2013 Rhode Island SOFT Conference

By Pam Healey

This year’s conference was defined by lighthouses, scallop shells and beach glass, each a symbol of the journey we share. SOFT has brought light to our often difficult journey and helped us negotiate the storms and shoals that have challenged us. The scallop shell speaks both of our personal resilience and the pilgrimage we take to come together in July to share our wisdom and hope, children and memories. Beach glass reminds us that what has been broken can be transformed by strong forces and grit and will hold light within. Disappointment is transient; beauty endures.

We, about 235 of us, with another dozen volunteers of family and friends, came to the smallest state, one whose edges are swept clean twice a day, making each day truly a new beginning. We came from 32 states, Puerto Rico, Canada and the UK. We brought kids, parents, friends, several service dogs and a cat with us. There were 38 SOFT kids, four attending only the picnic. They ranged in age from nine months to 33 years, eleven at least age 16. The SOFT children represented about ten diagnoses, full trisomy 18 the most common. There were only nine boys in the group, and several were caught flirting with the ladies. In child care Friday evening David left one of two coveted positions near a sunny window, the other claimed by a contented Angela, sidled over to Mary, about 20 feet away, and leaning against her wheelchair held her hand. Meanwhile the blanket girls were having a slumber party with Leilani whooping it up to Akiaya’s and Krissy’s amusement.

There were 72 families attending, after three planning to join us had to confront health problems. There were nine new families, including a few attending only the picnic. We were delighted to welcome back a few old timers, away much too long. It seems we needed to bring the conference to them. I suspect Margaret will want to leave Connecticut for the next conference. Three “old” SOFT families returned for the first time without their child. We tearfully watched their balloons ascend from the field, skirting trees, then rising over Narraganset Bay and drifting toward Newport. Three families, one with us in spirit, and spending the time of the balloon release at her grave, 2,000 miles from the Atlantic, mourn older children, lost in the last seven months. These were long time survivors who together represent more than nine decades of a great quality of life, when only weeks of fragility were expected. Through tears we smiled remembering them. As the last of the balloons lifted higher and receded from sight, the storm clouds arrived, the winds increased, the white caps covered the bay and the cooling rains came, bringing thunder and lightning. From the shelter of the carousel building, it was a great show.

We began the conference with the board meeting and a flurry of activity in our registration office. In the evening many early arrivals gathered in the Rotunda for hors d’oeuvres and beverages, a great opportunity to meet some new folks and reconnect with others we had hoped would attend. Thursday morning families in their team shirts with decorated wheelchairs and carriages strolled from the lobby, out the door into the heat, past the wide banks of blue hydrangeas and into the cool Rotunda room for judging and group pictures. Next, we divided up with nearly two dozen SOFT kids heading out to clinics with our doctors, John Carey and Scott Showalter, and kept on schedule by Gerri Meggett, who runs a tight ship. Each SOFT child or young adult was accompanied by a medical student from Brown, met with specialists and received a toy from Hasbro Toy Co. Meanwhile, many families, who had lost their children recently, a few years ago or in the distant past traveled to Jamestown on Conanicut Island, past lighthouses, a centuries old windmill, a pasture of rare belted “oreo” cows, farms bound by stone walls, a tidal marsh and a quaint village. At Fort

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Every human life is a story written by God’s fingers-Hans Christian Anderson 1805-1875

SOFTLY SPOKEN

By Kris Holladay, Founder

“How of the Storm”

In Arizona, during the late summer, we have storms called monsoons. The monsoons move in very quickly and bring dust, lightening, wind, and heavy rains. I recall one frightening storm years ago. Our oldest daughter, Tricia, came rushing inside from the backyard. She was quite worried because she could see a storm coming directly our way. Sure enough, I went outside and saw the dark clouds heading quickly towards us. Within five minutes, the wind was bending the trees until they almost touched the ground and sheets of rain were pounding down all around. Tricia and I sat by the window watching with a feeling of helplessness, fear, and even some excitement. I wondered with concern about the damage that would be done as a result of this ferocious storm. After an hour, everything calmed down and the sky lightened just a bit. Only then did I dare to come out from the shelter of the house. Once outside, I witnessed the glory of a most spectacular arch of magnificent colors, a rainbow like I had never seen before! As Tricia followed me out from under the porch, she too, saw the awesome sight. As the sky continued to lighten, the colors faded leaving us breathless and speechless.

Often the sky will return to a calm blue without much notice. But a rainbow is something different. It is the bonus for having endured the storm. But, we need to look for it. I wonder how many rainbows I have missed because I wasn’t looking after the storm.

I wish our lives didn’t have “storms” – the challenges, heartaches, and disappointments. But we do – every one of us has had to weather life’s storms. Some of these storms pass quickly and others seem to last forever.

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“Because of the Storm”

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How many of our life-storms have passed and because we were too frightened or hurt or angry at the storm, we missed seeing the rainbow that the storm has left behind?

When we were told of Kari’s condition at her birth in September 1977, our world crashed around us. It was a painful “storm” and I wondered what damage would be left as a result. I worried about our young family. I worried about me and as frightened as I was of Kari’s death, I was even more afraid of Kari’s life.

Yes, at first I was so frightened of Kari! She seemed more “abnormal” than “normal” so I didn’t act normal. But, when I finally realized that Kari had the same needs as every other child, I let go of my fears and began to embrace every opportunity to love her. Kari’s limitations did not decrease my love for her. She was a sweet young girl. She was not “special” because she was handicapped, but because of other special qualities that made her who she was. I enjoyed her for the warmth which I could see each morning in a smile even though I had awakened her. I delighted in her giggle as she shared her humor with me when I tickled her toes or chin. I cherished her closeness as she lay her head on my shoulder and grasp my other with her small hand. I admired her determination as she struggled and fought to regain health after a three-hour seizure. It was truly a pleasure just to have her near.

Although some of Kari’s “storms” were painful, others brought smiles. I remember how much I enjoyed going places with all our children only to have them “fight” over whose turn it was to push the wheelchair. And, we were like a walking tornado in department stores as we were “three wide and two deep!” Kari’s sister and brothers would all hang on or were riding on that wheelchair along with Kari. Ah that memory is a “rainbow” I still enjoy!

When Kari died at age 10 years, I felt devastated! But, gratefully in time, I have been blessed with more and more rainbows. Hal and I are close and we have a family that gives constant support and love, I have dear friends in SOFT, and my memories are precious and sweet. These things are my rainbows for today.

I have often been asked, “Why is the rainbow SOFT’s logo?”

My response, “Because of the storm.”

AFTER THE RAIN

You can’t find the rainbow
Til after the rain,
And you can’t share the joy
Til you’ve weathered the pain.
For life is a blending
Of laughter and tears,
That brings love and meaning
To all of our years.

“Because of the Storm”

Rhode Island Conf. . .

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Wetherill there was time to walk a cove to look for treasures, gaze out at sailboats and the broad lawns of Newport estates, and see the remnants of forts. Next, they visited Beavertail Light and looked south across wave worn rocks to the open Atlantic. There was time to wander through the large park, have some quiet time and relax in salt air, lulled by the rhythmic sounds of the incoming tide, and watch seabirds, sailboats, kite flyers, artists and fishermen. Mike Healey, a grief facilitator, riding his motorcycle ahead of the bus, and grief counselor Peg Bailey, Lelani’s nurse, in charge on the bus, led the group geographically and through a metaphoric journey. Francine shared that they had found it difficult to return to the Rhode Island landmarks they had visited with Natasha, but their time as a family at Beavertail meant a new destination, where they would carry her with them in a different way. The Midwesterners and Westerners particularly enjoyed the unique vista of the oceanside park. Hopefully, a few parents and siblings were greeted by monarchs. Come September the goldenrod and windswept bushes growing from the cracks in the granite that goes down to the sea are blanketed with monarchs heading south. The idea of the grief outing was to leave the confines of a hotel workshop room and support each other in an adventure that brought people to a special destination and encouraged some interior work in the company of SOFT friends who understand the pain of going on without a much loved child. The timeless forts, stately lighthouses at the water’s edge, red beach roses and blue hydrangeas, protected coves and endless vistas were to build new memories and connections together as the journey continues.

Thursday evening festivities stepped up in the Garden Pavilion, a huge, elegant, windowed tent with chandeliers and air conditioning, which, usually unnecessary, was a
Rekindling Relationships & Creating New Connections
By Edith L Gibson & Demetria (T18p)

In 2011, Demetria and I attended our very first SOFT conference in Chicago, Illinois. At the time Demetria was 4 years old and given the prognosis I did not know that other families even existed throughout our country and further to learn there are families living with Trisomy 18 from other countries that are surviving the odds was spiritually moving in my soul.

