SOFT dedicates this issue to the City of Boston, the victims of the tragedy, the runners, first responders, spectators, citizens and all those affected. We extend our prayers for healing during this difficult time.

Remembering Boston
By Pam Healey

The Boston Marathon is personal. Patriots Day is personal. I awaken every third Monday in April to the sound of muskets on the nearby battle green. I awaken and remember blood was spilled in 1775. Ordinary people began what gave us our freedom. This Patriots Day blood was spilled again by ordinary people. Again, we stand united.

Those who are not runners may not understand the motivation to run 26.2 miles through eight towns on an often too warm April day, Patriots Day. They do not understand the 50-80 mile weeks that constitute training, for months, in all kinds of weather. Although Boston was once a goal, I remained a middle distance runner and never a competitor. Michael ran Boston. My Texan nephew ran Boston. Many of my friends and colleagues ran Boston, some very well. At my first school, where I did my practicum, from our classrooms we cheered a teacher, “Johnny Kelly the younger,” who won ten years earlier, and his protege, a recent graduate, Amby Burfoot, who would win the next year. Boston is tradition: 117 years of it. It is our party on our state holiday!

At the Boston conference in 2001 a mini Boston marathon course was set up in an empty parking lot and families walked the course pushing wheelchairs, and earned ribbons. Landmarks on the real course mirrored the experiences of SOFT parents and were checkpoints on the mini course. Bill Rogers, who won Boston four times, was one of our sponsors and donated signed gloves and a hat, worn with an olive wreath by those SOFT kids who walked or wheeled themselves the 26.2 foot course on the track. The Bill Rogers memorabilia was won at the auction by Naomi Fast’s dad who had left Canada to run Boston.

I ran as many as a dozen races a year, including Heartbreak Hill, before I had known my own heartbreak. I ran the hills of Falmouth, down into the sea every August. Each time I ran I just tried to beat my personal best. That is what we all do every day as we manage challenges and make each day better than the last. We at SOFT are all running a long course, for all of us, an unexpected course. I began running five years before Conor was born and ran for twenty more years and still walk distance. I began walking within days of Conor’s death, running a few weeks later. I ran my way through grief. Each day I tried to find my personal best within myself. I trained and ran Falmouth for ten more years, carrying my child with me in (Continued on page 7)
Dear SOFT Family and Friends:

The VanHerreweghe family made it through our cruise and back home safely. Stacy enjoyed the warm weather and the beautiful palm trees. She enjoyed the fresh air and warm ocean breezes. Every night they brought her mashed potatoes at dinner and lunch with a little gravy. She ate them to the very last bite. Stacy discovered a new dessert on the boat that just happened to be in her white food group. Pancetta! She loved it. She became best friends with the restaurant manager who checked on and looked for her at every meal. He learned quickly that Stacy only ate soft pudding like foods. When they started serving dessert after the second night the head chef made sure she had a fruit mousse specially decorated and made just for her. The last night the restaurant manager came down with the pancetta for her. What a way to end her cruise. We enjoyed the beautiful port stops of St. Croix, St. Maartens, Antigua, St. Lucia and the Barbados. Stacy enjoyed the shopping on the islands. She especially liked taking the water taxi on St. Maarten. The guys just lifted her up and onto the boat. No care in the world. We enjoyed several shows while on the boat. Stacy watched and laughed as the cruise ship dancers performed right in front of her. Then we flew back to rainy cold Rochester. I don’t think this winter will ever be over.

Now we are on to next vacation time. The SOFT conference in

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President’s Corner

Rhode Island is our summer vacation. We are just a few months away. In three months we will all gather to learn, have consults with medical professionals and share with each other. Stories of those children we still hold in our arms and those we hold in hearts. Wednesday will be the time to just start getting to know each other. Thursday we see the doctors for consults and walk the SOFT Stroll for Hope in memory of Jonathan Cook. Get to the website and get your page started so you can get the pledges started now. Maybe your child will be the top money earner. The stroll is to help SOFT and fund some special things at the conference. Name your team and get dressed in your team gear and get walking. The next event is the Thursday welcome dinner. Friday we will all learn from the workshops. Will your state be the one to attend the Conference planning workshop and decide to bring us to your area the next time? It is all waiting for you.

Get your hotel reservations before the rooms are sold out! Saturday we have the Kari Deanne Holladay special video. Get your photos in to Kris so you can see your child on the big SOFT screen. Even if you can’t be there your child can. We will then be off to the picnic for good food, company and then The Ryan Cantrell Memorial Balloon Release. This is the time to honor the special children that have left us too early. Get your balloon release completed and send to us so we can release that balloon. Remember to give us your address so we can make sure you get your copy of the release tag. Get your reservations at the hotel and your registration in before the due date and we will see you in 3 months.

SOFT has had a lot of special things happening this year. We started the year with a new and improved website. Hopefully you have all been able to take the opportunity to see everything there is to offer. We are looking for everyone to get stories and pictures of the children on the family stories page. It is so important for the new families to meet and see all the children. We don’t want them to miss the joy we find in our kids. Write your story now. We had a successful month in March for Trisomy Awareness also. Gerri Meggett was able to get her Governor to proclaim March as Trisomy Awareness month. She worked hard to choose special pictures of your children and present two of the children each day. She was able to do this with the help of Ann and Frank ’Barnes'. If you missed the pictures get on the website and find the collage of all 31 days. In March the SOFT Board of Directors announced that membership will now be free to all those individuals that want to receive their newsletter on the website. You will still need to renew each year but for free. That is to keep our information up to date. Please also send in your address changes. It is also important to send in all your child’s surgeries so we can keep growing the surgery database so we are able to help families get in touch with families that have already been there. Will you be one person we can count on? This also helps us let Doctors that are not in favor of surgery for our children understand that many others have already had the surgery. Our chance to change the world we can hope.

It is an exciting time. Check it all out and meet us in Rhode Island.

SOFTly,
The VanHerreweghes

Did You Guess My Name?

#1

Megan Hayes

#2

Morghan Kubenä

#3

Megan Hayes
SOFT Conference Attendance: Why Do You Come?

Pam Healey

I was told that those SOFT members whose children have died, and who still go to conferences, come to see friends. My immediate reaction was one of surprise and indignation. It seems like such an over simplification and so wrong. I save all year, then still go into debt to go to the conference for our vacation. I can stay home, save the money, and see my local friends. I wonder why it seems so strange that so many of us only go to see each other. There is value in meeting up with friends annually, but there is so much more to draw us in.

I know I go to remember my son among people who understand that matters. It is not just about the balloon release, although that is important. Once a year I watch his balloon rise among so many others. I let go of the balloons of the children of friends who cannot be here. I let go of Paige’s, because she was here for so long. I am drawn in by the music and let it carry my emotions. I listen to the names as they are called and picture the children I knew. I wonder about the children whose names are not familiar. I look about me and feel both isolation as I create my own personal space and connection. There is fellowship standing with others in ceremony. I remember my son more actively all year around. I go to the conference standing with others in ceremony. I remember my son more actively all during the conference. I do not have to hide my feelings or move past what happened that changed me forever. I go as a parent to my first child. Many of my friends do the same. Some similarly go to be with their last child. What is important is that we go. Parents of surviving children have attended their first SOFT conference and said, “I have come home.” Many whose children have died years before have said the same.

I go to be with survivors. That is important because as painful as it is to know that the declaration of “incompatible with life” is wrong and interventions might have made a difference if we had known more, being with the survivors matters. I go to hear stories that confirm the humanity of every child. I go to watch kids walk, explore, tease, laugh, show preferences, focus attention and complain when they become bored. I go to see adult SOFT kids I knew when they were young. I go to see development I was told would not occur. I go to spend time with Liz, which is always unpredictable and delightful. It is hard to feel burdened or sad around Liz whose exuberance trumps any other feelings. She never fails to make me smile and laugh. We go back twenty years.

I go to learn. I go to hear about what is happening medically and educationally. I go to hear speakers who understand about the impact of loss. I go to hear those who draw from their own challenges and inspire others. I go to make memory once again, because there are so few memories. I go to hear about hope, progress, changes in medical attitudes, procedures and knowledge. I go to hear about policy and the need to change policy. I go to learn from John about what is happening on the research front. I go to be treated like a professional who has put in my time studying in the field. I go to learn about what others are doing that makes a difference. I go to learn what I can do to make a difference.

I go to watch kids dance, on feet and on wheels. I go to watch Mariah play with Gabby. I go to watch Gerri mix it up with the kids on the dance floor, encouraging even the shiest. I go to watch the sibs line up and board buses for a field trip, hoping it will be more fun than educational. I go to watch the sibs running around and laughing at the picnic, building sand structures, maneuvering in blow up gyms, and playing games. There is no difference between those with a surviving sibling and those without. I go to watch little ones hold a number high at the auction. I go to watch the littlest model held high at the auction. I go to watch protective big sisters and big brothers, some of whom are younger, as they easily include their sibling in what they do. I go to watch sibling interaction within nuclear families and within the larger families they have created through the years.

Sure, I go to see the friends that I have seen steadily or off and on for two decades, and catch up with what we have been doing for the past year or more. I also go to see friends I met recently or will meet. I go to have a glass of wine with Margaret, always promised when we put in long hours before the newsletter is done. Now you know the promise that keeps us going. I catch up with Heidi and plan an excursion or remember a past one. I go to laugh with Chris, Shannon, Heidi and others, who always have some tales. I go to see what Craig and Marie have made and spend time at breakfast with them. I go to watch Kris’ video with a room full of people who love it as much as I do. I go to be called Miss Pam by the Southern kids I have known, since they were babies. I go to bring what I have worked on all year in memory of my son. I carry two bags of preemie blankets, which will go to the hospital hosting the clinic and to Brenda, big sister of Erin Jorgenson. Brenda will carry those blankets and the hats and blankets Sara Hayes makes on the NICU flight that will transport infants across several northern midwestern states to the help they need at large urban hospitals. I have 30 colorful blankets completed now. Some years I go to bring angels that my daughter and I spent months designing and making. I go to bring the tangible results of productive time in which I remember my son. I go to the auction to see what has been made in memory of other children.

I go to take pictures, write notes on workshops and learn from families (Continued on page 5)
and professionals. I gather what I need to write for the newsletter over the next year. I get ideas for articles from conversations, questions, observations and requests. I try to capture what is important to people whose lives have been changed by trisomy. SOFT needs voices, and I try to be one. I may have the skills, time and perspective to say what others have thought or considered but are not yet able to share. Words, hugs, music, pictures and prayers all connect us. We contribute in different ways.

