started using an Airway Clearance System (The VEST) twice a day and sleeping with a BIPAP machine at night. This has helped her lungs but the big thing is to try and keep her as healthy as possible. Our school district is providing Ella with some homebound services. She will see each school therapist (OT, PT, and ST) and her teacher once a month.

We are trying to keep busy. We are going to a music for youth with special needs class once a week (there are only 4 kids in the class), and we are doing one on one with the same music therapist every other week. Ella absolutely loves working with this therapist. Ella uses a switch to “sing” along, holds and plays instruments, and just enjoys her singing. We try and get together once a week with a group of moms and their children with special needs who are also at home for various reasons. Ella is a very social young lady who enjoys this interaction. In September my mom, Ella and I were able to stay at another one of the accessible cabins near a beautiful resort area only two hours from our house. Ella loves spending time with her Nana; many of you have met my mom at the SOFT conferences we have attended. Ella spends our days at home using her gait trainer, swinging in her Jenn swing, reading books, playing with a variety of light up and musical toys, and using a special switch to access some interactive websites.

Well, this was quite the overview of what is happening in the Hameister household. I anxiously await future newsletters and more family stories.

Ann and Joe Hameister
Ella – Full Trisomy 18
annhameister@att.net
“Hope is a waking dream.” — Aristotle

Leila Adamson and me!

Above: I just love to nap on my Daddy.

Left: Our visit with Miss Mary Valentine. I am surrounded by my Mom and Grandma. Mary and her Mom are smiling for the camera.

All Dressed Up For The Wedding!

Keeping Up with the Effervescent Miss Ella Hameister
If you would like to support Larry and Krissy's effort with a donation, the donation link is still active at: www.crowdrise.com/runningwithkrissy

“We dream to give ourselves hope. To stop dreaming - well, that's like saying you can never change your fate.” — Amy Tan

“Hope is that thing with feathers that perches in the soul and sings the tune without the words and never stops . . . At all”

-Emily Dickinson

Larry & Krissy BEFORE the marathon!

Missouri Running Team

Go Krissy and Larry!

Krissy and THE MEDAL!
Krissy Krotzer: Trisomy 18 Teenager Participates in the Portland Marathon!

By Terre Krotzer

Kristina Krotzer, a 13 year old middle school student from Lake Tapps, WA participated in the 2013 Portland Marathon on October 6th in Portland, OR. Tens of thousands were there, each running for their own personal reason, running for their cause. So what made this one entry different or unique? Well the answer to that is Krissy herself and the reason she was participating. You see, Krissy is non-verbal and she can't walk independently.

Krissy was diagnosed prenatally with a rare genetic disorder called Trisomy 18 or Edwards Syndrome. In simple terms Trisomy 18 means that Krissy has an additional 18th chromosome, in other words she has "Designer Genes!"

Doctors gave us the grim statistics. They explained that this condition was "Incompatible with Life." They told us that Krissy would likely die before her birth. They were certain that if even if somehow she survived birth, she would die soon after. "Either way," the doctor said, "This is not a viable pregnancy. There won't be a baby to take home from the hospital." Today that baby is 13 years old!

Clearly Krissy had different plans and she chose to "ignore" their statistics. Statistics which said that of the very few children with Trisomy 18 that survive birth only about 10% live to celebrate their first birthday. Wait a minute, 10% does not equal "Incompatible with Life." 10% means hope. 10% means possibility. And Krissy is living proof! Where there is Life there is Hope!

So, why the Portland Marathon? The answer to that comes in meeting our friends Larry and Katie Wheat. You see Larry and Katie's lives had also been touched by Trisomy 18. Their precious daughter Abigail also had Trisomy 18. Sadly, the other part of the "statistics" touched their lives and Abigail was born "still" on August 9, 2002. Katie and I met on an online listserv when she was pregnant with Abby and looking for help and support. Then we met in person years later in 2007 when Krissy and I joined the Wheat Family for a balloon release in celebration and memory of Abigail's birthday.

Abigail is the driving force behind A Butterfly's Touch, www.abutterflystouch.org, an organization founded by Larry and Katie Wheat that supports families whose lives have been impacted by the heartbreaking loss of a child to early pregnancy loss, stillbirth, or newborn death.

What I didn't know was that since meeting Krissy in 2007, Larry had wanted to do something with Krissy to bring Awareness to infant loss and to Trisomy 18. When he and Katie contacted me a few months ago asking if he could push Krissy in the Portland (half) Marathon, Randy and I were first surprised and then thrilled. The perfect opportunity!

But Larry and Krissy didn't run alone. Krissy's stroller was adorned with colorful ribbons flapping in the cold morning air as they made their way along the course. Each ribbon represented angels like Abigail. Children for whom the syndrome was so complex that their time here on Earth was brief. But like Abigail, these children have names and their sweet lives, regardless the length, matter. There were also ribbons representing surviving children around the world.

We wanted to show that Krissy isn't alone, that there are survivors of Trisomy 18 (as well as other rare conditions like Trisomy 13 – Patau Syndrome, Trisomy 9 and many others.) We want people to know that these surviving children are quite compatible with life! We want people to see that these children live with love and joy despite the limitations and labels that are put on them. Our theme of Running with Krissy to bring awareness to Trisomy grew even beyond the Portland Marathon. It turned out that another trisomy mom, Simon's mom, Sheryl Crozier was training for the Missouri Cowbell marathon on the same day. Once she heard that Krissy and Larry were running for Trisomy Awareness in Portland, she gathered a team together and they also joined Krissy and Larry in Running with Krissy to Bring Awareness to Trisomy!