Before attending this conference, I had no knowledge of all the medical therapies, healthcare and/or educational programs available to enhance Demetria’s quality of life and to know that my love and faith in God alone provided great sustenance for Demetria to live, I felt empowered.

This conference became a place to gather, to connect and to grow. I gathered the medical, legal and educational resources to better advocate for Demetria in Michigan. I connected with other families to understand their experience in loving and caring for a child with Trisomy 18. I grew in some of the most profound ways as a woman, a single mother to a child with Trisomy 18 and as an emerging community leader in Michigan.

In this space, I formed relationships to share stories of great joy and minor pains from loving and caring for Demetria with other SOFT moms. I never expected for these relationships to be permanent or life-changing.

But this year in Rhode Island, I realized that my old and new relationships from SOFT are vital sustenance to enhancing Demetria’s quality of life in addition to my love and faith in God. We had the opportunity to create new connections with SOFT and non-SOFT families. Demetria became MeMe at this year’s conference.

MeMe spent time with our SHERO, Elizabeth! It is always such a joy and heart-lift to see & interact with Elizabeth.

MeMe enjoyed reconnecting with Zuri (the sister of Zia Moore) and Zuri became MeMe’s soul sister. She also formed a new relationship with her BFF Maddy from New Hampshire. MeMe had a chance to laugh, shop and play with friends who love and adore her. The big smiles and roaring laughs from Meme, Maddy & Zuri was soothing to my soul. It is a great feeling to know that someday Zuri and Maddy will grow up to become advocates & life-long friends to children like Meme & Zia!

Even though, we did not spend a great deal of time in workshops, the powerful relationships that we nurtured at this year’s conference served as a source of healing & hope. It is the love that we attain in our hearts not the knowledge we attain in our brains that truly sustain us...until we meet again!

We look forward to rekindling relationships and creating new connections at the 2014 SOFT Conference.
necessity as Rhode Island experienced more than a week of record setting heat. The Zion Lint Parade of Stars brought the children center stage one by one to receive the book, *Sammy the Little Broken Shell* by the evening’s speaker Carol Hamblet Adams, who placed a blue ribbon Sammy Award on each child. Andrew Winslow gave the book donated in memory of Natasha Winslow to each child. Jamie Lint gave each child a certificate signed by Carol and stating the child has successfully completed the requirements for the Sammy Award by “Using special gifts to improve the lives of others and teaching others every day. What matters most is what we are on the inside, in our hearts. We are all very special people just the way we are.” (email Healey-lex@aol.com if you would like a certificate for your SOFT child). Carol then spoke to us, explaining the lessons carried by what we find on beach walks. She spoke of recognizing our brokenness and seeing the beauty that remains. She spoke of the importance of the simple treasures we find along the way that help guide us and open us to possibilities. She spoke of taking time for transient activities that matter in the moment, learning to play and value the activity not the product made. It is okay to have our sandcastles swept out by the next tide; the value lies in building it. She spoke of finding peace despite the storms that enter our lives. She looked out at more than 30 SOFT kids and recounted Sammy’s story, a lesson in what matters.

Carol told us she had just returned a few days earlier from a two week journey down the Colorado River, not an easy vacation for a woman who had turned 70. In the weeks before her trip, she had visited SOFT’s website, read family stories, the newsletter, and articles. She had come to know and admire us, and she carried SOFT with her down the river and up the steep sides of the Grand Canyon. She knew what every SOFT parent faced was greater than what she was being asked to do with rafting class 6 rapids and scaling walls. The courage of the people before her Thursday night, kids and parents she knew she would be meeting, inspired her to do what seemed impossible, kept her from giving up. She spoke of gaining courage from those who live courageous lives, of being humbled by extraordinary people. Finally, she walked down among the tables and sang “Heroes”. Her energy, playfulness, spirituality, and wisdom were appreciated.

We are so grateful to R-FX-DJ’s, one of Southern New England’s most exciting DJ companies, who donated their time and talents with dinner music, dance music, announcements and positive energy. We learned one is a special education aide. When dinner was over, the dance floor overflowed with children ready to expend some pent up energy. Soon adults joined them, and some group dances united us. Amazing talent there! The spacious tent meant plenty of room for both rocking and quiet conversations.

Friday morning began with hustling the sibs off in two directions: rhinos and rigging, baboons and boats. They set sail for adventure. The heat wave continued and those going to Mystic Seaport enjoyed an air conditioned bus, as well as a few air conditioned buildings, even in a mid nineteenth century port. The next day thousands would visit the waterfront museum to witness the relaunch of the Charles W. Morgan, which has been attended to by shipwrights in a five year restoration project which has made her seaworthy once again. In 1924 she became the only wooden whaling ship remaining and is the oldest American commercial ship floating, a veteran of 37 voyages in 80 years, her last in 1921. The sibs watched craftsmen at work, saw maritime art and a plethora of boats and ships. The younger crew of sibs headed to the zoo, only a few miles from the hotel. The heat was oppressive but a water park at the zoo cooled our crew.

Meanwhile, the adults finished a hearty breakfast and remained at their tables to hear the keynote speaker, Elissa Al-Chokhachy, a hospice nurse and author of five books. The energy of the previous night’s speaker was replaced by a therapeutic calm, as she spoke of the connections our loved ones make after their passing. She spoke of her experiences as a nurse to ill children, a witness to their passing and a messenger to help their parents find peace. Her first child patient to die in her presence became her muse and teacher, and her book about him, *The Angel With the Golden Glow*, has helped parents understand and reframe their own trials and disappointments for nearly twenty years. She spoke Friday morning of the messages left, “coincidences” or angel moments that capture our imaginations and hearts, and lessons of hope crafted by those who leave us much too soon. She spoke of families facing the challenges and uncertainties of medically fragile children and parents and siblings who need reassurance that their loved one is at peace and remains connected to them in a way beyond our earthly understanding. She gave examples from her own experiences and those shared with her as she collected evidence that life goes on, love remains in miraculous ways and ties bind us forever.