I go to SOFT conferences for fellowship and that is different from going to see my friends. I go to remember in the company of people who also remember. I go because for a few days each summer I can bring an important part of my identity to the surface. I don’t have to explain. Now I find myself explaining. For a few days each summer I am the mother of a child, who was born, lived briefly and died quickly and too soon, and changed me. When I return home I tuck my son away. Years ago I added conference memorabilia to his baby book. I stopped doing that, although my name tags and his balloon release tags hang by my desk. Still, each time I go I am adding to his life book, after his life. I go to carry his influence. I go to live out the premise that every life, no matter how brief, is important. Even a small pebble thrown in the water sends out widening rings that reach the shore. I go to allow him to make his ripple felt through me. I know others do the same. I know that 90% of us who might join SOFT lost a child in his or her first year. Still others experienced difficulties in pregnancies which did not hold, and others held babies born still. Those parents have come to conferences, although many do not. Many parents said goodbye before the child was five. By the time a child is ten or fifteen, more parents are grieving the loss. We balloon parents are a potentially large portion of SOFT. SOFT is sustained financially by memorial gifts, but SOFT is sustained in many ways by those members who remember.

I wonder if by going to the annual conferences, along with others of my generation, we are giving permission to those whose losses are more recent to carry their child more actively. Many well meaning people out there expect there is a time table for grief, and sustaining it is not healthy or logical. By going we tell others that keeping your child with you is possible in constructive ways, is not pathological and is worthwhile for ourselves and others. I wonder if we also pave the way for those who cannot yet imagine what it will be like to release a balloon.

I do not have to go to the conference this year. It will come to me. I will greet not only the SOFT children and the family members they bring with them, but I will also greet all the families who come remembering their child. Their child has also brought them. On Thursday night we will all hear about the abilities that may be overlooked by more obvious disabilities or what some will consider brokenness. We will focus on possibilities. On Friday morning we will all hear how our children who have left our arms remain with us in important ways. We will also focus on possibilities.

I guess we do not just go to the annual SOFT conference for friendship. We go because we are on a journey, and we can choose the stops along the way. Come to Rhode Island for friendship, knowledge, enlightenment, hugs, discussion, fun, good food and music. There will be a time to mourn and a time to dance, a time to heal, and a time for peace. There will be time to build, sustain, repair and begin friendships based on common experience, heartfelt concern and our need for each other. Together we will find, there will be time for rejoicing, remembering, laughing, crying, embracing and keeping what remains important. There will also be time to walk into the warm waters of Narragansett Bay (okay, warm compared to the Gulf of Maine), feel sand between toes, build a sandcastle and collect some shells, beach glass, driftwood, and memories along the way. There will be time to watch sailboats across the bay, await the rhythmic swing of a lighthouse beam, hear gulls as they swoop and noisily vie for lunch and be stopped by the quiet dance of coastal butterflies. There will be time to smell salt air and beach roses. Don’t miss any of this. Come to Rhode Island.

**The Lighthouse**

_by Marjorie Wilson_

Burning upon some hidden shore
Across the sea one night
A little reef, the Captain said.
We saw a shining light.

He said there was a lighthouse there
Where lonely in the sea,
Men lived to guard that moving light,
And trim the lamp for me.

For me, for him, for every ship
That passes by that way,
I thought it must be strange and quiet
To be there every day.

They have no shops, no fields, no streets;
No whispering sound of trees,
But always shouting at their feet
The great voice of the seas.

And when we sleep at night they wake
And over every wave
They send that straight strong arm of light
Stretched like a rope to save.
It was in December 1977, Kari was 3 months old and it was the first time I had seen a “non-medical book” picture of a child with Trisomy 18. A few days prior to seeing this picture, I had talked to a mother on the phone and she promised to send a picture of her daughter. When it arrived in the mail, I opened the letter and there she was – Brandy Woodcox! I was mesmerized! I memorized every detail of her face. I can still describe her smile. I remember how her hair was combed. I remember the color of the outfit she was wearing. (It was Halloween and she was a little clown.) I know the design of the couch she was sitting on and the table next to it. I remember how she held her hands. I felt as close to that picture of Brandy as if I had taken it myself. That very special picture sat proudly displayed on our entry table and everyone who came into our home was introduced to “our” Brandy!

In the early days of S.O.F.T., I received many heart-warming letters from proud parents and grandparents. As I read each letter, I felt as if we were “old friends that had never met.” Included in many of the letters would be a picture. As I held each precious picture, I came to realize what steps it took for a mom or dad or grandma or grandpa or auntie, to send a photograph to me. In each picture I received, I held evidence of love. I knew what medical information these families had been told about their child and yet, they had a camera ready with film for a special moment. (By the way, this was long before digital cameras & cell phones were handy at a moment’s notice.) The steps for me to receive a picture were many. First, the family would dress their baby in adorable clothes. Then, they would say, “Isn’t this baby beautiful” and take a picture with their camera. Next, they would drive to the drugstore & have the film developed & come back & pick up their envelop of pictures. After that, they would look at the pictures of their precious child and see a wonderful picture and want to share it! Last, they would find an envelope, write me a note and place the picture inside. Finally, they would put a stamp on the envelope and send that particular picture to a stranger (me) living in a far off town in Utah! Patiently they would wait to hear from me and see if I had received the picture of their child. Perhaps they were hoping I would see what they could see; a child who was truly adored! I felt humbled and honored by each and every picture sent to me. The families trusted me to take care of their STORY told best by the picture.

Each year as Hal and I prepare for conference and the “Kari Holladay SOFT Friends” DVD, I still love to receive pictures and continue to be humbled and honored. When I look at each child, I delight with the celebrations. I smile at the faces. I cry with the heart ache. I sigh at the sleeping poses. I giggle at bath time. I am charmed by the siblings. And I fall in love with each child I come to know through their pictures! I know your children even before you know me!
Nearly all men can stand adversity, but if you want to test a man’s character, give him power. - Abraham Lincoln

Remembering Boston

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my heart. Many children were carried in hearts on the Boston course this year.

There is something to the “loneliness of the long distance runner.” There is something to processing what cannot rationally be processed by being in motion with what is outside of you silencing by. The brain works differently when the legs are in motion. Emotions are different against a rhythm. Breathing deeply helps, being under the sky helps, and exertion helps. As sweat cleanses the body, the mental processes that mix around and settle in during a long run help cleanse the mind working overtime to understand or shutting down to forget. I ran my way out of grief by thinking through what needed to be examined and, if possible, understood. Others have done the same. I consider what a good metaphor for grief a long, long run is.

I ran most races for nearly two decades in the faster company of Team Hoyt, a local father, who since 1977 has pushed his nonvocal, spastic quadriplegic son, who was immobilized by CP when deprived of oxygen at birth. They were always well rested, when I reached the finish line. They became fixtures in the New England running scene, then the national running scene. After having Conor, seeing Rick Hoyt took on new significance. They have participated in over 1,000 races and triathlons. They changed the face of disability. They redefined possibilities. They have inspired many. They have run Boston 31 consecutive times, including 2013. Boston is their race, and they bring to it courage, persistence and a celebration of love. Recently, a life size bronze statue of Dick and Rick was unveiled at the starting line in Hopkinton, Theirs is one of many stories of Boston, and now there are more.

I have been struck by the story of a Sandy Hook first responder, a physician, Laura Nowacki, whose own 10 year old daughter was one of the children, who ran from the school to safety. This pediatrician who ran the 2013 Boston Marathon fast enough to have cleared the finish line 40 minutes before the explosions, ran through the winter to recover, I suspect, from a scene from which no one could fully recover. She ran Boston as part of the eight runner Newtown Strong Fund, running to support the families. She and her teammates ran remembering each child, mile one to twenty, each mile dedicated to a child, alphabetically, perfect for little ones mastering the alphabet. The last six miles they ran remembering those who protected the children of Sandy Hook. The team was assembled to pay tribute, raise funds, support the survivors, and increase awareness, so we do not forget. By training and running these men and women both affirm and know that life goes on, and we support each other in what life presents us.

Before the start of the marathon there were 26 seconds of silence to remember the victims. At mile 26, .2 miles from the finish, within sight of the explosions was a dedication to those who perished in Newtown. I consider the grief of those parents, now traumatized again. I consider what a good metaphor for grief a marathon is. I consider now what has been lost, what suffering has occurred and what can be done now.

This summer there will be a presenter who is a grief counselor at The Children’s Room, a nationally recognized program for children recovering from the death of a parent or sibling. Michael works with a group of young boys. The program exists “so no one grieves alone.” One child explained the counseling helps to “bandage your broken heart.” Families, who come from over 80 cities and towns, are supported in bweekly counseling for as long as they need help with no fee. The Children’s Room has a team of eight runners on their Miles and Memories Marathon Team. They put in 2,400 miles of training. They raised $68,000 to help grieving families. All were safe, as were their spectators. Carol Hamblet Adams, a 2013 conference speaker, was in the Grandstand across from the bombs. She was there to cheer her nephew running in memory of her husband. She came to witness triumph and witnessed terrorism. For a woman who has mastered words, there are simply no words right now. One of my students runs every year for MS, to honor her mother who once ran with her. There were nearly 27,000 runners, some elite, many running to meet a personal goal, many more running for charity, raising money and awareness.

Help came quickly for the victims of the finish line explosions. With a nearby medical tent staffed with nurses and doctors, a large police presence and a strong organization of volunteers, help was immediate. Medical attention was given within seconds, and that made a difference. First responders, runners and spectators ran toward the victims, risking danger from a second bomb. Their actions saved lives. Boston is known for its hospitals and victims went to more than a dozen. The most gravely wounded went to the Brigham, where I lived for three months while pregnant and Conor lived for most of his life. The rest went to Boston Medical Center where my students from the Medical Genetics class are student doctors. Some patients are now leaving to go home for lengthy recuperation, expressing gratitude, despite serious injuries.

Physicians say this is the worst mass casualty in trauma centers in this country. Physicians who have served in war zones, have not seen worse. There have been seven amputations on five patients, including the

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PROFESSIONAL VIEWPOINT: Journal Club

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


The paper by Peroos and colleagues was published in the British Medical Journals, Case Reports, a special version of this prestigious journal devoted to papers on single medical observations of significance (case reports). The authors present an 8-year-old girl, who had full (non-mosaic) trisomy 13, Patau syndrome and - like the second paper - raise an important question: what are the factors that contribute to survival in trisomy 13? The authors point out that survival past infancy is “often attributed to mosaicism”, and their purpose is to document this child with “long-lived” survival and non-mosaic trisomy 13. This report is, of course, not surprising to any of us who have attended SOFT conferences, been in touch with families through SOFT, or even casually visited the Living with Trisomy 13 syndrome web page.

