A Message from our SOFT President

Dear SOFT Families:

Conference has come and gone and we are now in the waiting period to all get together again. Two months down and counting! This year was a very special time for all that attended. How great was it to walk up to the hotel and those that had living children saw their child’s name on a star! So special. We started with the welcome reception on Wednesday evening. There was great food and great old and new acquaintances. It felt like family right from that night forward! Thursday was the SOFT Stroll for Hope! Thanks to all that earned the money to help support SOFT and the conference. Everyone took the Stroll down the riverbank to the mermaid and back. Krissy and Larry even displayed Krissy’s new hot pink marathon running chair! How exciting was that? Thursday afternoon was the start of clinics for families and the grief workshop for others. Thursday evening we started with The Zion Lint Walk of Fame. Each child walked in as their name was called to receive their specially carved and painted mermaid. Smiles from ear to ear as they heard their name called. Everyone then enjoyed a delicious dinner, followed by hearing from Rick from Positive Exposure. We all knew our children have special beauty but he reinforced just how beautiful each and every one of them is. Thanks Rick for believing in our kids. Now next I think I heard there is some video of those of us that thought we might be able to do a little Zumba with Melissa Marohn leading us to Rolling on the River. I learned that it is great to have fun but Zumba probably isn’t what I am best at! Then dancing the night away as the kids rolled around in their wheelchairs, walkers or as they stood on the dance floor.
Friday we started the workshops, had a chapter chair luncheon and learned many new and helpful facts about our children or how best to work with them. The Dad’s and Mom’s workshops were the largest ever and a great time to share with each other. Then we were off to the ball field for dinner and to watch the Tidewater Tides. Saturday morning was the video with all our children and their beautiful pictures so lovingly created by Hal and Kris Holladay. Always special in every way. Then we were off to the Vintage Kitchen on the River walk for a delicious picnic. It was then time to honor the life of our special Angels who left us way too early. Each name was called as we watched a single balloon disappear from our eye sight. Then one large balloon with many tags of other friends and to represent those children we do not know and those to still be born. Each one of them still in our hearts forever.

That evening we had the annual auction to assist with the costs of the conference and to have fun as we bid against each other and tried to guess what the special surprise Craig Donaldson had crafted this year. Many beautiful quilts handcrafted by friends, family and you! This year was our first year offering some of the items on-line. The auction was successful, fun and a great time to share time with each other. Sunday brought the closing service and we were off for some extended vacation or for the long travel home only to hold our new friends in our hearts and counting the days till 2015.

Salt Lake City here we come! They have already had their Walk Run and Roll event to start kicking off their fundraising to get ready for next year. So keep the dates open July 8-12. Start planning now. Prepare for the Stroll for next year. Don’t miss another great year.

We thank our old Board members and welcome the new Board members. Thanks to the Whole Conference committee it was amazing. Thanks to Terre Krotzer for the wonderful directory allowing us to know each other and to continue to communicate with each other after the conference. Thanks also to Terre for all the special videos and pictures she has created for us this year. Thanks to Ann and Frank Barnes for their daily commitment to our website which helps us keep up to date and to help new families learn from the minute of their diagnosis. The CareBook is now available right on line and we hope to have the Guidebooks ready soon. Thanks to the admins on Facebook especially Therese. Helping us learn from each other Facebook to Facebook. It is amazing to see those birthday stories daily with the help now also of Christine Werner. Make sure you put your child’s story up on the website so their story can be presented on their special day. Go to www.trisomy.org then click family stories.

Cherish each and every day. Hope to see you all in Salt Lake City to support our Heroes, our children!

Barb VanHerreweghe
Just the other day, I was thinking back on all the experiences we have had and all the many things learned from having a child born with Trisomy 18. I wondered if I were given the chance to change anything about her life, and even her death, would I do it. Then, in the same thought I realized, I am who I am because of her life and I am eternally grateful to our daughter, Kari Deann Holladay, born with Trisomy 18 on September 8, 1977.

I remember reading the book by Robert Fulgham called All I Really Need to Know I Learned in Kindergarten. I recall thinking that he had simple yet profound wisdom. Along that same thought, I would like to share some of the things I have learned.