Nine workshops followed. Parents learned how a physician, Janine Winters, takes cues from children whose illness or syndrome suggests no positive blueprint, opening the way to possibilities based on what is carefully observed. Colleen Shannon, grief counselor and program director of the Children’s Room, the largest nonprofit organization in Massachusetts solely dedicated to supporting grieving children, teens and families, worked with a large group, who shared their stories and told why they were there and how they were coping with their grief. They each sat in a chair with a strip of fabric draped on it. One participant shared, “We each wrote the name of the person we lost on the back of each strip of fabric, and then we tied and linked all of our special ones to make one long piece of fabric linked together. I guess somehow all of our children have managed to link...” (Continued on page 6)
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together all of their families no matter
what culture or part of the world we
come from. Our kids tie us and link us
just like chromosomes link us all to
each other." Colleen shared that her
sister who had trisomy 20 and died as a
young child influenced her life. She now
provides services to families that were
not available to her as a grieving child.
A smaller group gathered with Cindy
Cook and other conference veterans to
learn how to put on a conference. Still
others joined professor and researcher
Debbie Bruns and her assistant Emily
Campbell who presented their latest
research findings on long term surviv-
ors of trisomy 18 and 13.
After a delicious luncheon and the
Chapter Chair meeting there were a
few more workshops. Dr. John Carey
had generously spent the morning giv-
ing Grand Rounds to physicians, not
only at Hasbro Children’s, but from the
other hospitals at the Rhode Island
medical campus and from satellite loca-
tions across the state. He then met with
smaller groups at Hasbro in the late
morning. We are certain John conveyed
his experience borne message that the
rarer trisomies are not necessarily le-
thal, well considered medical care is
important, evidence of successful pro-
dcedures is documented and survivors
with trisomy 18, 13 and the even rarer
trisomies bring joy to their families, out-
weighing any assumed burden. John
returned to the hotel and gave his an-
nual, greatly appreciated presentation
on the genetics and medical care of
trisomy 18 and 13 for families. Paula
Rizzo is the Recreation and Integration
Coordinator at the LABBB Collabora-
tive, a 40 year old internationally recog-
nized program, which is now housed in
five communities and serves 350 stu-
dents ages 3-22 from 60 cities and
towns. She spoke of the importance of
recreational activities for those with se-
vere special needs. The opportunity for
exercise, social interaction and being
part of a team provides enrichment and
supports development in crucial ways.
After school bowling, swimming, walk-
ing, weekly dances for teens, and
field trips to see Christmas lights, play
at Dave and Busters, and even spend
a week at Disney World, are enjoyable
adventures that build so-
cial skills and motivate. Through
Special Olympics motor skills are
built and showcased. Through Best
Buddies activities based integration
occurs between those with disabili-
ties and mainstreamed students,
changing perceptions, opening op-
portunities and creating friendships.
An education workshop on empow-
ering parents was designed to help
them better communicate their
child’s potential to the IEP team.
Conference favorites, the Moms
Only and Dads Only groups were
important forums for sharing wis-
dom, frustrations, tears and laughter.
Friday night it was off to Newport,
where after crossing two bridges
families enjoyed seafood, shops,
galleries, a harbor view, a sunset,
cool breezes and a peek through the
cast iron fences of the summer
“cottages” (make that palaces) of the
Gilded Age. One bus driver gave his
passengers a tour of Newport’s
beaches and grand homes that was
greatly appreciated. Some made a
return trip to Newport to tour man-
sions, travel the Cliff Walk, visit the
Tennis Hall of Fame, check out boat
building, and shop some more.
Saturday brought another filling
breakfast, a time for grieving families
to share, then Kris’ video, which was
spectacular and brought more
laughs than tears. Chris Werner
Donahue and Scott and Sheryl Cro-
sier were elected to the Board and
the Barnes and Healeys cycled off.
The picnic was next and despite
the heat that had settled into usually
temperate Rhode Island for more
than a week, there was some ocean
breeze through the many open
doors of the carousel, and the set-
ting was shaded. Locals, trans-
planted New Englanders, and those
who were willing to try what the na-
tives favor, enjoyed hot clam chow-
der, despite the heat. Salads, bur-
gers and ‘dogs, beans, corn, water-
melon and cake with the conference
logo filled us. We beat the heat with
lemonade, soda, seltzer and water.
Some swam or walked the beach. We
walked to an open field for the annual
Ryan Cantrell Balloon Release, stood
in the shade, listened to music, gath-
ered our balloons, and walked onto
the field and watched our balloons skirt
trees and ride the wind southeast
across the bay and out of sight.
Saturday night we gathered for the
auction and were duly impressed by
the talent among us and the support
from nurses, grandparents, aunts and
friends who also donated original
items. Contributions included hand-
made jewelry, decorated glass blocks,
large bibs, hand knit blankets, throws,
scarves, and socks, and many quilts,
including a sib quilt with sib shirts and
conference logos, pieced and quilted
by young Gabriella Papillion in memory
of her sister Della. Tricia Holladay ar-
rived from Washington DC with a quilt
she had made in memory of her sister
Kari. There were decorated concrete
blocks, and art work, as well as, a
Gryffindor scarf, baskets, books, deco-
orative items and food. Craig and Marie
spent the cold Canadian winter making
Carey Ann’s Treasure Chest and its
secret contents, but sadly, UPS failed
in its mission to deliver the goods, and
the box was smashed and the contents
greatly damaged. We share their dis-
appointment and appreciate their an-
nual efforts.
Sunday there was to be a time of
reflection and sharing after breakfast,
but the happy chatter at the tables and
intensity of engagement suggested
spontaneous sharing was enough. We
later spilled into the lobby and said our
goodbyes, gave hugs, held kids one
more time, and promised to stay in
touch and return to Virginia in a year.
Late Sunday morning, Steve
Cantrell came into the hotel lobby with
a red balloon he had picked up in the
parking lot. We knew it was one of
ours, with the signature thin string the
color of the balloon. I had kept a red
scallop shell on my desk, then my sew-
ing machine; only one of the hundreds
I found was red. During the conference
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Advocating for your child at school
Striving for educational opportunities

assumptions. Consider what abilities and understanding might be hidden by what a child cannot do. A child with radial aplasia has limited use of his or her hands, so exploration is curtailed. A child with limited sight has fewer chances to observe and satisfy or develop curiosity. Opportunities include what you have learned other districts (anywhere) are providing that sounds good. This could include integration time, recreational opportunities, therapies, motor training built into daily activities, less time in wheel chairs, daily written logs by well-trained observers, communication boards, or ipads and apps. This translates to more quality time, more learning, more assumptions that learning is possible. Challenges are what is getting in the way. These can include the absence of a suitable program in the district, no inclusion opportunities, limited therapies, a tendency in the program to teach to children who are or are perceived to be more capable, a passive approach to teaching, limited opportunities to explore, test limits, or engage in mastery tasks, and a mind set by some that learning may not be possible.

The next exercise is to make a two column page and list how you see your child and how others seem to see her or him. Keep these parallel and give specific examples to refute the assumptions of others. With this done before meetings, the parent has a chance of changing perceptions. This helps if you take the time to list your observations of behavior that reveals some intelligence. Think of provocative behavior, testing limits, deception, defiance: all of this supports important psychological growth, a growing sense of self and agency. I was given the example of a child with full trisomy 18, who would hear the voice of the dreaded physical therapist and feign sleep, until she heard the door close. Other psychological growth is seen in mastery motivation, that is, sticking with a task. Does your child give evidence of boredom? When? what is the reaction? Boredom means your child expects and deserves adequate stimulation, and knows the difference between engagement and being ignored. What evidence of memory has your child given? Does she recognize and react emotionally to people she has not seen in a long while? Does he recognize music, a toy that has been put away, food? Keep track of instances, because you might forget them.

Next, it is important to give examples of what has worked for your child at home, in the community and in school. Be armed with specifics, and know what those behaviors say about learning, intelligence and psychological growth. What your child has done lays the ground work for possibilities.

Know that each parent is an important member of the child’s evaluation team. You will be asked about your vision for your child. Think about this before the meeting, write down what is important and insist that what is important to you be included. Look credible. Keep a fat binder of everything that has been written about your child. If someone takes notes at the meeting, you have the right to ask for a copy of the notes. You have a right to copies of anything brought to your child’s meeting. It does not hurt to dress nicely, arrive on time and greet others with a smile. I still remember the woman who came to an early morning meeting wearing bedroom slippers (blue rabbits) and another who made eight people wait 20 minutes, while she stopped at Starbucks. Be a credible, responsible member of the team, but know your rights and insist on what your child deserves. You know your child best. It is easier to be effectively assertive, when you have acknowledged what has been positive and approached and treated others respectfully. It is essential that you come across as credible, not crazed.

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PROFESSIONAL VIEWPOINT: Journal Club

By: John C. Carey, MD, MPH, Medical Advisor, SOFT


This interesting paper is the latest piece included in the relatively new section in the journal Pediatrics under the heading of "Ethics Rounds." Two years ago I reviewed another contribution to "Ethics Rounds" in Pediatrics (in fact the inaugural paper in this new series instituted by the journal). In this recent paper, the authors present the case study of a fetus diagnosed with trisomy 18 and a complex congenital heart malformation consisting of a double outlet right ventricle. This particular heart defect is a serious and complicated one regardless of any overall syndrome diagnosis. The parents in this case "requested any maternal of neonatal interventions be performed that could extend their daughter's life." The parents specifically requested that the trisomy 18 diagnosis not be included in the decision making about their daughter. Of note, the parents in this case study are co-authors on the paper. The story evolved in a notable way, as some of the clinicians did not feel that they were able to participate in the maternal or neonatal interventions because they felt that the burdens of these interventions outweighed their benefits. Because of this conflict, an ethics consultation was requested for "additional guidance."

The paper proceeds with discussing the response of the fetal medicine team and the comments of the parents. The paper then summarizes the conclusions of the ethics committee, and Dr. John Lantos, a pediatrician and medical ethicist comments to close the piece. Some of the members of the perinatal team felt that life-sustaining intervention "would only prolong the dying process." These members of the team recommended "palliative care only." The parents believed that surgery was in their daughter's best interest. Some of the doctors on the team advocated that since there was some chance of survival that surgery was "consistent with the parents' values." As mentioned, the ethics committee of the hospital was convened. They interpreted the conflict as one between "a desire to respect the parents' wishes and the individual clinician to act on his or her conscience." One of the issues that emerged from the discussion of the ethics committee was whether or not it was appropriate to transfer care to another facility. The ethics committee and team agreed that it would have been difficult to transfer care because of the discussion that already had occurred. Of note, the paper points out that there is a complexity here in balancing the "clinician's right to refrain from patient care that he or she finds mildly objectionable with the burden posed by the patient having to seek care elsewhere." The committee and team resolved this issue by agreeing to care for the patient at their institution but also to schedule "nonobjecting" staff to be scheduled to accommodate the parents' care plan.