This paper is significant for two reasons: First, the observation adds to the relatively small number of case reports in the medical literature documenting a child with full trisomy 13 (non-mosaic) who is over the age of 3 years. I have been keeping track of these reports over the last 25 years, and this brings the number - from my count - to 15 older children greater than 3 years. Review of the Registry maintained by SOFT indicates that there are 28 children and individuals with trisomy 13 over 3 years, almost double the figure of the medical literature. In most of these published reports (unlike the Peroos et al. paper), the authors do not perform a chromosome analysis from a second tissue sample besides blood; this is important because examination of cells from another tissue in addition to blood (usually skin or cells from a cheek swab) helps exclude (or diagnose) the possibility of mosaicism. (Mosaicism is the presence of multiple different cell lines; in this case the examination would be looking for the trisomy 13 cell line and a normal cell line, which could modify the physical presentation of the trisomy 13/Patau syndrome).

The second reason why this paper is relevant is that it illustrates the value of case reports in the scientific literature. This type of paper, i.e. the case report, is often relegated to the bottom rung of the hierarchy of scientific papers; yet case reports often describe individuals with new conditions, generate important medical hypotheses, and teach lessons regarding medical care. Interestingly only about 50% of medical scientific journals still publish case reports. Note that the first paper on trisomy 13 by Dr. Patau and colleagues in 1960 from the University of Wisconsin was, in fact, a case report.

The second paper noted above, Hsu and Hou, was an article that I found in reviewing the background for the Peroos et al. report. This paper essentially describes an older individual (a 7-year-old, with full, complete, non-mosaic, trisomy 13) as one of a group of children with trisomy 13 and discusses some of the factors that may be related to long-term survival. This is an issue that I have pondered over the years for both the trisomy 13 and trisomy 18 syndromes. These factors include prematurity, gender, the presence of certain medically serious anomalies (type of heart defect), the degree of medical intervention, and, in the case of trisomy 13, the presence of the brain anomaly called holoprosencephaly. Currently, other investigators (Dr. Debbie Bruns and Dr. Tomoki Kosho) are studying this issue of variables related to the outcome and survival, and we will hear more on that issue in upcoming papers in the American Journal of Medical Genetics.

Trisomy 18/13 Research Project

Pam Healey, who conducted an experiences at diagnosis survey in 2001-2, is conducting a similar study to compare experiences. This is open to parents who received a diagnosis of trisomy 18 or 13 in the past five years. This includes a prenatal or postnatal diagnosis and is for parents of all children with a diagnosis of trisomy 18 or 13 (full, partial, mosaic), including stillborn, elected termination, and liveborn. It is important that as many people as possible participate. There were 117 responses to the first study, and many parents wrote that it was therapeutic for them to share their story and have their child be part of a study that will help other parents. All responses will be coded and kept confidential.

If you are interested please email your interest and address to Healeylex@aol.com, call 781-862-8273 or write to Pam Healey 18 Richard Rd. Lexington, MA 02421.

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:
   Douglas Lauber
   NetworkForGood.com, supported by friends who used their search website
   Martin Laird
   BP Matching Fund Program
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   United Health Group, Employee Giving Campaign
   Sandeep Maram
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   Joseph J. Hetzel, BP Foundation Matching Gifts

Donations to the Joey Watson Fund, established to help financially challenged families attend the SOFT annual conference:
   In Memory of Natasha Maria Winslow
   Her family and her memorial fund: “Make each day count. Life is a gift not a given, find the sunshine in each day. Natasha will forever be our sunshine and rainbow.”

   In Memory of Joanna Hassan
   Lynn Syneck

   In Honor of Samuel Jackson
   The students, faculty and staff of the Milan Tennessee Special School District in recognition of Trisomy Awareness month.

   In Memory of Tristis Amore Matteson
   Sara Matteson

   In Honor of Nicholas Wright
   Shannon K. MacMaster

   In Memory of Ellie Cushman
   Chris and Wendi LaCivita: “Please know that we are keeping you in our hearts”

   In Honor of Natalia-Marie Siegel and
   In Memory of her grandparents Roger and Dianne Miller

   In Honor of Phillip Serb
   Sharing Spirit 2012, North Shore University Health System, Evanston, IL

   In Memory of Gabriella Romano

Peter Romano and YourCause at Hewlett-Packard

   In Memory of Ellen Roma Nelson
   Ellen Adam

   In Memory of Lauren Coelho
   Louise Connors

   In Memory of Rose Fleischhacker
   Gloria Jorgenson, her daughter, and Kim Jorgenson

   In Memory of Erin L. Handel,
donated to the 2013 SOFT Conference:
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   In Honor of Caleb Ridgeway
   Kelly and Patrick Ridgeway
Reflections By the Sea
The Books of Carol Hamblet Adams

Thursday night at the SOFT Conference Welcome Dinner, Carol Hamblet Adams will speak to us and meet our SOFT children. She is looking forward to both. She will speak about seeing the strengths in those who are different and recognizing that what makes us different is often the gift that others need most. Certainly, she will see before her a long line of children who live out that belief by bringing important unexpected gifts to those who love and care for them and to those whose paths they cross during their journey, no matter how short. Carol is an inspirational speaker, who has spoken across the country. She is the author of many books on finding hope, taking lessons from simple experiences and finding peace, inner strength and guidance at the ocean’s edge. She is an articulate, energetic woman of faith and humor, who changes people’s expectations and perspective for the better. She writes small, beautifully illustrated books with memorable language and big ideas. She uncovers what is within all of us. She gently takes our hands, as we travel with her on a New England beach to notice what is about her and discover what can help each of us with our own disquiet. Whether she is speaking to an audience, to a small group of like minded people or to her readers, her words remain in the heart and mind and change the way life’s challenges are understood and negotiated.

Many SOFT members are familiar with her first book, My Beautiful Broken Shell: Words of Hope to Refresh the Soul, since it has been available at some SOFT conferences both in the Memory Room and at the auction. In My Beautiful Broken Shell, Carol considers that we are all broken in some way, and through God’s grace we can learn to embrace that brokenness, see what it provides us, and move on to focus on all that is right in our lives. In that now classic book she visits the beach to “refresh my weary spirit and refuel my tired soul.” She appreciates that time at the seashore is unhurried and provides many sensory experiences that draw her in and bring a sense of peace at a time of turmoil. Once relaxed by what she finds, she is brought to a sense of her own purpose and wholeness. She leaves the shore knowing she is more whole than broken and is held in God’s protective hand.

Walking alone one morning she searches the beach for shells and walks past a broken scallop shell. She suddenly realizes that a broken shell is more appropriate for her at that time than the perfect shells she seeks. She backtracks to collect the broken shell and while holding it considers the ways in which people are broken. Sorrow, unfulfilled dreams, pain, loneliness, fear, and grief threaten to crush us, but as the shell has done, we survive with our brokenness. Through our brokenness we learn life’s most valuable lessons. We learn to appreciate what is left. We also learn to embrace what does not go in ways we expected or wanted.

At the time she wrote her first book, Carol was absorbed by her husband’s devastating illness and the constraints it placed on their lives. Her life script and that of the family had been altered, and adjustments and disappointments were inevitable. Later, she faces her death and meets new challenges. Through observations, reflection, insight and prayer she learns to live with what seems brokenness. She seeks and finds her own beauty and worth. She realizes she does not stand or walk alone. What she shares carries the reader not only on her personal journey, but the journey of life’s challenges we all share. The book is beautifully illustrated with pastel water color paintings that bring both the expanse of sand, sky and water to the reader and the detail of what the sea leaves on the shore. On many pages there is a prayer related to the realization she expresses on the preceding page. As she recognizes that she is not fully broken, does not stand alone, and is able to reach out to others, she prays, both expressing gratitude and asking for help along the way.

Her subsequent books also focus on the strength and lessons we draw from the seashore and the opportunities it provides for those open to trying something new or an activity buried in the past. In My Beautiful Sandcastle Moments: New Beginnings of Hope and Healing, she focuses on activities which allow us to live in the moment and find joy, despite what troubles and challenges us. Elaborate sand castles are built to last a short time. Twice a day the tide comes in and removes them, but there is value in their transient presence. There are miracles in simple times and activities, and we owe it to ourselves to find our younger spirits and be refreshed by sandcastle moments. We need to be invigorated by joining in activities whose value lies only in doing them, not in a product that will last. We need to embrace opportunities around us that free us from life’s constraints and burdens. Engaging in such transient pastimes reminds us that life itself is transient, and we need the wisdom to accept that and playfully make the most of the moments we have.

More recently Carol wrote Waves of God’s Healing: Finding Rest in the Storms of Life. Advice is not to judge a book by its cover, but the reader is drawn in by the illustration of a lone Adirondack chair with a red garment draped on it, two wind swept trees bending away from the ocean and the Lighthouse that stands tall and straight. In this book Carol considers how comforting the ebb of tides, the constancy of waves and the serenity of the shore can be when life presents personal storms and turbulence. She considers what disrupts our serenity and mental and spiritual health and
(Continued from page 10)

We could never learn to be brave and patient if there were only joy in the world.-Helen Keller

responds by focusing on those waves that will bring healing and a sense of peace to our lives, when we open ourselves to positive actions and beliefs. Each idea is developed through a personal reflection of time spent at the ocean, a prayer for what is needed to bring healing, a passage from scripture, and an illustration of something that attracts our eyes in the sand or on the horizon.

Each illustration holds our attention and brings the sea to us: a lone seagull against a wafer like sun, the foam brought in by the last waves, a rustic fence cutting through dunes, an abandoned sand castle and the pail and shovel used to construct it, a skiff reflecting the hues of the rising sun, and a sail that catches the wind and billows, pulling the lone boat a bit sideways. In each section an idea is developed through the sensory experience that suggests it to exploration of its meaning. She addresses what we need to work for or draw from to be at our best. She suggests that the waves that work rhythmically in our lives can draw us to what we need to do and be. Each idea is familiar but also a big order if we are to do what is necessary to achieve what is best.

Carol presents the ideas through situations that are commonly faced. She speaks of forgiveness, courage, strength, hope, peace, patience, gratitude, love and faith and the joy that comes when the rest are realized. Not a bad list. What else could we require to be at our best? What else do we need to find happiness when life presents turmoil that seems to close off possibilities? She includes a prayer in which she acknowledges life’s blessings, admits to needs, names the negative emotions and situations that drain us, and expresses gratitude for the gifts in her life. The scripture passage is always perfect for the theme of each section.

This is the kind of book to keep on a bedside table, tuck in a knitting bag or pick up from the living room table in the late afternoon and enjoy with a cup of tea. Such books need to be visited often. What she presents is an antidote to the and televisions that make demands capture tract us. Each gives a pause in the day that brings a sense of peace. I have been a fan of Beautiful Broken Shell for many years, but I am now captured by Waves of God’s Healing.

All three books, published by Harvest House Publishers in Oregon, are perfect gifts for friends and family members who are meeting challenges and need support. When you do not know what to say, these books will express your concern and caring perfectly. Each book will carry your love and be your voice when feelings are too deep for ready words. These books will offer a quick trip to the ocean and bring readers to possibilities within themselves.