Things I learned from Kari:

1. **Open your heart.** Allow love to completely take over and the unconditional love will begin to heal even a broken heart.
2. **Keep smiling.** Even if at that moment I didn't feel happy, I found out if I smiled, I eventually did feel happier.
3. **If you are having a bad day, make the most of it.** I knew that I could only feel sorry for myself for a short while, so I made sure I indulged in a bit of “me time”, too.
4. **Look for rainbows.** There is some good in every experience, even if the challenge seems to beat us down, look up.
5. **Stand up for your convictions.** It is possible and even effective to learn how to disagree without being disagreeable.
6. **Share your story.** The examples of others can pave the way for our own journey. I know I have learned from your stories and thank you for sharing them with me!
7. **Keep a balance.** It's okay to cry. It's even better to laugh. And, don't forget to sing & dance, eat & drink, work & play.
8. **Be strong.** Sometimes our strengths are hidden amongst our weakness, so keep looking.
9. **Believe in hope.** Even when I heard that Kari's life was hopeless, I didn't believe it! I knew there was always hope. I hoped for Kari to have respect and value and love in life and in death.

Robert Fulghum writes: “I believe that imagination is stronger than knowledge. That myth is more potent than history. That dreams are more powerful than facts. That hope always triumphs over experience. That laughter is the only cure for grief. And I believe that love is stronger than death.”

Hugs….Kris
Conference Wrap-Up 2014

Getting to the conference involved multiple airports for some, and traffic jams for those heading south through a long metropolitan corridor. After getting traffic reports from those arriving a day earlier, we planned to travel New Jersey at night. Ahh, but night is bridge painting in Bridgeport and road work in New York. We breezed through Maryland and Delaware, a section that took three times longer on the daytime return trip. We arrived in Norfolk with the sun.

The 2014 SOFT International Conference in Norfolk, Virginia, was well attended with many new families discovering what they have been missing, reunions of old families, remembering Nicholas and Philina our much loved older kids whose loss was particularly felt at conference this year, and discovery of nearby attractions ranging from gardens, a zoo, beaches and good food.

This year’s SOFT reunion was a compact conference on the banks of the Elizabeth River. We looked out over a broad river and watched as ferries, fireboats, a tug pushing a massive barge, a three mastered schooner, yachts and small sailboats plied the calm waters against a backdrop of the crane and shrouded ship of naval industry, high rises and steeples and a yacht club. Some of us were lucky enough to watch the draw bridge open to let a large ship pass through.

By Wednesday evening following the long board meeting and the early arrival of many SOFT families, many were ready to Meet and Greet. We enjoyed good food and an opportunity to catch up with old friends and meet some new. This is a wonderful recent addition to the conference traditions. We talk with enough people to get in the SOFT spirit and begin to recognize SOFT folk. We know the people pushing wheelchairs are SOFT members, but we needed to look for name tags on others before we met them. Thursday brought a range of activities and some rain. Make that a deluge. First, was the Stroll for Hope along the river walk under gray but dry skies. The broad walkway was perfect for clusters of families to walk together pushing decorated wheelchairs and strollers and carrying signs that proclaim wisdom born of experience and love that survives when babies do not. There were children sporting bows, jaunty hats, flowers, beads and boas, flanked by siblings, caregivers, parents, grandparents, aunts and uncles in team shirts of various colors. The broad smiles, often boisterous, always happy camaraderie, teams that include members from several states, and comfort with what has been our destiny announces to passersby the diagnosis may unite us but not restrict us, and beyond any demands and concerns is joy. What would you do with any extra chromosome? Our presence in the Stroll for Hope confirms that we take life as we find it and find adventure and enjoyment along the way.
Thursday afternoons parted us for a few hours. Those going to clinics at Children’s Hospital of the King’s Daughters hopped and rolled onto buses and left to educate others as much as learn from the expertise of the local physicians. I wonder about the arrival of so many of our children at the local hospital, those same children who across the country left NICUs tied to necessary life supports and heartfelt prayers and grew stronger and met developmental milestones, developed distinct personalities, started school and wrote their own histories day by day and year by year. I wonder whether those amazing children erase from the minds of the clinicians they meet all the dreary accounts in textbooks that defined what they knew these children to be, or assumed could not be. I have sat in clinics and watched the smiles, games, energy of the children waiting to be seen by the volunteering doctor. I suspect many of those doctors, who helpfully give suggestions from their expertise that will guide SOFT parents, will also look at the next infant with trisomy differently in important ways. Knowing the possibilities, knowing a child carrying some extra DNA has engaged others, shown agency, and required love, may influence a future decision about treatment for another child. We send these children off not so much as patients but as ambassadors opening possibilities by becoming the face of trisomy for another group of clinicians.