At term and before delivery, the baby died in utero. The family then chose to return home for delivery by their own obstetrician.

This case raised a number of issues, many of which were already discussed in the Ethics Rounds of 2011. These issues include accurate data regarding outcome quality of life, parent autonomy, and the potential suffering of the child. Two issues struck me as being more unique in this case, however: The fact that there was an open discussion of possibly transferring care (and the ethics committee and team decided against this) and the issue of some clinicians finding it themselves against their conscience to be involved in the care. Dr. Lantos's closing comment -- I would suggest -- goes to the essence of the issue and summarizes my own view (and one stated by others in recent years regarding this conflict): "Given the data, decisions about...to pursue life-sustaining treatment or to choose palliative care after birth for infants with trisomy 13 or 18 should clearly be made by fully informed parents." There are a number of key concepts in Dr. Lantos's comments: "The data," "fully informed parents."

I applaud Pediatrics, the most prestigious and high impact journal in the field, continuing to facilitate the dialog with publications in the "Ethics Rounds." I look forward to continued discussion of the topic, especially around decision making regarding heart surgery.
May you live all the days of your life.-Jonathan Swift

SOFT Goes to Carnegie Hall by Steve Cantrell

How do you get to Carnegie Hall?

I really hadn’t paid much attention to that question until recently. Violinist Jascha Heifitz was asked by a man on a New York street, “How do you get to Carnegie Hall?” Heifitz replies, without breaking stride, “Practice, Practice, Practice!”

After our son Ryan passed Peggy and I were physically drained and so emotionally depressed that life had no meaning. We had exhausted every option, fought every battle and done everything possible but we still felt defeated and empty. Peggy’s gift of music fell silent and she thought her career was over.

A few weeks later we heard about the first SOFT conference in Salt Lake City. Our initial thought was “what good could it possibly do, Ryan is gone”? I guess God had other plans and on blind faith we decided to go. Checked into the hotel and wandered down to the ballroom still wondering why we were there. It literally still felt like we were in a daze. To our surprise we were met by Kari Holiday smiling ear to ear completely alone in her wheelchair all by herself. Stepped inside the room and there was Kris and Debbie Stutz with hugs and warm greetings. I’ve shared my first impression of what I saw in the room a million times and it’s still true today: “Everyone here looks normal”! At that very moment the fog lifted and the weight of the world was gone. Families shared stories and life long friendships were born.

We spent a few days after the conference to soak in what had happened and the day we left discovered Peggy was pregnant with Lauren. Amazing! Almost immediately back home Peggy’s niece called and wanted her to sing for her wedding. We heard Sinatra in our ear: “Pick yourself up, dust yourself off and start all over again”. This led to new connections, coaches and performances that re launched her career. SOFT was almost completely responsible for reanimating our souls and giving us permission to hope again.

Recently, Lauren had been encouraging Peggy to audition for the St. Louis Symphony Chorus and she did. While in Providence we had another SOFT moment. An email arrived welcoming Peggy to the Symphony and to start packing her bags for Carnegie Hall. We shared this with our New York SOFT friends Chris Donahue and the Bona Cohen’s who said: “We’re Coming”. Chris is in charge of the party so who knows what will happen.

**So How Do You Get to Carnegie Hall? Practice, Practice, Practice**. and have SOFT friends on your side!

Mark your calendars, **VIP SOFT FRIENDS ONLY November 22, St. Louis Symphony Orchestra Carnegie Hall 7PM New York City.**

Lauren and Peggy
SibSpeak

My Brother Jacob

By Chris Swanson

My brother is not able to walk or talk. There is no formal way to communicate with him but he has taught me so much. My brother Jacob was born severely disabled with cognitive, physical, respiratory, and neurological problems. Doctors didn’t expect him to live past the age of two and said he would never feel happiness, only pain. My brother was undiagnosed back then and his disability is still a mystery today. It has been a long road but growing up with Jacob has taught me many important lifelong lessons. Jacob is fourteen years old now and is happy with a simple touch or kiss. It is astonishing how Jacob brings the best out in me.

Jacob has significantly influenced my life. Jacob has made me a much stronger person. My coaches believe being mentally tough is a trait necessary to win a game, well I believe it is needed for much more than that. Mental toughness doesn’t come easy. Living my life for years where at any second my only brother could be hospitalized sending my family into a crisis, has made me mentally strong. Being mentally tough I rarely get mad or upset about anything. Every problem I could get mad or upset about seemed small compared to what my brother and family had to deal with on a daily basis. I became very mature at a young age. My family needed me to be. I stayed out of trouble and became independent so we could focus on bigger things like Jacob’s life. As I became older I became an extra parental figure, as you could imagine handling Jacob was a handful for my parents. I needed to fill the role of watching him or my sisters when the situation demanded. I worked extra hard in sports and school because I couldn’t fail, I couldn’t let my family down, not when Jacob was struggling to get by. I had to be strong and I had to succeed, for him. I believe this is where I learned to be so flexible, organized and reliable.

I have grown accustomed to hospitals, nurses and medical equipment because I have been around them so much. Jacob has had nurses for as long as I can remember. I have gotten to know them and have watched them take care of him. I couldn’t help not to ask questions and be drawn to why they were doing what they were doing. He takes daily medications and formula through his G-tube. Being around this my whole life and taking care of Jacob, I have learned to use most of his equipment. This has brought my attention to the medical field and the field of biology. There is no doubt that growing up with Jacob is a big reason why I am so interested in how the body works and how to help it.

Through Jacob, I have met wonderful people and have had great experiences through Jacob’s school, Mary Cariola. This year I brought my football team to Mary Cariola’s walk. I have walked and raised money for the last few years and this year we did it as a team. It was an amiable experience to watch my team give their support to my family and other kids like Jacob. There is something pure about these kids, how you can connect with them without necessarily having a conversation. Being around these people has made me set high expectations for myself and fulfill all my capabilities because others may not have any capabilities. I play three sports and I am captain in two of them, I do great in school, and I help out at home, whenever I can. Basically, I don’t take life for granted and that is the greatest thing that Jacob has taught me.

Life can be funny, Jacob and I have never talked or fought or shared the last piece of cake like other brothers do but Jacob and I have a special bond that is superior. I will carry these lessons and values that I have acquired from Jacob and apply them into every aspect of my life.

*This was one of Chris Swanson’s college application essays.* Jacob is 17 now and truly adores his big brother and three younger sisters. Chris will be entering his junior year at Syracuse University, majoring in pre-med and playing defense on the SU men’s lacrosse team.

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

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It’s not what you look at that matters, it’s what you see. –Henry David Thoreau

**SibSpeak**

**My Brother Jacob**

By McKenzie Harris

My name is McKenzie Harris and my brother Jacob is a SOFT kid. I was excited to be able to go with Jake to his conference this year and spend some quality time with him. Going to the conference this year really showed me how special and valuable life is. If I was ever thinking that life was rough, I would look at those kids and see how happy they were and I would just smile. It was really cool to be around people who didn’t stare, didn’t laugh and didn’t point or look scared. When we take Jake places it makes me so angry when that happens. Being in that SOFT atmosphere made me never want to leave. I loved hanging with the kids and my brother. Older brothers (Jake is 17 and I am 14) don’t want their little sister around, but Jake never seems to mind. He’s a pretty awesome big brother!!

Jake had back surgery in September and watching his strength and courage going through all that he did really touched me. Seeing all of the SOFT kids and knowing how much they have been through and how they still face each day with a smile is really inspiring. So, the most special part of the conference, for me anyways, was seeing how happy all of the kids were. You would think that they would be down or upset; wishing to be normal, but that’s their way of life, that’s what they know and they are happy. This conference really showed me the value in life and how being different is really special. All of those angels at the conference are very special to everyone and each kid had his or her own impact on me.

See page 20 for Mom, Nancy Swanson’s story)
When Barb asked me to write a little something about SOFT and what it meant to me, a million things ran through my mind… the first being panic!! There is a reason I am an art teacher and not an English teacher. However, Barb has done so much for so many people, especially my family, that despite my fear, I knew I could never say no. So please excuse my awkwardness, but know that this comes from the heart….