Finally, Carol has ventured into a new direction. She has stayed at the ocean, or in this case, taken a dive into the ocean, in Sammy the Little Broken Shell, a children’s picture book. This is a tale of a young scallop whose life is changed when in an act of courage he is injured enough to be different from the other sea creature children at his school. Only one friend stands by him; the others cruelly spurn him. Eventually, what is seen as a defect becomes advantageous, and Sammy saves the day. Sammy, although changed externally, remains courageous, intelligent and caring and cleverly draws on his disfigurement to make a difference all the sea children can appreciate. In this gently told tale, with bright, bold whimsical artwork, children are introduced to unfair attitudes toward those with physical differences and are lead to a new understanding of seeing abilities not disabilities. The powerful message is, “The very gifts that make us different may help others the most.”

I think of the many times SOFT parents have shared that their child with the once frightening diagnosis is just what they needed, perfect in a different way. They come to see not just the positive quality of life the children have but the ways in which they enhance the quality of life of those around them. These children, too, have judgments made about them, but hearts are changed. Even those who seem powerless to many are powerful in their own way. Carol will welcome the children in our Zion Lint Parade of Stars, and share her insight that resulted in adding Sammy to the cadre of memorable characters in children’s literature. –Pam Healey
Remembering Boston

(Continued from page 7) sister of the child who died. Some have experienced traumatic brain injuries; many will need support for PTSD. Dozens remain in critical condition, fighting for their lives and to keep limbs. Children remain hospitalized. Siblings remain hospitalized. Couples remain hospitalized. There have been three deaths. Boston remains in pain but moves forward. The country shares our grief and that helps.

We in SOFT are a community of grief and hope. Many joined SOFT after their child died. Most joined SOFT as parents of a child whose life was thought to be short. We launch after their child died. Most joined SOFT for grief and hope. Many joined SOFT of Utah for support and to the notion of fighting for their lives and to keep limbs. Children remain hospitalized. Siblings remain hospitalized. Couples remain hospitalized. There have been three deaths. Boston remains in pain but moves forward. The country shares our grief and that helps.

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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.
Happy 18th Birthday Nicholas Wright!

We celebrated Nicholas’ 18th birthday on April 6th with a Dr. Seuss party. It almost didn’t happen that day because his J tube clogged and we had to take him to the emergency room at our local Children’s Hospital. His Aunt Janet and Uncle Eric went to pick up his “special” free Dr. Seuss themed cake. I heard about Icing Smiles on a Trisomy Facebook page. They contact a local baker that donates their time and talent to children with chronic medical conditions up to age 18 with a free birthday cake. Their siblings can get a birthday cake on their birthday too. One birthday cake can be a “special” cake. We had a lovely local woman donate her talents for Nicholas to have his cake this year. We thought it was adorable! We had his party later in the day and the new musical toys received as presents were a big hit with Nicholas. Icing Smiles can be found here: www.icingsmiles.org

Nicholas has had some health issues lately. He was hospitalized almost all of February and March because he can’t keep his electrolytes balanced due to kidney dysplasia. He now has cysts covering both kidneys and he is being followed by a nephrologist who ordered blood work three times a week following his hospital stays. He came home with a picc line for easier blood draws. Nicholas failed a swallow study at the hospital. He cannot keep his airway protected. They think he is aspirating everything from his stomach also, so they decided it would be best to put in a GJ tube. That is one pesky J tube. The first one flipped up inside and flooded his stomach with formula, so they decided to put in a longer J. The new one has clogged 4 times now. We’re getting the hang of frequent flushes to the G & J tubes. We were told a small amount of Coke helps keep the j tube from formula build up too. He has to have a formula/free water/sodium chloride mix for his electrolytes to stay somewhat stable. We adjust it according to what his labs show for that day. So he is on continuous feeds for 20 out of 24 hours now. And eating by mouth used to be one of his favorite things to do. He was very upset with us for several days when we put him in his wheelchair. He thought he was going to eat by mouth. Crawling is very limited now, and that was another favorite activity Nick enjoyed. His nephrologist said he is his most sensitive patient, meaning any small change will cause his sodium/potassium/bun to turn the wrong direction quickly. Despite his recent limitations, Nicholas is still a smiling, happy boy and we are blessed to have him in our lives. The Children’s Hospital of Illinois is a teaching hospital, and I think Nicholas has taught the doctors there that children with Trisomy 13 ARE “compatible with life”. One doctor said, “he’s awesome, he’s just awesome!”

Blessings to all our SOFT families,
Mark & Jayne Wright
Hudson IL
Love is not consolation. It is light. - Friedrich Nietzsche

I look to her
not with pity or fear
but with admiration
... wishing that I could be
just a fraction of who she is
her traits I wish to emulate
but have had the hardest time
trying to realize

she enjoys the simple things
the common people in her life
will bring her a huge smile
to spread across her lips
the sun beating on her skin
while sitting on the porch
on a quiet day
will keep her satisfied for hours

she does not complain
about the things she cannot do
about the unfairness of life
she does everything
with reckless abandon
living each day
as if there might be no more
for there is today

she has overcome such odds
yet does not even know it
her stubbornness
pervades all that she does
and her laugh fills the air
so very often
she wasn’t supposed to live
but she was not willing to die

she is the one
I love
who is my hero
the one I only have to remember
to change the way I think
she is the one
I want to be like

For My Sister
by Michelle Newman,
about her sister Stacy (T9M)

Stacy, 26, and her best friend and sister, Michelle, 28.

Best Friends
Michelle is currently 29 years old and Executive Director at AHEAD With Horses Inc., a non-profit developmental therapeutic riding program. Stacy had started riding in the program right before she turned three. Michelle began volunteering with them the summer of 1999, while Stacy was still a participant. She knew all the great work that could come from horses because of what had been done for her sister and all of the other children she worked with. Michelle still sees her sister on a weekly basis. Stacy is currently 27 years old and attends an adult day care program. She still resides with her mother, Phyllis, and father, Floyd, along with their two dogs who keep her thoroughly entertained. Stacy still loves to sit on the front porch and considers her sister Michelle her best friend.

Stacy's 21st birthday
Stacy celebrated her 21st birthday in Las Vegas. She won $100.00 on a slot machine! She is shown above with sister, Michelle.
Friendship is born at that moment when one person says to another: "What! You, too? Thought I was the only one" - C.S. Lewis

“Jeepers Creepers, where’d ya get those peepers? Jeepers Creepers, where’d ya get those eyes?”

Move over Kammie, Chelsey and the elite others . . . Leilani has joined the club of teenage T-18’s with glasses. We’ve always heard that spectacles make you look smarter and more distinguished. I’m here to tell you that those rumors are true. I am smarter and more distinguished. But enough about me, this article is about the adventures of Leilani and her new eyeglasses!

As many of you know, Leilani is a bit of a punk rocker in that to soothe herself, she fervently rocks and sometimes bangs her head from side to side. We affectionately call it ‘her sleepy dance.’ We couldn’t wait to see the debut of the flying spectacles during the premier performance. Believe me, it was a sight to see. Get it? A sight to see . . . I crack me up!

It’s been a few weeks now, so she has apparently gotten used to them, or at least has chosen to tolerate them, at her own discretion of course. Even though we can’t get her to hold a pencil, she most certainly can use her index finger and thumb to remove her eyeglasses when she’s good-n-ready. Ingenious, if you ask me . . . Faking a chromosomal disorder just to get out of chores, homework and of course reading aloud in school.

In other news, Leilani also just returned from a 7-day Royal Caribbean cruise. As usual, she was the belle of the ball (or should I say belle of the boat). With a travel party of 8 there was much fun to be had by all. Leilani won the prize for best vacationer of the group. While we all took an opportunity to try new things, Leilani slept in and went to bed early every single night. Shout out to Team Stacy for the travel agency referral.

As we close in on final preparations for the conference, we are looking forward to seeing our SOFT family in Rhode Island. I think Barb and I are planning to drag race a couple of tricked out mobility vans down the main street! Stay tuned!

Gerrri Meggett, Chair DC/MD/DE Chapter And Team Leilani

Other Trisomy Children, Other Parents, Other Countries

Pam Healey, International committee

With open, free enrollment into SOFT we are getting an influx of international members. Membership costs have always been higher for those living outside the United States, because the cost of mailing newsletters is greater. This has discouraged some families with children with trisomy, and they have not enrolled or not kept up memberships. Through the years we have had members from the United Kingdom, Sweden, Columbia, Australia, Japan, Italy, and of course, many from our neighbor Canada. We have had contact with those running SOFT organizations in England, Scotland, Ireland, and Australia. In the past few years we have had inquiries from families living in Brazil, Italy, Malta and Germany. Recent international members come from Iceland, Ireland, Australia, and the United Kingdom, including new members from England and Scotland. We welcome them and look forward to expanding our membership worldwide.

With translation software making communicating easier, translation of some materials into Spanish versions, and English being taught in schools worldwide, and of course the Internet, it becomes easier to support each other no matter where we live. Trisomy conditions occur randomly in all populations. (Did you know that mice have a triplication of chromosome 16 which results in a mouse version of Down syndrome and Macaque monkeys, both rhesus and pigtailed, have babies with trisomy 18. These have been studied to increase our understanding of genetics and social behavior). Cultures vary in how prenatal medicine is used, or how widespread termination of affected pregnancies is, which determines prevalence rates. In all cultures babies are born with trisomy conditions and parents need support.

Do not forget to check out the SOFT UK website and download their spring/summer magazine at http://soft.org.uk/News/SOFT-Magazines. Meet some children and parents and find out what is going on across the pond. Previous editions are also available for download. You might also want to see what is going on at SOFT Ireland: http://www.softireland.com/.
Unable are the loved to die. For love is immortality - Emily Dickinson 1830-1886

Tribute to Sarah Marcela Poole, 9-10-10 to 12-2-12

Sarah was a born fighter, our five pound warrior, alert and curious even at birth. The doctors would say incompatible with life and, maybe just days or weeks. Those were heart wrenching days, for her and us. The cardiologist put off her heart repair for five months, but Sarah refused to get sick enough to give anyone excuses to deny her care. I cannot imagine how hard it must have been for her. She was in such pain. But God wanted us to know that He was greater than any prognosis, that He was greater than the doctors. We prayed God’s mercy on her, and He served up kindness to us.

The heart repair came, and God let us keep her. For almost 2 years and 3 months, God let us keep her. And it was a life that was perfect in how ordinary it was. Sarah lived each day purely and simply. She smiled easily and loved lots. Sarah loved when we would clap for her and she giggled when the dogs barked. She loved dinner time and beamed as she watched her brothers tell stories, talk and joke. She loved dancing with dad in the living room. She loved lights and music. She loved being handled roughly, and patted hard on the head and cheeks by her brothers. She couldn’t help but smile when you blew in her face. Her eyes were the perfect shade of brown, so rich, deep and thoughtful.