For those who attend the conference carrying their child in their hearts, there was an outing to the Norfolk Botanical Garden, a magnificent 155 acre arboretum, lake and garden grounds that was developed in the late 1930s as a WPA project and further enhanced with special collections. Under increasingly threatening skies we took a tram that slowly circles the garden. We saw groves of crape myrtles, unfamiliar to us northerners, passed an extensive rose garden in full bloom, reds, yellows and oranges, more than 400 varieties of roses represented in 5,000 plants. Any one of those plants looks better than my roses planted in memory of Conor, adding a tinge of guilt and a promise of more effort going forward. There are lakes, ponds and fountains. There is a Renaissance Garden, a statue area, a colonial herb garden surrounded by boxwood, a butterfly house and garden and a medicinal garden. There is a children’s play area, World of Wonders, with fountains to cool the young ones, and many families alighted at that stop. The lush camellia garden was amazing, appreciated by those knowing how challenging it can be to nurture one small windowsill plant. The shed with a moss roof captured our attention, as did the eagle statue in front of the lake.

It rained during our trip but the tram protected us and we arrived back in time to visit a great gift shop. A few SOFT stragglers who first visited the zoo were not so lucky and completed their tour in drenching rain and booming thunder. In the van trip and on the tram we had a chance to visit. There was no grief work, just butterfly bags for those on their first SOFT grief outing and quiet talk about our children.
For many the loss is recent and the peacefulness of the gardens and the company of those who understand must have been comforting.

We arrived back, our driver deftly negotiating underpasses underwater. It was party time soon. The banquet began with the Zion Lint Parade of Stars, and one by one names were called and our amazing SOFT children and adults came forward to be recognized and to receive hugs and a hand designed wooden mermaid, a SOFT replica of the mermaids all over Norfolk. A touching addition this year was the poster remembering SOFT angels that was displayed near where the awards were given. Food, visiting, pictures and dancing followed. The tables were decorated with jars of shells thousands of years old deposited by tides or preserved in middens, dug up, and scrubbed to grace our tables in clear jars, flanked by flags. We ate well then danced, a highlight was an energetic line dance routine led by Melissa Marohn and soon learned by dancers of many generations. The band, “Side Tracked” was great and dancing was enjoyed for hours. Morghan Kubena plunked herself close to the band and put on quite a show, as she rhythmically waved her arms and bounced to loud music that made her smile. Wheelchair dancing, independent dancing by young and old, and dancing in arms filled the floor.

Friday brought a hearty breakfast, an introduction of new families, then packing the sibs off for a day of fun at the Children’s Museum, Sports Hall of Fame, and Waterpark. Parents busied themselves at workshops, making sometimes hard choices about which to attend. The workshops were informational with many experts willing to share their knowledge with parents hungry to learn, discuss and think about new information and ideas. The workshops ended with the Moms Only! and Dads Only! workshops, great opportunities to get to know other parents better, learn from them and realize that tasks and situations, daunting, stressful and confusing are shared, as are emotions, frustrations disappointments and joys. In the safe and open forum provided by these workshops, our community tightens, and we help each other, laugh together and cry knowing our tears whether of sadness or frustration are understood.

It was soon time walk the river walk to Harbor Park to root for the Norfolk Tides, a triple A farm team for the Baltimore Orioles. We enjoyed a barbecue supper before the game, then found our seats. It was a beautiful night, not too hot, an impressive sunset and no threat of rain. Some stayed for the double header against Gwinnett; others felt nine innings were sufficient. We visited more than watched. The Tides won a squeaker, 12-11, then lost 7-4 in the second game. There was plenty of action and some tense moments and it was hat night!

We returned to a happy reunion with the Harpers, an original family in the 1980s early days of SOFT making connections across the country. Joan and John,
parents of Kyle, mosaic trisomy 18 and his two older sisters, were newsletter editors and conference leaders for the 1992 SOFT Lights Harbor Place conference, the first for many families who have missed few conferences since. Liz Bona Cohen stood proudly behind Kyle’s chair, grabbing his arms, making him laugh, then finally announcing to the gathered crowd and to a few hotel guests as they entered the nearby side entrance and had no idea what SOFT is, that Kyle is her fiancé. Way to go Liz! Make a public announcement defining your relationship with a man without the language skills to protest or explain. I did see him smile; we’ll take that as agreement! Somewhere I have a picture of five year old Liz pursuing a slightly older Kyle across the playing field in Maryland. SOFT is about coming home, the first time, the twentieth time and the first time in a very long time. Welcome back Harpers. Now that you have met so many new families that have become old families in your absence, so many people that have kept what you helped begin going, and now that you know how much fun, love and poignancy you have missed, we are certain you will be back.