Years ago when Barb asked us if we (my kids and I) were interested in attending this conference for kids with Trisomy 18 and 13, I didn’t quite know what to say. My son Jacob was undiagnosed; he did not have Trisomy 18 or 13 so I didn’t think we would fit in. She continued to tell me that it included “related disorders” and since we had no idea what his “disorder” was, related or otherwise; we would fit in; so we gave it a try. Barb was right! We have LOVED attending the conferences and being part of SOFT for many years. Unfortunately, due to Jacob being on oxygen for 15 years and being unable to fly we missed a few conferences. Then, my daughter ended up being an awesome lacrosse player so we started to travel to play lacrosse in the summer; we ended up missing conferences due to that as well. This year, thankfully, she broke her ankle and because of that we were able to attend this year’s conference in Rhode Island. There is always a silver lining, and in this case there was a silver lining AND a rainbow!! We were so excited to be going to the conference. McKenzie (my daughter), Jacob and I loaded up the van (well Jake kind of just sat there…he can be such a slacker at times) and headed out on our adventure. This is the first year we were able to travel to the conference in Jacob’s new wheelchair van. Thankfully Jacob was okay with us taking it…he can be rather bossy when it comes to his van!

McKenzie really didn’t know what to expect, she only remembered bits and pieces of past conferences as she was pretty young when we were able to attend. On our ride we talked about SOFT and what it stood for and how this weekend was for Jacob and for us to reconnect with him. Jake has watched about a million lacrosse games and has been taken here or there to support his brother and sisters (his dad has two sisters at his house as well, so Jake has 1 older brother and 3 younger sisters!!)

This weekend was for Jake. We snapped our “selfie” and away we went.

We were very late registering for the conference because we didn’t think we could go. Therefore we missed the cut off time for the clinics. However, SOFT people hate to disappoint, so they got us in to see one doctor…we thought. However, when we got to the Hasbro Children’s Hospital we were greeted with open arms, a Mr. Potato Head, Play-doh and several doctors. It was wonderful. The genetics team was rather intrigued by Jake and they gave us the names of some new genetic tests that we should try. Dr. Carey stopped in and reaffirmed that these tests were in fact new and a great idea to try. We ALWAYS and I mean ALWAYS get some type of information that is life changing for Jacob and our family at these conferences. I can’t say enough wonderful things about our clinic experience and I can’t thank SOFT (especially Pam, Barb, Faye and Jerry) for helping us to get there.

The dinner was next and was just one magical thing after another. Seeing all of our kids dressed up and dancing and smiling and truly enjoying themselves was priceless. Knowing that if Jake started blowing raspberries or singing loudly no one would give us dirty looks was beyond priceless. I don’t know how many times I am just sweating by the end of an event, from nerves, trying to keep Jake quiet. The annoyed looks and glares never seem to cease, except around our SOFT family! Carol, the author and keynote speaker that evening, was amazing. She stayed and danced with us, and the book that she wrote and gave to all of the kids was awesome, along with the wonderful certificate. The words on that certificate are so beautiful. We saw old friends that we hadn’t seen in many years and met some really wonderful new friends. We re-connected with the importance of our kids and the impact they really have on every life that they touch. We laughed, we cried and Jake did some pretty great boogying as well.

The workshops were wonderful, the author and speaker about “our angels” was wonderful. Kris’s video was beyond wonderful…who knew that once you become a grandmother you also gain amazing technical skills. I was blown away by all of the detail that she had in this year’s video; it was fabulous. The picnic was very nice also. We saw old friends that we hadn’t seen in many years and met some really wonderful new friends. We re-connected with the importance of our kids and the impact they really have on every life that they touch. We laughed, we cried and Jake did some pretty great boogying as well.

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A man should learn to detect & watch that gleam of light which flashes across his mind from within.-Emerson

To Me . . . By Nancy Swanson

(Continued from page 12)

such an auctioneer, he did such a great job. However, when it was all said and done the best part of the conference is always being around and listening to the other kids “singing” or “raspberrying” or blurt out words or noises and realizing that we are not alone. It’s connecting with friends who really understand what you are going through but don’t pity you, they empower you. It’s watching our kids being treated like any other kid. SOFT people truly value each other’s children for who they are. Everyone talks to everyone. No child is ignored due to the fact that they may not be able to answer back. Everyone understands that a touch or a smile speaks louder than words do on some occasions. We all understand that because our kids may not always make eye contact, or look like they are engaged, including them in the conversation is even more important. SOFT enables us to include our kids in everything we want them to be included in and no one judges or makes negative comments about them being there. SOFT also gives us the option to take a break if we need to and has people there to help us if we would like to do that. Everyone has a story and words of wisdom, or a trick or tip that works for them that can help make life easier. I love seeing what wheelchairs are used, what feeding pumps are being used, what tricks are used for diapers that just don’t hold what they should. I don’t know about you, but in my day to day life and work, no one really has to deal with those issues. It’s pretty cool to be “normal” somewhere. I love that we can laugh about the crazy things we go through, together. The “mother’s only” workshop was just hysterical (Cindy, you did an amazing job running that mob of women). I think we all could have stayed there for many more hours. The nods of “oh yeah, that has happened to me” and the laughter along with the kids singing was just awesome. Listening to the pride and strength and wisdom of other mothers was truly empowering. If I am being honest, I sometimes find myself feeling a little sorry for myself and that workshop really snapped me back to where I needed to be. There are a few quotes that I found that describe some of the feelings I came away with this year; especially from the “mother’s only” workshop…

“Courage and strength is not the absence of fear - it’s refusing to assume the role of a victim”- Anne Wafula Strike

“The longer I live, the more convinced I become that life is 10 percent what happens to us and 90 percent how we respond to it.”- Charles Swindall

If you ever need a little “lift of spirits” or a “reality check on what’s important” or you just want to be surrounded by amazing people who will empower and inspire you, a SOFT conference is where you need to be. In all of our crazy, busy lives, it makes us stop; realize what is really important and re-energizes us to carry on.

“Sometimes it’s important to work for that pot of gold. But other times it’s essential to take time off and to make sure that your most important decision in the day simply consists of choosing which color to slide down on the rainbow.”

Sibling outing at Mystic

August/September/October 2013, The SOFT Times, Page 13
Never to suffer would never to have been blessed—Edgar Allen Poe

New SOFT Artwork

Every year the Trisomy children make some type of artwork that will be used for the Bereavement cards. This year, the Trisomy children, along with the siblings, made a rainbow of fingerprints and toe-prints! The art will be made into cards that will be sent to all SOFT families who have an Angel Day for their child.

Submitted by Cindy Cook

Happy 13th Birthday Lindsay

Lyndsay enjoyed her 13th birthday with a party at her Nana’s house with friends and family in Suffolk, VA. We celebrated her birthday just prior to leaving for the SOFT Conference in Rhode Island.

It is amazing to us that Lyndsay is 13 years old, a ‘teenager’. When she was born she weighed only 4 lbs, 3 ozs and was in heart failure from a large VSD heart defect. If it had not been for her heart surgery when she was 2 weeks old, she would not be with us today. Now she is in middle school, weighing 63 pounds, walking in a gait trainer and eating her food by mouth. We feel blessed to have Lyndsay in our lives everyday and know that she has touched so many people in her short years.

Lynne Stockman
Mom to Lyndsay-full Trisomy 18
Suffolk, VA

THIRTEEN & COUNTING
Friendship is born at that moment when one person says to another: "What! You, too? Thought I was the only one" - C.S. Lewis
The way I see it is if you want the rainbow, you gotta put up with the rain. - Dolly Parton
The only true wisdom is in knowing you know nothing. –Socrates
All big things are made up of trifles. My entire life has been built on trifles.-Mahatma Gandhi
Rejoice with your family in the beautiful land of life! - Albert Einstein
One should pay attention to even the smallest crawling creature for these too may have a valuable lesson to teach us. Black Elk
Winners never quit and quitters never win. –Vince Lombardi
Love is not consolation. It is light. - Friedrich Nietzsche

SOFT SMILES

Through the pitch-black night, the captain sees a light dead ahead on a collision course with his ship. He sends a signal; "Change your course ten degrees east."
The light signals back; "Change yours, ten degrees west."
Angry, the captain sends; "I'm a Navy captain! Change your course, sir!"
"I'm a seaman, second class," comes the reply. "Change your course, sir."
Now the captain is furious. "I'm a battleship! I'm not changing course!"
There is one last reply. "I'm a lighthouse. Your call."
Brokenness Transformed: SOFT Angels 2013

This year’s angels given at the Ryan Cantrell Memorial Balloon Release Ceremony consist of pint preserve jars holding a lighthouse fabric cushion topped by lots of beach glass. Turning the jar over reveals a lighthouse from one of eighteen states, all represented by conference goers (if we count the filmmaker from Oregon), except Georgia, but since the lighthouse is of St. Simon’s Island where the Crosiers vacation, that counts. The lid was covered with blue fabric stamped with a scallop shell, representing that we had come from many destinations to be together. On the outside, covering the front of the jar was a lacy felt angel in either white or yellow. They signify we heal in time, find light to guide us and come together to celebrate. I define sea glass as being in process, still on the journey, not yet smooth enough, not yet done, and beach glass as well worn, polished pieces that have come ashore to be put in someone’s pocket and brought home as a symbol of the grief journey, brokenness transformed, light held within what was once clear glass.