Every night, she and her brothers went to bed together, in the same room. She would hold her pacifier just so and squeak it on her gums or grind her teeth, which drove us CRAZY! Her brothers would snuggle and cradle her. Her dad would massage her. She loved having her feet on you and would somehow manage to put them on her brothers whether they liked it or not. To fall asleep she would roll herself to her tummy and rock her bottom side to side.

All this sweetness lulled us into a false sense of security. We believed that we had many years ahead. But every night we thanked God for another day with Sarah. Every night the boys lifted up a prayer of gratitude to God for Sarah. We were grateful for each simple fabulous day. We are wounded to go on without her but, thanks to Sarah, we will live our ordinary lives with more courage. We will live our lives worthy of her. We will challenge ourselves to make her proud of us. We will live lives grateful for each other. And that is why Sarah’s life means so much. She taught us the exceptional truths to a life joyfully lived. She taught us to love a person unconditionally simply because they are. To count ourselves blessed within each moment. And through her we learned of God’s great mercy and kindness that we now carry in our hearts.

Thank you Sarah for your great sacrifice for us. God must love you so deeply to entrust you with such a great purpose. You have been a bold and tender teacher. And thank you God for entrusting her to us. We would do it all over again if we could, for this is a journey of experiencing a love so deep and pure; a love known only to those of us who have ever loved one of these extraordinary people.

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Missing your Sister
By: David Poole, age 9
It will get better
It will never get perfect
You will never stop caring about her
You will always miss her
Later on you will think more about the good times
than the bad times.
Later on you will miss her less and think more about her in heaven.
Your days will get better on the way.
You won’t want her back on earth because it would be too painful to have to say good bye again.

I Remember Sarah
By: Nicholas Poole, age 6
I remember her rolling on top of me
I remember she laughs when we bounce balloons on her face
I love Sarah forever.

May/June/July 2013, The SOFT Times, Page 16
His loved ones are very precious to Him and He does not lightly let them die—Psalm 116:15

Finding Her Way Erin Handel - 1978-2013

Erin Handel 1978-2013
By Pam Healey

I have an uneasy relationship with our GPS. Having reached a dead end at the edge of a small drop-off in South Dakota, locked the doors on a winding dirt road that brought banjo music to mind in Mississippi, and looped three times around a series of parking lots in New Hampshire before locating a trailhead, I tend to proceed cautiously, my map and my written directions always a ready back up. We need to reach our destinations.

On a cool but sunny early spring afternoon we were heading for Erin Handel’s memorial service in the next state. Before we turned onto I-95 the GPS voice seemed to tell us to head “I-95 south westerly due north.” All I could think was, “Sounds like grief to me, no direct route, no logical course, just head in a few different directions at once and hope for the best.” Grief is a time when knowing where you are may be impossible and knowing where you are going unimaginable.

We were heading toward people who were grieving, unexpectedly facing what had long ago been expected. When Erin was born and diagnosed with trisomy 13, Bob and Lisa had been told she would live only days, then weeks, then months. The medical experts were wrong; she lived decades. They were told to expect limited development, and minimal quality of life, and they were advised to put her in an institution. They brought her home, where she stayed and reigned for 35 years. Her development may have been limited, but it was important and encouraging, and it surpassed the expectations of even the most optimistic. With loving parents, a growing family surrounding her with abundant love and providing or allowing countless adventures, her quality of life was rich. Erin flourished and found her own direction and brought those who loved and cared for her along for a spectacular ride. She might have travelled “south westerly due north,” while living in East Hartford, but the route has been fine, and the destinations have been just what her fellow travelers needed.

Fifteen miles down the road, I looked up and read a highway sign. I realized the GPS voice had said, “I-95, South, Westerly (a RI border town), New York,” a statement of where the road would go, but we would not. Direction had been clarified, but I-95 South was still heading West and would for a few more hours’ drive for those remaining on it. Maybe this was not just about grief but about unimagined possibilities and roads that illogically carry us to our proper journey’s end.

We left the interstate and drove northwest to East Hartford on an unfamiliar and pleasant route, passing through marshy woodlands checkered with snow patches, small lakes and...
Finding Her Way Erin Handel - 1978-2013

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smaller vernal ponds, steep hills and long stretches of rock strewn sunken landscape carved by the last glacier. The hillsides facing northwest still held a snowy expanse. There was little evidence on an afternoon in late March that spring had come to Connecticut.

Although the funeral was certainly to be a celebration of a life lived beyond expectations, with the church filled with people who felt fortunate to have known Erin, it was still to be a time of deep sadness. It was not that she was denied any possibilities, although those who saw her diagnosis and not her spirit might assume that. It was that she lived her possibilities with exuberance, agency, and affection that drew others to her, even when she was not grabbing them and pulling them nearer with small, strong fingers. There was so much to miss in a future without her.

Although respiratory illness posed health challenges when she was young, Erin had been healthy for many years, able to participate in community activities in school, then her adult day program, and at church, playing fields and social gatherings. She thrived on being out and about. She loved not only being in the thick of things but also instigating some of the action. This was tempered with her recent illness, but her family members hopefully expected she would bounce back.

In the late fall of 2012 Erin was hospitalized with pneumonia. Her recovery after more than a month’s hospital stay had been slow and uncertain. Months passed, with no further hospitalizations, which seemed a good sign, but her illness had weakened her. Being in her mid thirties with full trisomy 13 meant there was no road map. The permanent effects of lengthy respiratory infection were unknown.

Erin survived through the mid winter holidays, spent time with family and friends, and visited her day program and greeted her boyfriend on Valentine’s Day. She celebrated her 35th birthday in late February. She wore green to celebrate St. Patrick’s Day, a fitting holiday with her Irish name and red hair. Two days later she passed peacefully on the morning before spring’s arrival. She was to be buried on Palm Sunday, the beginning of Holy Week. That was also fitting, although still untimely.

Erin, who like others with limited vision, gravitated to sunlight, seeking its bright intensity and its warmth. She took the light she sought and carried it into the lives of many others. At the afternoon memorial service, with the sun illuminating the stain glass window before us, we were to be reminded of that image in a description of an errant Erin rapidly scooting to a patch of sunshine coming through a church door window and sitting there quietly and peacefully. We were to be reminded by the minister that Jesus is the light of the world, and that Erin had certainly done God’s work and brought light to many.

I was thinking back to when I first met Erin in 1991. She was a thirteen year old crawling quickly around a large backyard in Sturbridge at a New England Soft Gathering. She was fast, determined and adorable. I watched her try to climb on a moving bench swing, stack wooden shapes with a sense of at least brief focus and determined mastery, and grab and go with anything not tied down. She was having a wonderful time, playing to the crowd and checking out what she might carry off. She was the Artful Dodger with an extra chromosome.

It was the first time I had met anyone with trisomy 13, and it was a perfect introduction. We had been told trisomy 18 was incompatible with life, and I had thought the same was assumed of trisomy 13. Someone got that wrong. I observed what she could do and marveled at her vitality and curiosity. I was just managing to keep up with a recently mobile one year old and an active three year old. Lisa and Bob had an eight year old and a four year old, as well as Erin. I could not imagine the

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When Angela Met Erin

By David Ricker

My wife Melinda and I met the Handel family for the first time at a kind of mini SOFT Conference that took place at Pam & Mike Healey’s house in August of 2010. The following is an excerpt from a longer reflection I wrote about the event at that time.

Monday, August 30, 2010 1:10 PM

The backyard of the Healey residence in Rhode Island is a soft mat of grass with majestic oak trees overhead. The day is sunny but cool. In the shade of the trees, it is perfect. I lay down with Angela, and since I have been driving since 6 am and up since 3 am, I quickly fall asleep spooned around her as she also nods off to sleep. Small mercies. I wake up later and join Pam in the house where she is preparing food. There is a table laid out with fruit and chips and nuts, and on that table is also a picture of her son Connor, who died as an infant. In one of the other rooms is a large collage of SOFT kids, both surviving and deceased. I recognize a goodly number of these kids from other conferences and from the organization website. Another couple arrives. I spend the next hour talking to the mother, comparing notes on illnesses, sleep deprivation, school issues, wheelchair modifications, assistive devices, in short all the challenges, physical, logistical, philosophical, and emotional of having a severely disabled child. She is beaming and effusive about our discussion and relieved to know somebody else knows of her fears and challenges. These get-togethers are like an island for these parents. They are largely bobbing alone in a vast sea the rest of the time, in uncharted waters, with very little support, and even fewer people who understand their travails. When they gather together, it is like a coming home. Another couple arrives, no kids, just photo albums. The parents of surviving kids bring their children; the others bring their photo albums. You feel strongly obliged to look at them. I have seen hundreds of pictures of these twilight children, cleft palates, tubes up noses, wrapped in blankets, days old, being held in hospital chairs, surrounded by family, children that have been in the world for a couple of days and then are gone. You never forget their eyes. Even in the fuzzy photographs. They are here but a few bewildered moments and are gone, in the grand scheme of things, not unlike the rest of us. You sit politely as they go through the pictures, often rushed affairs for the photographer, stolen moments, the last grains of sand falling through the hour-glass, trying to catch that elusive light in the child’s eyes, or smile, or maybe just a moment where the face is smooth, not contorted in pain or lifeless with the faint ochre of eternity. I recognize this, because I too have been behind the lens in this situation. It is all too familiar. And the bereaved parents view your living child with a mix of sadness, of a wistful what-could-have-been, and let’s be honest, given all the difficulties, perhaps some relief as well.

This gathering was as I have experienced gatherings of this sort in the past until Erin Handel was brought into the back yard. The child in the wheelchair was my child, but not my daughter Erin Ricker, but my daughter Angela Ricker, except she was 32 years old. I felt my hand go to my face as I stared in disbelief upon first seeing her. Here was my child, 26 years from now, same look, mannerisms, cry, complaint, smile. I was stunned. Erin is perhaps the oldest living full trisomy 13 child on the planet. And she and Angela could be sisters. Born on February 22nd in East Hartford, CT, in 1978, the same winter the Hartford Civic Center collapsed after Blizzard Larry, to a young couple experiencing their own peculiar and unusual tragedy. Erin came into this world just over the mountain from a carefree 14 year old boy living in Avon, CT. That 14 year old boy was me, oblivious to the fact of her birth or much else for that matter except rock and roll, hormones and basketball. Who would have thought that 32 years later our destinies would converge under such strange circumstances, and after such far flung peregrinations? Erin was fussy and disappointed in her wheelchair. She thought she was going somewhere else is seems. She did not want to be motionless in the chair. She wanted to move. So her father took her back to the front of the house and began wheeling her up and down the nice quiet suburban street. I could see him walking the chair up the road, turning around and wheeling it back down again, and turning around and walking back up again, thoughts of Sisyphus coming to mind.