In addition to raising awareness this was also a fund-raiser benefiting SOFT and A Butterfly's Touch. It was incredible to me to see the support from the Trisomy Community as well as our friends and family who have shared our journey. All of the children’s names submitted were also on the back of the shirts that the entire Running with Krissy team wore. The names will also appear on The Running with Krissy – Bringing Awareness to Trisomy and Infant Loss Wall of Fame! at TrisomyTalk.com I heard from Larry and Katie as they were heading back home to San Antonio. It appears that Larry’s goal of Running with Krissy is just getting started. Watch for future Running with Krissy events including next year at the Portland Marathon. Larry says next year he’d love for them to do the whole marathon! Go Larry and Krissy!
By Barb VanHerreweghe

Introducing Stacy VanHerreweghe, born 5/21/81 and yes, 32 years old. I often wonder where the years have gone.

32 years ago they told us Stacy had outlived her life expectancy. They never used the words incompatible with life. I guess they have changed their language over the years. I don't believe they mean anything different but we chose to ignore the words and let Stacy prove the doubters wrong. She faced many challenges those first five years of her life.

We spent many times in the hospital for pneumonia.

Stacy ate by mouth for the first five years of her life. Unfortunately, she still was only 19 pounds at five. We chose at that time to have a g-tube surgery done. The first month after the surgery she gained 10 pounds! Good job getting yourself moving up on that growth chart! Stacy seemed to get healthy as we were able to get better nutrition in to her.

She started school at the age of 6 ½ years. We took extra precautions to keep her healthy. Her own toys washed by us weekly, her own wash bucket for feeding tubes etc. It worked and she thrived at school. I think she might have been one of the healthiest in the class. Stacy enjoyed school but really enjoyed being social with others in her class especially the boys. She always had one or two boyfriends in her class each year. Transitioning to new teachers seemed to be more traumatic for me than for Stacy. I like to feel comfortable and a new teacher was always a challenge until they got to know her. We were blessed almost her complete school years with wonderful teachers. But as life is there are always some that throw us more challenges than we wanted for that year and one time we actually had to request a different class to complete the year. It all comes down to educating the teachers and some didn’t care to learn. Those 21 years were over before we knew it. Talk about challenges, moving on after school was really scary! We made it through but not without a lot of planning to go to a day habilitation. The September after she graduated she did start her new program. Stacy goes to her program Monday through Friday and looks forward to going. They go out in the community every day and volunteer at various places from food cupboards, cleaning church or just calling BINGO at a nursing home. Life has been good.

Stacy started with her first pediatrician and stayed with him for 25 years. She was also fortunate to have many dedicated specialists. The most supportive and helpful for us was her Developmental Pediatrician. It was that second opinion we had on a regular basis. We did have to change a few doctors over the years but we were always careful not to burn our bridges as we moved on. We had to do what was best for Stacy and our family. When she was 25 we moved to a med-peds specialist. We are fortunate she has pediatrics training as well as internal medicine training. The specialists in the adult world have not been as easy as this transition. We are still trying to build a good team of specialists and we are still trying to find that perfect team. It is very hard as the adult world doesn’t even know what Trisomy 18 is. That is good and bad. We are struggling right now in trying to figure out why her magnesium level continues to stay below where it should.

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Traveling with Stacy VanHerreweghe, 32 years and counting

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be. She doesn’t pick every day issues but has to challenge us with figuring out what we need to do. We are trying to find the reason for the loss and building a team to assist us. This part of her life has been a real challenge!

Stacy in her years has been an active participant in her community. She has played baseball, bowling and volunteered. She attends Country music concerts with her favorites being Toby Keith and Rascal Flats. She has been on five cruises and loves to be in the warm island breezes. She enjoys her life and her family. This past weekend she went to New Jersey for her cousin Cory’s wedding. What a treat to get to see family from Florida, South Carolina, Maryland and Minnesota. Cory has always been pretty special to Stacy as he is the one who walked her down the aisle in her cousin Christine’s wedding. That is when she was 12 but what a special time. We have had many special times in our family and we are blessed to have the extended family we have.

Stacy loves to travel and wants everyone to join her at the conference in Virginia in 2014.

What’s in the Mailbag?

Update: Jack & Judie Laird Send Thanks, Say They Miss their SOFT Family

To our wonderful SOFT friends, here is an update about the Lairds.

As many of you know, Jack was diagnosed in March 2013 with kidney failure, and he started hemodialysis dialysis just two months later in May. That same week in May was eventful because he was also told he had COPD and would need to be on oxygen. That week sure changed our lives! He has been hospitalized for several weeks since May, but we think he is on a pretty stable course now. Jack goes to dialysis three evenings a week for three hours each time. We have been able to adjust my work schedule so I can continue to do the work I love and leave in time to be at the dialysis center to bring Jack home at 10pm. It all seems to work for us, and I am grateful that the families I work with understand our situation. The VanHerreweghe family has been wonderfully supportive. Jack and I weren’t able to do the usual registration work for the conference, and we are grateful that SOFT families, particularly Debbie and Jim Dye and Ann and Frank Barnes, stepped in and helped Barb get details in place for the July conference. We truly missed seeing all our friends. SOFT is a big family, and we have always thought of the conference as a Family Reunion that we wanted to attend. Jack and I have no idea what next summer will bring, but we HOPE to see everyone at the Virginia conference. Thank you, thank you for the delightful and touching poster that so many of you signed at the conference. It is hanging proudly in our home, and we smile at the comments every day.

Blessings and SOFT hugs to all,
Judie and Jack Laird

Sure HOPE we can go to Norfolk.

Jack & Judie at a SOFT ball-game outing during a previous conference year.
Join SOFT in 2014

The next SOFT conference will be held in Norfolk, Virginia July 9th-13th, 2014. The hotel conference site will be The Sheraton Norfolk Waterside in downtown Norfolk on the Elizabeth River.

The medical clinics will be held at Children’s Hospital of the King’s Daughters.