Angels of Light

Angels, more space than felt, sweet spirits of flight; Angels glow gold or white, warm colors of light. Flashing signals warn, coastal beacons of night; Jars for summer’s bounty hold contents tight.

Beach glass bearing light and promise fills the jar. Breaking starts the journey, then tide tumbled far. Sea glass, nicked and shiny, stays in motion, Softened by grit in the turbulence of ocean. Beach glass, smoothed and rounded is carried home, Treasures found in sand by those who beach comb. Seaweed nestled, shell paired, wedged by rock, Surf wet treasured findings on a low tide walk. Search the tangled wrack line, catch what waves toss, Move flotsam and jetsam, find glass without gloss. Beach glass concludes a decades’ long migration; Soft finish binds light, affirms brokenness’ negation. The covenant of beach glass is time will ease strain The journey brings changes, transformed from pain.

Deep green harkens spring’s promise and hope, Emerald lessons in light that may help to cope. White abounds, holds the paradox of warm frost, A tangible sign what matters can’t be lost. A common thin shard of chestnut still brings Scriptural pledge to be raised by eagle wings. Turquoise is old, conjures thirst of hot August days, Thick, sometimes fluted, now stripped of its glaze. Lavender started as clear glass but was kissed By summer’s warm rays and autumn’s cool mist. Dense black is the oldest, rocklike and dark, Hold to strong light and release summer’s spark. Cobalt, maize, ruby, pink, rare but look around; Years of searching, still orange won’t be found.

Storm glass, refuse, trash to treasure, brings delight, Rounded jewels, mermaid tears, carry beauty and light, Time and tide scrape, abrade and make things right. All carry a glow, shore treasures to ease grief’s night.

Pam Healey
Mom to Conor, T-18, who for 27 years has left green beach glass in her path, at least one piece on every beach trip.
DO YOU HAVE GRANT WRITING EXPERIENCE? SOFT COULD USE YOUR HELP!

It's so curious: one can resist tears and 'behave' very well in the hardest hours of grief. But then someone makes you a friendly sign behind a window, or one notices that a flower that was in bud only yesterday has suddenly blossomed, or a letter slips from a drawer... and everything collapses."

~Colette
Don't forget to renew your SOFT membership!

Make Your Own Therapeutic Grief Relief Bags to Share

By Pam Healey

Since practical (fiscal) considerations and SOFT policy required the first annual conference outing for parents without their children to include a charge for the bus, there needed to be more than transportation and a supportive inner and outer tour provided. A few years ago I made a de-stress kit for special education teachers at a time of particular stress and low morale. This could be adapted. While cleaning my room, I came across a bag of fabric I bought when a favorite fabric store closed. I had forgotten about the pale crackled beige fabric with blue and maroon butterflies I put away until a worthy project. This was certainly the worthy project I had imagined. I cut out sixteen bags, lined them in blue fabric from the banquet center-piece mats or from the Sammy awards, then attached a bright button and added a sunny yellow chain stitched loop.

What went in the bags was determined by imagination and what I found in my desk drawer, at Staples and at Rite Aid on senior citizen day. I added a paperclip for when nothing comes together and an eraser to get rid of negative comments that were at best stupid and more often thoughtless, and never helpful. I sprinkled in buttons, because too often you know you have lost a few. I bought tiny clear containers and filled them with rosemary for remembrance and added confetti angels, balloons, butterflies and stars: all SOFT symbols for a child missed. The container was held snug by an elastic (rubber band) for when you are ready to stretch beyond the comfort zone. I added gifts from the sea: a piece of lace wampum, which is a shred of thick quahog shell, punctuated by tiny holes and tracings left by a soft sponge attaching itself and smoothed by the sea: transformation. A piece of green beach glass speaks of spring’s hope and that brokenness can be transformed by storm, tide and time. White beach glass holds winter’s frost and summer’s light. Similarly, a piece of rare black beach glass symbolizes being softened by strong forces, and since it looks like a rock, but held to light glows, it announces that things are not always what they seem. A wavy candle will light the way on what will not be a direct journey. There are two quarters: one with an eagle as reminder of scriptural promise to be raised by strong eagle’s wings and the other a state quarter because whatever state you are in, it will change. Each bag included a pen in a rainbow hue, because each of our children were rainbow children, however briefly, and together create a full rainbow. I bought tiny composition books and glued pictures and suggestions for therapeutic activities. I added an owl from old bookplates, for wisdom, which seems beyond grasp in the grip of grief, then a sticky of eyeglasses, because loss mean you forever will see the world differently. A smiley face and a heart would bring positive thoughts and the reminder that love remains. Inside were pictures of lighthouses by day and by night and the questions: How has your child or sibling been someone to light your way? What helps in your darkest moments? Beneath a butterfly was the question:

When our children die, we drop them into the unknown, shuddering with fear. We know that they go out from us, and we stand, and pity, and wonder. Henry Ward Beecher

The deep pain that is felt at the death of every friendly soul arises from the feeling that there is in every individual something which is inexpressible, peculiar to him alone, and is, therefore, absolutely and irretrievably lost. ~Arthur Schopenhauer

(Continued on page 26)
What are your butterfly moments? In relation to the outing: As you watched the waves rhythmically roll in over the rocks, then recede, how did you feel? Close your eyes, listen, what do you hear? smell? What colors do you remember seeing? What did you see today that lifted your spirits? What caught your eye from a distance? What caught your eye close up? What helped you sustain a quiet moment? What thoughts or feelings came to you that you might share? What would you like to share about today with your child or sibling? Other additions to a bag might include: a teabag for a quiet moment, a penny to remember “In God we trust,” a candy kiss, a knotted thread, because as Tagore realized, “The tapestry of life’s story is woven with the threads of life’s ties ever joining and breaking.”
Sadness flies on the wings of the morning and out of the heart of darkness comes the light.-Jean Giraudoux

Megan’s Story

by Ann & Frank Barnes

Megan Elizabeth Barnes
7/8/85 – 12/29/04

Our Megan was a late in life surprise and a content, sweet child who blessed our lives for nearly two decades. We were a military family with 2 teen daughters and a preteen son when she was born at the Naval Hospital at NAS, Jacksonville, FL. She was full term but not quite 5 pounds; weighing 2-3 pounds less at birth than her sibs. This little baby completed our family in so many unique ways for Megan was a teacher who gently guided our hearts. In hindsight, she had a very healthy start for a baby with trisomy 18 which was not diagnosed until she was over 2 months old. We had declined amniocentesis and the triple screen was not yet in use. Breast fed, gaining weight and becoming interactive with smiles, a skin biopsy was done at 6 months old because her geneticist suspected mosaicism. The results still showed full t18. With time, she did struggle with the health problems common to her disorder, especially frequent pneumonias. At different times, she had surgeries for esotropia, cleft lip, hip dislocation, hydrocephalus, and G-tube placement which were all successful. But spinal fusion using a CD rod, followed a year later with a revision, did not stop the progression of her scoliosis. We approached cardiology about VSD surgery in 1987 or 88 but it was never repaired. Thus, in her last 5-6 years, she needed oxygen and medications to treat heart failure, and Bi-Pap when asleep. Her last years would have been more comfortable if a successful heart repair had been done. Early intervention, special education and therapies became a routine part of her day and our life, benefitting both her and us, and home health nursing began when she was about 8 years old, which allowed mom to return to work, part time.