After a while, I rose from the gathering and went out to walk with Erin’s father, to perhaps try and lighten his load a bit. I refer to him as Erin’s father, because that is how I am often referred to in my community, not as Dave, but simply as “Angela’s daddy”. I walked with him for about an hour. He was a farmer working the same land his father had put his life into. He and his wife have not been more than 24 hours away from Erin for 32 years. They rarely traveled. For this trip someone had given him a GPS so he could get to the gathering successfully. Problem was, they did not program the way home and he was fretting about this (somebody at the gathering eventually did this for him). Thirty-two years had been a long road (without benefit of map or GPS). When their child was born, very, very little was known about these children, there was no internet, no support organization, nothing. They were at the ends of the earth. Alone. The doctors told them to leave the child and just walk away. I told him that they had told us the
When Angela Met Erin

(Continued from page 19)

very same thing. He was amazed that they would still be doing that so many years later.

As we were walking, I noticed that Erin had a scar from an encephalocele on the top of her head just like Angela. I mention the encephalocele and the father just smiles. He knows I know. The whole time we are walking up and down this street, I am looking at this child in utter amazement. The similarities are so striking. I wonder out loud how I could last 32 years with Angela and he tells me that I have to believe that I have been chosen for this task because of who I am, and that I can handle it. I am not sure I believe him, but I don’t argue with him. I am perhaps one of the few fathers on the planet who has any inkling of what this man has gone through in the last 32 years of his life. Is he sad, broken down, a shell of himself? I don’t know. He is quiet. He moves slowly and methodically up and down the road, gazing at whatever is at hand to provide some interest, the trees, a lawn-mower, or some kids playing down the street. He is not bitter. At peace is what comes to mind, patient, circumspect, content with simple things. I find myself becoming similar, just happy for a stolen moment on a cool day to look at the clouds or a patch of interesting trees. Twenty four hours in 32 years.

When Angela Met Erin

We toy with the hypothesis that they like the hardness and the cold. It is not too late at all. You just don’t know yet what you are capable of. - Mahatma Gandhi

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Unable are the loved to die. For love is immortality—Emily Dickinson 1830-1886

Remembering Joanna Hassan, 1974-2013

By Pam Healey
On February 3, 2013, Joanna Hassan, SOFT’s oldest person with trisomy 18, died, about six weeks after being hospitalized with pneumonia. Joanna was 38 years and three months. When she was born in a New York hospital in 1974, her parents Chris and Boni, were told there were no children surviving with trisomy 18. In time they learned there were others and joined SOFT. They went to SOFT conferences, their last in 2001. In Pittsburgh in 1999 Joanna happily held the littlest children, joined the party and was delighted to be wheeled about to where the action was. She was spirited and curious. Joanna by defying the conventional wisdom about trisomy 18 opened possibilities for the many children who followed her. Her parents were actively involved in SOFT for many years, helping others to learn what to do and what to expect, serving on the board, expanding our presence internationally, and giving support to Spanish speaking parents. Joanna is survived by her mother Chris and her sister Mary and by her extended family. Joanna is fondly remembered for her cute smile and liveliness, along with her unimagined longevity.

“When remembering the person I have loved allows me to slowly heal. Healing doesn’t mean I will forget. Actually it means I will remember.” — Alan D. Wolfelt Ph.D.

When Angela Met Erin

(Continued from page 20)

Saturday night, through Boston on I-93, there were fireworks above Fenway Park, a blimp, the lights of the tunnels, the shush and growl of the traffic, and myself behind the wheel in the dark. Everybody else in the car was asleep, and I was thinking of the day’s events. Two things stuck in my mind. One is the intense bonding that normally occurs for a short period when a child is small is extended with these children. They are small children longer. Sometimes for 32 years. This is something unusual, a wrinkle in the curve of the lens through which most folks view the universe. Two, the likeness these children bear to each other despite age, gender and racial differences. They are more alike to each other than they are to their siblings or parents. They are truly their own little tribe. And this can be tough on surviving parents who see their own children, often strikingly so, in the children of others. Finally, I am astonished that we could live so differently, and inhabit such different times, yet because of these children, and what a powerful organizing principle they can be in our lives, we end up inhabiting the same spaces, and coming to similar conclusions. It gave me an insight into the processes by which the subtle yet powerful mechanisms of the universe go about minting its inalienable truths. That abacus was more than an abacus; it was a testament to a long shared yet independently arrived-at and inevitable conclusion, one that was drawn across many miles and many years, something akin to what you might call the original old time religion, in short a rare glimpse into the workings of the penultimate organizing principle, or what is more commonly referred to as the hand of God. This weekend I peered into the future and saw how my own child will look if she and I are still alive when I am 72 years old, and the continuing challenges we will face. To have someone to love in this way for so many years would truly be a gift of inestimable value, albeit a very difficult one. One only hopes that it is possible to survive such riches as these.
Finding Her Way Erin Handel - 1978-2013

(Continued from page 18)

energy, adaptability and fortitude they had needed in recent years.

The last time I saw Erin was at another New England SOFT Gathering 19 years later. She was not as mobile, arrived with a bit of an attitude, since the long ride did not bring her to her cousins’ house, where she expected to be, but she settled in, relaxed on her blanket spread on the lawn, interacted with anyone close by, and ate. She got to know young Angela, who was intent on checking out Erin’s toys. I think she shared. Angela’s parents could see in Erin, the possibilities they held for their daughter. At one point Erin grew restless and needed to move about, and her dad pushed her wheelchair through the neighborhood. Erin was still on her journey, checking out new places, teaching others, directing others and capturing all of us with her distinct personality.

I thought about Erin decked out in red, white and blue in Boston in 2001, when her curiosity, sociability and determination were evident. She didn’t stay long. Erin needed her own bed and even a luxury hotel could not compete with what was familiar. While there, she held court, met John from Scotland, another redhead with trisomy 13, and Aaron Barg, and checked out numerous other SOFT kids and their parents.

Last Sunday the GPS worked, and we arrived at “our destination,” a picturesque church in a neighborhood near the Handel family farm. We went inside, stopping at posters filled with pictures of Erin. One poster was labeled “Red,” the other “Trouble” and “Badness,” all nicknames Erin had acquired. In those pictures we saw her grow up, reach out and act out. The minister later reminded us that Erin was an instigator, looking to mix things up and cause some chaos. Even from her wheelchair tucked in the back corner of the sanctuary, she could divert attention from scripture and sermon. The many family pictures displayed showed her enjoying life: happy and active, insatiably curious and sociable, feisty and intense.

Before entering the sanctuary, people were invited to choose a bandana that had been Erin’s. She had a vast collection in varied colors and patterns to match her many outfits. I chose a bright green, yellow and white one with stripes and polka dots. It was cheerful, as Irish as her name, whimsical, and suggested spring, the season of promise. The church filled. Men wore bandanas in their breast pockets or as arm bands. Women tied theirs around purse handles or held theirs gently. Erin’s cousins, sitting in the front pews wore bandanas in their hair. Teddy bears sat in some pews, a new tradition to welcome young families, but they were fitting for celebrating the life of Erin who despite her years, developmentally remained a child.

On the worship aid were printed the words to Neil Diamond’s “Skybird” which spoke to finding direction in Erin’s unique journey: “Skybird make your sail, / and every heart / will know the tale. / Songbird make your tune, / for none may sing it / just as you do. /… Nighthbird find your way, / for none may know it just as you may.” In her unexpected longevity, wandering ways, and mission to bring others to what is truly important, Erin found her way.

The service started with “Joyful, Joyful, We Adore Thee” and we sang to “Melt the clouds of sin and sadness, drive the dark of doubt away,” asking, “Giver of immortal gladness, fill us with the light of day!” Van Dyke’s century old words spoke of trust, joy and hope, resonating with those singing. Beethoven’s “Ode to Joy” must have caught Erin’s attention. Soon, the minister told anecdotes of Erin protesting long sermons, getting louder, her comments coming faster, until he did as she wanted and just got to the music. She loved the music, the louder the better. We complied. Finally, the minister played a song with a message those mourning Erin should remember: love remains. Beyond the sadness, beyond the painful loss of her presence would always be the love. Love remains.

The service ended with the congregation singing “Rise and Shine” while some people left their seats with bells and noisemakers, winding their way up and down the aisle, through some pews and spontaneously enveloping Erin’s wheelchair, which was brought from her corner down the aisle to the front of the sanctuary. The minister gave the Irish blessing, and we sang “On Eagle’s Wings.” We left knowing Erin a bit better. We left touched by her strong spirit. We left knowing: Love Remains.

I thought back on Erin’s life marked by exploration, defined by love. I thought of Bob and Lisa, Jared and Becky, and all Erin’s grandparents, aunts, uncles and cousins, and how their lives had been enhanced by Erin, as they explored with her. It was love that led Bob and Lisa to spurn the advice offered and take Erin home to care for in the time they would be given. They must have held trust and hope. They were given joy. Now, three and a half decades later, they are left in their home with so many memories and so much love. They have returned to where they started, but everything has been changed by Erin who brought not only love but wisdom, faith, joy, laughter, light and just enough of the unexpected to keep them alert as they accompanied her on her explorations. T.S. Eliot’s words from “Four Quartets” came to mind.

We shall not cease from exploring And at the end of our exploration We will return to where we started And know the place for the first time.

Erin’s GPS may have been a bit quirky, directions often contradictory, her way that of a skybird bound by no roads, but she brought everyone back to where they were meant to be, where, changed, they knew both the place and themselves for the first time.
The Erin Jorgenson Memorial SOFT Sibling Scholarship

The Erin Jorgenson Memorial Scholarship was established by the 2010 Conference Hosts, Kim and Gloria Jorgenson, of Waubay, South Dakota, in honor of their daughter Erin, who had a trisomy 18 condition. This $500 annual scholarship is awarded based on criteria explained in the application and is available to those attending college, university or trade school. Applicant families must be current SOFT members but attendance at the annual conference is not required. The deadline for applying is 1 June, each year.

ERIN JORGENSON MEMORIAL SOFT-SIB SCHOLARSHIP

Qualifications
1. Must have/have had a sibling with Trisomy 18, Trisomy 13, or a Related Disorder.
2. Family must be paid-up SOFT members.
3. Applicant must be entering at least 2nd year of college, university, or tech school.
4. Attendance at the upcoming SOFT Conference is desirable but not mandatory.
5. Past recipients are not eligible to reapply.

Deadline
Applications and accompanying materials must be postmarked by June 1, 2013. Applicants are encouraged to submit applications early, so if any needed material is missing, it can be corrected before the deadline.

Presentation
The $500 Scholarship award will be announced and presented at the upcoming SOFT Conference. The money will be given directly to the recipient to be used as needed:
   a. Tuition and fees required to enroll or attend an educational institution, OR
   b. Fees, books, supplies, and equipment required for courses of instruction.

If the recipient is unable to attend the SOFT Conference, the check will be mailed to him/her.

Application
Copies may be made of the following application, or to receive a printable application online e-mail Gloria Jorgenson at Gloriajayne1957@gmail.com
Questions may be e-mailed or call Gloria at 605-947-4752(home) or 605-947-4461(work).

ERIN JORGENSEN MEMORIAL SOFT-SIB SCHOLARSHIP APPLICATION

I. Personal Information
   Name ____________________________________________
   Address ____________________________________________
   City, State, Zip _____________________________
   Phone _____________________________
   E-Mail _____________________________________________________________
   Career Goal ____________________________________________
   _____________________________
   Extracurricular Activities, Volunteer Activities, Work History
   ____________________________________________
   _____________________________
The Erin Jorgenson Memorial
SOFT Sibling Scholarship

II. Academic Information
School you will be attending_____________________________
Address_____________________________________________
City, State, Zip________________________________________
Phone (admissions office)______________________________
Anticipated Graduation Date (month/year)__________________

III. SOFT Sibling Information and Essay
SOFT Sibling Name___________________________________
Diagnosis___________________________________________

Please attach an essay of no more than 600 words about your SOFT Sibling and the impact he or she had on your life.

IV. Please include two signed letters of recommendation. These may be from employers, instructors, church contacts, etc.; not family members.

V. Application Certification, Signature and Date
I hereby certify that all of the information provided in this application is complete and true to the best of my knowledge. I hereby grant permission for the scholarship committee to contact my references and/or school if necessary, and if granted this Scholarship I agree to the publication of my name and likeness.

Applicant’s Signature__________________________________
Date Submitted______________________________________

Mail completed application, postmarked no later than June 1, 2013, to

Kim and Gloria Jorgenson
10 High Plains Avenue
Waubay, SD 57273

Be sure to include with the signed and dated application:

● Your essay AND
● Your two letters of recommendation

The Light-Keeper II
by Robert Louis Stevenson

As the steady lenses circle
With frosty gleam of glass;
And the clear bell chimes,
And the oil brims over the lip of the burner,
Quiet and still at his desk,
The Lonely Light-Keeper
Holds his vigil.

Lured from far,
The bewildered seagull beats
dully against the lantern;
Yet he stirs not, lefts not his head
From the desk where he reads,
Lifts not his eyes to see
The chill blind circle of night
Watching him through the panes.

This is his country’s guardian,
The outmost sentry of peace,
This is the man
Who gives up what is lovely in living
For the means to live.

Poetry cunningly guilds
The life of the Light-Keeper,
Held on high in the blackness
In the burning kernal of night,
The seaman sees and blesses him,
The Poet, deep in a sonnet,
Numbers his inky fingers
Fitly to praise him.
Only we behold him,
Sitting, patient and stolid,
Martyr to a salary.

... Robert Louis Stevenson

The way I see it is if you want the rainbow, you gotta put up with the rain.-Dolly Parton
Conference Schedule
July 17-21, 2013

Wednesday, July 17
8:00am - 6:00pm SOFT Board of Directors Meeting

About Rhode Island
In Providence see the capital and visit museums at Rhode Island School of Design and Brown University. Federal Hill along Benefit Street, a restored Georgian Federal and Victorian neighborhood slated for demolition in the 1950s and brought back to life with renovated homes, brick walks, gaslight and small gardens. Modern Providence includes the Providence Performing Arts Center, in historic Federal Hill and sites of fine dining, brick oven bakeries, boutiques and seaside benches to catch your breath and look out the bay.

About the conference
The SOFT Conference, will be held at the Crowne Plaza, Warwick, RI. Located at 801 Greenwich Ave., Warwick, RI, 02886. The hotel is located 10 minutes from downtown Providence, and 2.5 miles from downtown Warwick, part of metropolitan Providence. It is one of the nation’s oldest hotels. Our hotel is in the heart of the hotel, with access to restaurants, shops, boutiques and seaside benches. Mention the SOFT conference when making a reservation to get the SOFT rate. Reservations end June 25.

S.O.F.T. (Support Organization for Trisomy 18, 13 and Related Disorders)
S.O.F.T. is a network of families and professionals dedicated to providing support and understanding to families affected by Trisomy 18, 13, and related chromosomal disorders. Support is provided during prenatal diagnosis, the child’s life and after the child’s passing. SOFT is committed to respect a family’s personal decision in alliance with a parent and care in Trisomy 18, 13, and related chromosomal disorders. 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 related chromosomal disorders. Support is provided during prenatal diagnosis, the child’s life and after the child’s passing.

Hotel Accommodations
The SOFT Conference will be held at the Crowne Plaza, Warwick, RI.

Medical Clinics
The SOFT Medical Clinics will be held at Hasbro Children’s Hospital/Rhode Island for all families attending the conference with a living SOFT child if there is a subspecialty medical need. The conference with a living SOFT child if there is a subspecialty medical need, will be held at the Crowne Plaza, Warwick, RI.

S.O.F.T. Conference will be held at the Crowne Plaza, Warwick, RI. Located at 801 Greenwich Ave., Warwick, RI, 02886. The hotel is located 10 minutes from downtown Providence, and 2.5 miles from downtown Warwick, part of metropolitan Providence. It is one of the nation’s oldest hotels. Our hotel is in the heart of the hotel, with access to restaurants, shops, boutiques and seaside benches. Mention the SOFT conference when making a reservation to get the SOFT rate. Reservations end June 25.

Email: info@soft.org
Website: http://www.trisomy.org

Nobody will believe in you unless you believe in yourself. - Liberace
Picnic and Balloon Release Information

For questions, please email Cindy at newbeg08@aol.com.

The SOFT balloon release, held during the picnic on Saturday, July 20th, will be 6:30pm. The annual Auction will be held on Saturday evening at 6:00pm.

May/June/July 2013, The SOFT Times, Page 26

http://www.mysticseaport.org/

http://www.rwpzoo.org/

http://www.softannualvideo.com

http://www.gonewport.com

No matter how bad things are, you can always make things worse. — Randy Pausch, The Last Lecture
**SOFT Conference Registration – Providence 2013**

**Member # ____________________ Member(s) Name: ____________________**

**Email: ____________________**  
**Mailing Address: ____________________ City: ____________________ State: ________**

**ZIP: ____________________ Country: ____________________ Phone: ____________________**

**Travel Mode: ____________________ Arrival Date: ________ Time: ________ Departure Date: ________ Time: ________**

**First-time attendee? (circle) Yes/No**

Please indicate if your SOFT child will eat conference meals: (circle) Yes/No

**Clinic Transportation Needs:**  
**Picnic Transportation Needs:**

**Friday Night Outing to Newport Needs:**

Please Indicate Number of people attending Chapter Chair Luncheon: ________ (Chapter Chairs & Prospective Chapter Chairs ONLY)

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<table>
<thead>
<tr>
<th>Attendees</th>
<th>Friday Sibling Outings</th>
<th>Child Care</th>
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</table>
| Badge Name (First & Last)  
* Please print legibly! | Child Age | Type | 6-11 | 12+ | Wed | Thurs PM | Friday AM | Friday PM | Friday Eve. |
| | | | | | | | | | |
| | | | | | | | | |
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| | | | | | | | | |

* Registration Type: A=Adult, S=SOFT Person, C=Child 11 yrs. and younger, P=Professional  
** For Board Members Children Only  
● If attending either Sibling Outing, please specify T-shirt size

**CLINICS**

The clinics offered this year are as follows. They are available only to families attending the conference with a living SOFT child. Identify 4 choices of clinics (with #1=most important, #4=least important). Please make sure clinic transportation needs are specified above. Pre-enrollment required.

**DEADLINE FOR SCHEDULING CLINIC REQUESTS: 6/15/2013. No clinics will be accepted after this date.**

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<tr>
<th># Attending</th>
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<tr>
<td>Pediatric Craniofacial Therapy</td>
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<td>Pediatric Cardiology</td>
<td>Pediatric Orthopedics</td>
<td>Developmental Pediatrics</td>
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**OPTIONAL GRIEF OUTING**

For those families not eligible or choosing not to attend the clinics, we are offering an off-site bus trip to Jamestown & Beavertail State Park with a grief counselor for families that have lost a SOFT child. Cost is $15 per person.

**Grief Outing Transportation Needs:**  
**Workshops**

**Thursday & Friday Workshop Pre-registration:**

Please indicate how many people from your family will attend the following workshops.

If you are requesting a Certificate of Attendance, please provide name(s) on the certificate: ____________________

<table>
<thead>
<tr>
<th># Attend</th>
<th>FRIDAY MORNING – July 19th</th>
<th># Attend</th>
<th>FRIDAY AFTERNOON – July 19th</th>
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<tbody>
<tr>
<td>Keynote Speaker – 9:15 – 10:15am</td>
<td><strong>SESSION 2</strong> – 1:15 – 2:15pm</td>
<td>A</td>
<td>Trisomy 18, 13, &amp; Related Disorders</td>
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<tr>
<td>Keynote Speaker: Elissa Al-Chokhachy – Miraculous Moments</td>
<td><strong>SESSION 3</strong> – 2:30 – 3:45am</td>
<td>A</td>
<td>Mom’s Only Workshop</td>
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<td>B</td>
<td>Dad’s Only Workshop</td>
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<td><strong>SESSION 1</strong> – 10:30 – 11:30am</td>
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<td>A</td>
<td>Letting the Child Lead</td>
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<td>B</td>
<td>TRIS: Long Term Survivors w/ T18 &amp; T13</td>
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<td>C</td>
<td>Grieving After the Loss of a Child: (Parents &amp; Siblings)</td>
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<td>D</td>
<td>So you want to host a conference: What you need to know.</td>
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</table>
Ryan Cantrell Memorial Balloon Release Celebration Information

The annual balloon release will be held during the picnic on Saturday afternoon, July 20, 2013. You need not be in attendance to have a balloon released for a child who has passed. Fill out and return the following information, and we will ensure that a balloon is released for your child.