Caring for Megan was a hands-on-education about trisomy and much more. She gave us purpose and inspiration and was dearly loved. In the end, it was so hard to lose her. Eventually we requested her records and learned we had trusted the wrong doctor. We did not know that it was possible for a life support order to be written or changed without parental knowledge or consent. It is a heartbreaking lesson from Megan that is addressed in the “Care book” and also in the Family Support section of the website. Go to www.trisomy.org > Family support > When in the Hospital. Or open directly at http://trisomy.org/wp-content/uploads/2013/04/When-in-the-Hospital.pdf. The “Care book” was written with the mentoring of Dr Carey because there was no literature available for parents about living with these children and doctors had little, if any, knowledge about survivors. Megan, as well as the many SOFT children met at conferences and online, inspired and contributed to this work which has been kept up-to-date with revisions as new information has become known.

Now it is our angel Megan who watches over us, waiting to greet us with her big hugs and smiles. The marvel of her first deliberate hug and the feel of her last big bear hug are memories we cherish. One of the early 1985 SOFT newsletters was given to us by her geneticist and we took Megan to the first of the annual SOFT conferences just before her 2nd birthday. It was amazing to finally meet other families and the compassionate Dr. Carey. SOFT has been a part of our lives ever since. “Care of the Infant with Trisomy 18 or Trisomy 13, is often referred to as the “Care book,” and it is Megan’s legacy. It was given to SOFT to help families and can be obtained at http://trisomy.org/shop-soft/. In this same time period SOFT published separate guidebooks about each syndrome that are also available for purchase through SOFT.

Ann & Frank Barnes
Chapel Hill, NC

Ann & Frank Barnes
Chapel Hill, NC
New Conf Addition: Thursday Grief Outing

Every conference has special moments that make you smile long after that week in July is over. They can be moments with old friends; meeting new friends; the family outing; the picnic; the moms workshop; the list goes on. This year there were many things for me but one agenda item that I cannot stop talking about was the Grief Outing on Thursday. What a wonderful addition to the conference! We all give kudos to the Healeys and the entire conference committee for thinking of this wonderful outing.

Prior to this conference, Thursday has always been a difficult day. We have added The Stroll in the morning but in the afternoon, those of us with angels were offered a grief workshop or take the afternoon for ourselves. The workshop was a good option for the first 2 years after losing Jonathan, but lately that did not feel right anymore. We still went, because spending time with others was what we were craving. Lately, we used that afternoon to go out with other SOFT friends and see the sights of the hosting city. We all seem to go our separate ways.

This year, we were able to do both. We were able to stay close to our SOFT family and see some amazing parts of Rhode Island. We were treated to a treasure that we won’t soon forget. With our tour guide (Michael Healey) close by on his motorcycle; our bus took us to two places. The first was a perfect cove, shallow enough to take a small dip, collect some shells and climb some rocks. We stayed for a brief time and marveled at the beauty while watching the siblings play in the water and on the stones. It was beautiful.

The second stop was the most beautiful ocean view that many of us have ever seen. It was just where we wanted to be. We were provided with special satchels made by Pam Healey with meaningful mementos inside. We then stood, with each other, looking at God’s creation, while we held our angels close, even though just in our hearts. Whether we blew bubbles (the sibs!), wrote in journals, sat alone and pondered (get it Francine!) or talked with friends, no one wanted it to end. The interesting thing about this trip was that we never really talked much about our grief. We talked about our children, we talked about journeys, and we talked about our futures. Some may have cried, some may have laughed, and all were uplifted.

I don’t know why we have never added this to our conference agenda before? It was perfect. It was a way for the angel families to do something special, just for us, while the other families went to the clinics. We all wish we were at the clinics, it is a difficult reality to see the excitement and we are not able to take part. We always enjoy hearing about the trip to the clinics and the wonderful doctors everyone met. We just never had anything to add about the day. This year we did and I’m still smiling about it. It made the day so well rounded. With so many of us who come to the conference with a child in our hearts and not our arms, it made us feel “whole” that day. Thank you again Rhode Island Conference Committee- YOU DID GOOD!!!

Softly,

Cindy Cook
Jonathan’s Mom

Ps- Take note future conference planners!!! Please make this a keeper!!! We really need it.

If a mother is mourning not for what she has lost but for what her dead child has lost, it is a comfort to believe that the child has not lost the end for which it was created. -C.S. Lewis

There’s no tragedy in life like the death of a child. Things never get back to the way they were.-Dwight D. Eisenhower
President’s Corner by Barb VanHerreweghe

Dear SOFT Families:

Another conference is over and done. It is a time for special moments, special friends and memories that have to last till next year. The conference is such a special time for our family. We wait for it all year long and it is over in such a short time. It is already time to plan for the next year. So where will we meet? Norfolk, Virginia here comes SOFT! We will be at the Sheraton Norfolk Waterside Hotel July 10th-July 13th. The rate is $115 per night. You can call in your reservations to 1-800-627-8042 or directly to the hotel @757-622-6664. Make sure you let them know that you are with the SOFT group for the special rate. Help us out by using the room block we have reserved for our attendees. SOFT needs to sell our room block or we will have to pay for conference space which increases our conference registration rate. When you call to register make sure you ask for any extras you may need so they can plan for your stay. For those that want to plan two years in advance meet us in Salt Lake City. There will be more details to come on both conferences real soon.

In March for Trisomy Awareness month, SOFT announced that membership is now free. Hopefully, you have all sent in your registration to keep you up to date. If you need to send in a renewal you can do that online also. Remember, we will need you to continue to renew yearly so we can keep all addresses, emails and surgery information up to date.

At the board meeting this year SOFT made several decisions that you will see in the near future. We have decided that with the registrations we are receiving very few want to receive the newsletter in the mail and nearly all wanted the E-Newsletter, found in the website Newsletter Library, instead. It was decided that this issue, the conference newsletter, will be the last issue that we print. This allows us get the newsletter to you quicker and you will be able to find past newsletters in the newsletter library. If you have misplaced an issue, now you can find it. If there is anyone that is unable to get the newsletter by computer you will need to let me know and I will print and send you a copy. The newsletter will be what you all make it. We want to receive your stories about your children and family. Keep us up to date. If you see something that might help other families let us know. We encourage you to send in your stories and pictures. This is another way we can keep informed and up to date on all families during the year. We are not going to include the Board list and Chapter chair list in each newsletter each time since these are on the website. Please refer to those on the new and updated website. We are saving that extra room for your story.

Check out the website. All the books have been reduced in price. Now is the time to buy a copy for your Doctors and help them to understand more about your child. All books are now reduced to $6.00 each. What a deal! While you are on the website to buy your books keep looking around to find the many other articles, photos, family stories and conference information. Add your family story with a picture to family stories. You do not need to be asked to share your story. You can update your stories so we know what is always happening with your family.

At conference each year we have three board positions that rotate off. We would like to thank the families that have served over the last three years. The families were the Healey’s, Barnes’ and the Kubena &Kaufman family. Three families were elected to serve on the board this year. The Kubena & Kaufman family, Christine Donohue-Werner and the Crosiers were elected to fill the open three year terms. The families are expected to attend each of the next three conferences as well as serve on a committee. Thank those going off the board and welcome the new board members.

We want to work together to get pictures of Sibs, kids and their families enjoying the summer or other activities together. When you are enjoying the great summer weather or vacations remember to snap a shot and there will be more details soon from Terre on how to get your picture ready as we did for Trisomy Awareness, Mother’s Day and Father’s Day. We are going to make this a joint effort with Hope for Trisomy. We are waiting for your creative ideas to make this fun!

For those that signed the poster for Jack and Judie at conference, I wanted to let you know they really enjoyed it. They are framing it for their office wall. Keep your prayers and good thoughts coming Jack’s way as he continues to grow stronger during his kidney dialysis.

We welcome any new ideas you have for the newsletter, website or Facebook group and pages. Please help us make each of these what you want! We don’t know unless you share with us. We are looking forward to your stories in the newsletter and on the website.