Please complete & mail before the conference

Child’s Name: ____________________________ Date of Birth: ______________ Date of Death: ______________ Disorder: ____________________________

Submitted by Name: ____________________________ Relationship: ____________________________

Address: ____________________________ City: ____________________________ State: ______________ ZIP: ______________

Phone: ____________________________

SOFT-wear ORDER FORM

We will have the following items for sale at the conference. Help us avoid disappointing you by ordering early so that we can place our orders and have the items you want. **DEADLINE FOR ORDERS: 6/15/2013**

<table>
<thead>
<tr>
<th>Type</th>
<th>2-4 (XS)</th>
<th>6-8 (S)</th>
<th>10-12 (M)</th>
<th>14-16 (L)</th>
<th>Total</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth T-shirt</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$10</td>
</tr>
<tr>
<td>Adult Short-Sleeved T-shirt</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$14</td>
</tr>
<tr>
<td>Adult’ Short-Sleeved T-shirt (Larger sizes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult’ Long-Sleeved T-shirt</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$16</td>
</tr>
<tr>
<td>Adult’ Long-Sleeved T-shirt (Larger sizes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Non-Taxable Total) ____________________________

CONFERENCE COST COMPUTATION

<table>
<thead>
<tr>
<th>Attendees</th>
<th>#</th>
<th>Cost (each)</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current SOFT members: Full Conference Adults &amp; Children 12 &amp; over (INCLUDES PICNIC)</td>
<td></td>
<td>$110.00</td>
<td></td>
</tr>
<tr>
<td>Non-SOFT members: Full Conference Adults &amp; Children 12 &amp; over (INCLUDES PICNIC)</td>
<td></td>
<td>$135.00</td>
<td></td>
</tr>
<tr>
<td>Full Conference SOFT Children and siblings 4 and under (INCLUDES PICNIC)</td>
<td></td>
<td>FREE</td>
<td></td>
</tr>
<tr>
<td>Full Conference Children (5 – 11 years old) (INCLUDES PICNIC)</td>
<td></td>
<td>$85.00</td>
<td></td>
</tr>
<tr>
<td>Friday Sibling Outing (12+ yrs. old) Mystic Seaport (Includes lunch &amp; t-shirt)</td>
<td></td>
<td>$20.00</td>
<td></td>
</tr>
<tr>
<td>Friday Sibling Outing (6-11 yrs. old) Roger Williams Zoo (Includes lunch &amp; t-shirt)</td>
<td></td>
<td>$18.00</td>
<td></td>
</tr>
<tr>
<td>Optional Grief Outing</td>
<td></td>
<td>$15.00</td>
<td></td>
</tr>
<tr>
<td>Professionals: Workshops on Friday Only</td>
<td></td>
<td>$35.00</td>
<td></td>
</tr>
<tr>
<td>Friday Night Outing in Newport</td>
<td></td>
<td>$15.00</td>
<td></td>
</tr>
<tr>
<td>Picnic* Only (Saturday afternoon): Adults &amp; Children 12 &amp; over</td>
<td></td>
<td>$25.00</td>
<td></td>
</tr>
<tr>
<td>Picnic* Only (Saturday afternoon): Children 11 &amp; under</td>
<td></td>
<td>$15.00</td>
<td></td>
</tr>
<tr>
<td>Late Fee, EACH Adult, postmarked after 6/15/2013</td>
<td></td>
<td>$25.00</td>
<td></td>
</tr>
<tr>
<td>SOFT-wear TOTAL (from above)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donation to Joey Watson Fund</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A donation to the 2013 Conference Fund will be appreciated</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donation to SOFT National (Any donations will be appreciated)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* The picnic cost is included for full conference attendees

(Grand Total) ____________________________

Please enclose one check or money order (in U.S. Funds drawn on a U.S. Bank) payable to SOFT, or include VISA or MASTERCARD information below, and return this registration form to:

**SOFT/VanHerreweghe; 2982 S. Union St; Rochester, NY 14624**

or FAX to SOFT @ 585-594-1957

VISA or MasterCard # ____________________________ Exp. Date: __________ / __________

Last 3 digits on the back of card: ____________________________

Registration questions? Contact: Pam Healey healeylex@aol.com

For the very latest information, see our website at: http://www.trisomy.org

**Remember!** You must make your own hotel reservations with the Crowne Plaza

by June 29, 2013: 401-732-6000 or 1-800-227-6963 or via internet at providenceri.crowneplaza.com.Use our 3 letter group code of SOF. Make sure you make known any special needs you might have.

**IMPORTANT: No registration will be processed until final payment is made!!**
Don't forget to renew your SOFT membership!

**SUPPORT ORGANIZATION FOR TRISOMY 18, 13 AND RELATED DISORDERS**

If you prefer to complete a membership form on line, go to [www.trisomy.org](http://www.trisomy.org) and click on the membership tab to access the form.

| PARENT Name(s): | | | | | |
| --- | --- | --- | --- | --- | |
| Mail Address: | | | | | |
| Phone: | # Street | City/Town | State/Province | Country | Zip Code |
| E-mail: | | | | | |

| CHILD’s Name: | Sex: | Date of Birth: | Date of Death, if applicable: |
| | | | |

**Cause of Death, if applicable:**

Diagnosis: 18 ☐ 13 ☐ Other ☐ Full ☐ Mosaic ☐ Partial ☐ Translocation (please specify): ____________________________

Other (please explain): ____________________________

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

<p>| Birth weight: | Birth Length: |</p>
<table>
<thead>
<tr>
<th>lbs/oz</th>
<th>inches</th>
</tr>
</thead>
</table>

Current/Last known Weight: (lbs/oz) Current/Last known Length: (inches)

<table>
<thead>
<tr>
<th>Circle how was your child fed?</th>
<th>Tube only</th>
<th>Orally (mouth) only</th>
<th>Both orally &amp; tube</th>
<th>Other: explain</th>
</tr>
</thead>
</table>

**Immunizations:** (circle answer where applies)

1.) Is/ was your child up-to-date with State recommended immunizations? **YES** **NO** Don’t Know
2.) Did your child receive the Synagis series for prevention of RSV? **YES** **NO**
3.) Does/ did your child receive a seasonal flu vaccine every year? **YES** **NO**
4.) If your child had a reaction to any vaccine, please explain which immunization and reaction.

**Surgical Information:** If there are not enough spaces, please provide requested information on paper and mail with form

<table>
<thead>
<tr>
<th>#</th>
<th>Date</th>
<th>Name of Surgery</th>
<th>Name, City, State of Hospital</th>
<th>Name of Doctor</th>
<th>Successful?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SOFT Survey:** (Circle answer which applies) Providing this information is optional.

1.) How did you learn about SOFT? **Health Care Provider** **SOFT parent** **WEB site** Other (explain) ____________________________
2.) Barb VanHerreweghe, SOFT president, is the contact person for states that do not have a local chapter chair. Have you been in contact with Barb? **YES** **NO**
3.) Have you been in contact with your state’s local SOFT chapter chair? **YES** **NO**

<table>
<thead>
<tr>
<th>SOFT MEMBERSHIP IS FREE, including the on-line quarterly newsletter. A mailed copy of the newsletter can be ordered from the website’s Shop SOFT Tab at <a href="http://www.trisomy.org">www.trisomy.org</a> (USA addresses only), or by sending payment with this form. Mailed USA subscriptions are $25 per year.</th>
</tr>
</thead>
</table>

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

If you wish to donate to the Joey Watson fund, please enter the amount here: __________

**SOFT SURVIVES ON DONATIONS!** If you wish to donate to SOFT’s general fund, please enter the amount here: __________

$25 Newsletter Subscription, if desired (USA only): __________

TOTAL AMOUNT: __________ THANK YOU!

Circle Card Name: **VISA** **MasterCard** Card #: __________

Last 3 digits on back of the card (security code): __________ Exp date: ____/____ (month/year)

Signature: __________ Date: __________

PLEASE SEND THIS FORM (and any donation, by check or credit card) to:

**SOFT Membership Committee, c/o Barb VanHerreweghe, 2982 South Union St., Rochester, NY 14624 (800)-716-7638**

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

[MembershipForm3-26-2013.docx]

GO TO [http://www.trisomy.org](http://www.trisomy.org) FOR INFORMATION ABOUT SOFT, CONTACTS, MEDICAL AND FAMILY INFORMATION, AND THE NEXT CONFERENCE.
Remembering

SOFT

Angel Wings

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

<table>
<thead>
<tr>
<th>NAME</th>
<th>BORN</th>
<th>Angel Wings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erin Margaret Jorgenson</td>
<td>November 4, 1994</td>
<td>May 4, 1995</td>
</tr>
<tr>
<td>Jessica Riley Warpehoski</td>
<td>May 4, 2002</td>
<td>May 4, 2002</td>
</tr>
<tr>
<td>Matthijs De Kievit</td>
<td>February 23, 1999</td>
<td>May 9, 1999</td>
</tr>
<tr>
<td>Morganne Jayme Dye</td>
<td>October 8, 1998</td>
<td>May 13, 1999</td>
</tr>
<tr>
<td>Noah Thomas Campbell</td>
<td>October 10, 2000</td>
<td>May 14, 2001</td>
</tr>
<tr>
<td>Madison Gabrielle (Gabby) Aultman</td>
<td>April 17, 2008</td>
<td>May 21, 2009</td>
</tr>
<tr>
<td>Isabella Josephine Wolfe</td>
<td>May 23, 2011</td>
<td>May 24, 2011</td>
</tr>
<tr>
<td>Aimée Marie Sahota</td>
<td>February 25, 1999</td>
<td>May 31, 1999</td>
</tr>
<tr>
<td>Kari Deann Holladay</td>
<td>September 8, 1977</td>
<td>June 3, 1988</td>
</tr>
<tr>
<td>Jordan Elizabeth Chamberlin</td>
<td>June 4, 2009</td>
<td>June 7, 2009</td>
</tr>
<tr>
<td>Gabriella Ann Romano</td>
<td>February 2, 1992</td>
<td>June 13, 2000</td>
</tr>
<tr>
<td>Ryan Cantrell</td>
<td>October 4, 1985</td>
<td>June 15, 1986</td>
</tr>
<tr>
<td>Michael Edwin Weber</td>
<td>June 18, 2011</td>
<td>June 18, 2011</td>
</tr>
<tr>
<td>Carey Ann Neufeld</td>
<td>September 27, 1983</td>
<td>June 18, 2012</td>
</tr>
<tr>
<td>Christian Mansfield</td>
<td>June 24, 2000</td>
<td>June 24, 2000</td>
</tr>
<tr>
<td>Fegan Kathryn Parks Cuzzolini</td>
<td>January 20, 1994</td>
<td>June 25, 1994</td>
</tr>
<tr>
<td>Brandy Kaye Woodcox</td>
<td>September 25, 1975</td>
<td>June 29, 1994</td>
</tr>
</tbody>
</table>

Email Jack Laird for family contact info at jlaird@rochester.rr.com
Carey Ann’s Treasure Chest is back for the raffle at this year’s SOFT conference. Craig and Marie say the value exceeds $500, but we know it is priceless! To acknowledge the location, Boston and The Colonies, the surprise inside the box has the following two clues:

1. “The British are back, the British are back!!”
2. “You shall not tread on us.”

CALL for AUCTION Items

Sponsorship Opportunities Available for the Following Items:
Contact Pam Healey at healeylex@aol.com for more information

- Busses
- Childcare supplies $600
- Lanyards and Nametags $300
- Wednesday night welcome need funding amount not known
- Friday luncheon funding needed
- General Conference contributions
Deadline for the Fall/Post Conference Issue of The SOFT Times is 1 August 2013

POSTMASTER: address correction requested

Remembering Boston Strong