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.
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 fund
Mollie Quay Wolfe
Jennifer H Donovan
Victoria Miller
SOFT friends who raised funds on
www.firstgiving.com
Papillion Family
Scott Crosier/Peabody Energy Dollars for Doers Program
JoAnne Kandel
Kristi Poulin
Laura Roush

Donations to the Joey Watson fund,
established to help families
attend the annual SOFT conference
Mollie Quay Wolfe
Jennifer H Donovan
Janice and John Hertig
Papillion Family
Scott and Vivian Showalter

In Honor of
Megan Hayes’ 33rd Birthday
Ron, Sara and Megan Hayes

In Memory of
Garrett Stephen Twardowski
Gale and Steve Twardowski

In Memory of
Erin Handel
A. Philip and Maureen M. Handel
Denise Hills
Sylvia and Owen Dobbin
Ken and Mary Beth Blaschke
Michele Bock
Mary Lawson
Claudette Flanigan
Jacqueline Morrison
Kathleen M Bradley
Rev. Albert and Charlotte Turner

In Memory of
Siddhi Shah
Ajay and Falguni Shah

In Memory of
Megan Barnes
Kathleen Davis

In Memory of
Sabastiaan Xavier Keg
Frank and Antonia Keg

In Memory of
Isabella Wolfe
Mollie Quay Wolfe

In Memory of
Emerald Ireland Donovan
Jennifer H Donovan

In Memory of
Keira Faith Salom
Amie Wojtech

In Honor of
Makenna Lee Brown
Harold Martindale,
Makenna’s Great Grandfather

In Memory of
Hailey Rayelle Saunders
Deborah Morris

In Memory of
Keira Faith Salom
Amie Wojtech

In Memory of
Hudson Carter Null
Planning and Zoning Resource Corp,
Oklahoma City, OK

THANK YOU THANK YOU THANK YOU THANK YOU THANK YOU THANK YOU THANK YOU THANK YOU
Making Conference a Reality

Island face of SOFT. Barb was involved throughout, working from a conference blueprint, meeting many deadlines and monitoring the dynamics between costs, registrations and donations.

We doled out tasks to our local committee. Andrew and Francine Winslow worked with Pam to develop a theme for the Zion Lint Parade of Stars and donated books to the evening’s speaker to all SOFT kids at the conference and to families remembering their children. With Erin’s passing the Handel’s role changed. Erin’s memorial donations supported so much of what we wanted for the conference, and her spirit inspired us.

All did not go smoothly logistically. Jack, our Jack of all SOFT trades and our registration database/printing mainstay, became ill, and monitoring and working from registrations became impossible, until Frank Barnes became involved and created and forwarded spreadsheets, so orders could be made. He remained involved daily, as late registrations, questions and requests trickled in. Judie continued to monitor the donations that came directly to Rochester. The Dye’s took charge of name tags and balloon registrations and tags before and during the conference. Debbie also worked hard with the auction inventory and bids. Gerri Meggett was in charge of name tags and balloon registrations and tags before and during the conference. Debbie also worked hard with the auction inventory and bids. Gerri Meggett was in charge of name tags and balloon registrations and tags before and during the conference. Debbie also worked hard with the auction inventory and bids.

Farrell and Nicole Parmenter for their momorial donations supported so much of the conference blueprint, meeting many educational opportunities for each child. Enough is known or assumed about what these kids, cannot do, let’s build a collective case of what they can do with optimal learning environments. Send examples and comments to Healey lex@aol.com.

Advocating Workshop

(Continued from page 7)

The task for all of us is to build a repository of observed behaviors that refute what may be the assumptions about the cognitive limitations, learning capabilities and educational needs of those with trisomy 18 and 13 particularly. Let’s create an educational blueprint to help parents present their case specifically. Send me examples of what your child can do, what your child remembers, and how your child asserts himself or herself. Send examples of mastery motivation (perseverance), learning, preferences, and curiosity/exploration. Include diagnosis and age at time of observation. I have examples from SOFT parents that participated in my doctoral study and will add yours, so we have a resource all can draw from to improve educational opportunities for each child. Enough is known or assumed about what these kids, cannot do, let’s build a collective case of what they can do with optimal learning environments. Send examples and comments to Healey lex@aol.com.
Palliative Care
2013 SOFT Conference Workshop

Presenter:
Dr Janine Winters
Physician Director of Palliative Medicine, Assistant Professor of Pediatrics
Nationwide Children’s Hospital - Ohio State University Department of Pediatrics, Columbus Ohio

Dr. Winters is a member of the Ethics committee at Nationwide. She organized and implemented an inpatient palliative care consult service and home-based hospice and palliative care program. Her presentation began with sharing how she became a palliative care physician and the influence of growing up in a family with loved ones who were seriously ill, some living longer than expected.

She pointed out that it is a myth that childhood deaths are rare and noted that 1/3 of USA children have a chronic health situation. Management of care should be based on “letting the child lead”. A child with a number of health issues might not receive the same recommendation for care as a child with only one issue. She recommends a Bio-Physio-Social approach which is Humanistic medicine. Humanistic medicine provides whole person care plus an eye for suffering. She did mention briefly that there is a “dark side of medicine” and noted there is a difference in a tragic versus evil.

Palliative Palliative care uses a team approach consisting of a social worker, chaplain, nurse, physician, massage therapist, and child life specialist. Communication is part of the job and key to preventing misunderstanding. Families are asked 1.) What can we do to help? 2.) What do you understand? 3.) Benefits versus burdens are discussed. Conversation before crisis allows anticipatory guidance and the medical system and parents can partner in the care of the child. Developmental pediatricians are recommended for those being cared for at home as these professionals see the “big picture” and can make referrals as needed.

The goal of Perinatal Palliative care for the expectant parent of a fetus with a life-limiting diagnosis is to create a birth plan. In personal communication with this physician she expressed concern about uncertain outcomes from surgical intervention that might result in suffering and extended hospital stay, as occurred with a patient familiar to her.

Submitted by Ann Barnes
The SOFT Utah Chapter is excited to welcome the 2015 annual SOFT conference to Salt Lake City once again. Our last conference was in 2007 – and things have changed in our beautiful city since then. Of course you can see our beautiful mountains every day –Purple mountains at their best. The city has changed quite a bit since 2007. THE HOTEL…..

UNIVERSITY OF UTAH GUESTHOUSE

Enjoy beautiful views from just above the city. The hotel has remodeled and added 50 new rooms and another elevator. Every room has a microwave and fridge included in your $109.00 price. Two laundry rooms are in the hotel making it convenient for our members.

City Creek Center

In the heart of Salt Lake City, City Creek Center is the retail centerpiece of one of the nation's largest mixed-use downtown redevelopment projects. This unique shopping environment features a retractable glass roof, a creek that runs through the property, a pedestrian skybridge and more. This world-class fashion and dining destination offers over 100 stores and restaurants including Nordstrom, Macy's, Tiffany & Co., Michael Kors, Coach, and Texas de Brazil Churrascaria, in a casual, pedestrian-friendly environment.

TRAX – Utah’s Light Rail – now comes to the Hotel from the Airport

We are trying to plan everything that we can on campus near the hotel so that will leave more ‘free time’ to explore and visit our beautiful city. You don’t have to rent a car-with our light rail system TRAX in place now running from the airport to the hotel. You can easily access many restaurants and our new City Creek Center by TRAX. Make a note that workshops will be on Thursday & clinics on Friday for 2015. We’re going to switch them. Make sure you come in on Wednesday so you won’t miss all the fun. The only thing we know for sure is the hotel, the date, and of course, the Clinics at Primary Children’s. We are looking forward to hosting everyone in beautiful Salt Lake City, July 8, 2015.
### Remembering SOFT Angel Wings

I thank God upon every remembrance of you. - Philippians 1:3

<table>
<thead>
<tr>
<th>NAME</th>
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<td>Isaac Steven Stumpf</td>
<td>8/12/2011</td>
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<td>Avianna Marie Terrell</td>
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<td>Rachael Kleimola</td>
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<tr>
<td>Mark Andrew Humphrey</td>
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<td>10/6/1993</td>
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Email Jack Laird for family contact info at jlaird@rochester.rr.com
Happy Birthday to you, Happy Birthday to you, Happy Birthday Dear Megan & Greta, Happy Birthday to you

On a recent Saturday afternoon, Sara and Megan Hayes and Margaret and Greta Thompson met in Ardmore, Oklahoma for lunch. Sara drives down from Oklahoma City and Margaret drives up from Richardson. We meet, hug, have lunch, feed lunch, visit and then visit some more. Since we had not been able to attend the conference, we thought we needed our SOFT Time, without the hotel lobby. Megan and Greta had just celebrated their 33rd birthdays and we wanted to celebrate with them. Happy Birthday young ladies of SOFT!

Earlier this year Craig and Marie Donaldson traveled to China. They shared their photos of a wonderful trip. Craig even modeled his special order clothing from the trip at the SOFT conference.

Happy 33rd Birthday
Megan and Greta

On Margaret's 70th birthday, Greta and her friends tp'd her car just to be festive! What are friends for, if not this!
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.

Sheraton Norfolk Waterside