Saturday began with another great breakfast and sharing by families who have faced losses. We all awaited the Holliday’s video and settled in for laughter, amazement and a few tears. These masterpieces get better every year. Our founders have kept pace with technology and music, (despite their age), and add new creative touches each year. A business meeting and election followed, then it was off to the picnic, just down the river walk in front of the restaurant catering it. Ideal! The food was great and artfully presented, and we enjoyed it at tables under the tent, at riverside cafe tables and on blankets under the cool shade of trees. The women face painting the children stayed busy, and cheeks, knees, hands and entire faces were soon adorned with butterflies and flowers, names and masks. Games and bubbles occupied the children while parents visited and ate. We readied for the balloon release, a bit trickier this year, since local regulations limit balloons per hour. So, does that mean we start twenty minutes before the hour and go twenty minutes after the hour for two hours’ worth of balloons or do we have to read names slowly and exhaust two hours? Either way, two hours of balloons were not quite enough, so we doubled up two names to a balloon on some. This year the programs were in memory of Nicholas Wright and the mermangels with tie-dyed wings and sparkling fishtails were in memory of Philina Lockwood. Our balloons sailed on a gentle breeze and a paper lantern with our children’s names written on it lifted gently through them and out of sight. There were moms and dads who have released their child’s balloon annually for more than two decades, each time still difficult but comforting to remember among friends, and moms and dads releasing a first balloon, in one case just weeks but many thousands of miles later. The balloons drifted away from the river, skirting our hotel on their way over the historic city and skyward.
With only a brief walk back to the hotel, people lingered by the river. There was
downtime before the auction and yes, more food. This year there seemed to be more
quilts than ever, and the rapid and high bidding affirmed the artistic value. Kris
fought to win daughter Tricia’s quilt, well at least one of them. There were beauti-
ful hand knit afghans in memory of Regan Lawson again this year. Rhonda Den-
nis had us all sign our child’s name on a Longaberger basket, and the bidding was
high for that special SOFT item. There was also a sign post, one slat for every con-
ference. Last year, Craig’s donation for Carey Ann’s Treasure Chest was greatly
damaged in transport and the raffle was not held. The secret was not revealed and
what he had made was repaired by another wood shop teacher. It was handed over
the first day of the conference, and it was in Craig’s hands to do any more touch up
and make things good as new. He had made a treasure for this conference but kept
the size small so he could travel with it. The raffle was then for the choice of two
prizes with Craig offering to buy back each for what the winner had paid in raffle
tickets. Tickets sold rapidly and well. Liz pulled the winning tickets. Philina’s
brother, Tom, won the first drawing and chose the larger (and older) prize. Last
year for the Rhode Island conference, in recognition of the historical venue Craig
cchose to make a stone chessboard with a wooden storage unit for the Colonial and
British soldier chess pieces. Virginia, also a colony, kept it relevant. Tom was
pleased with his prize. Irony: a great photo opportunity for Philena who was al-
ways ready to click. The next ticket was won by a group of young girls, attended
by friends excited for them, so the winner was not clear to an observer, just the ex-
citement. They won a lacquered coaster set that fit in a decorated chest. The auc-
tion continued with the usual wine and food baskets, jewelry pictures, and gift
items. I just wanted to mention a donated a baby toy that went without a bid for
on the silent auction, then with some urging from Ray brought in three times what
it cost, and worth every penny! The auction wound down, kids tired, parents tired,
and the conference was finishing up. With a 14 hour drive ahead of us, we were
packed by 7:15, but some stalling meant we left with breakfast: caffeine and carbs --
good for the first 200 miles. As we headed over and under the Chesapeake Tunnel
Bridge, I reflected on a quick, intense but fun filled few days. We would have to re-
turn from vacation to rest.

Pam Healey
Remembering…
Philina Lockwood

Part of the 2014 logo and given in painted wood to each Soft child, then in felt to each family, mermaids were pervasive in Norfolk and at the SOFT conference. What a great symbol for SOFT: of us but ethereal, connected to another world but beloved in ours, real but not as expected, mysterious, elusive, beautiful, despite, let’s face it, with a scaly fish tail and no legs, serious anomalies. Mermaids call us with a siren song, pull us into another realm, traditionally luring sailors with their song and charm. Beautiful painted mermaids grace Norfolk, on street corners, on buildings, next to fountains, hidden in gardens, each capturing our imaginations and tying the land dwellers with a long history with the sea.

This year’s angel, felt angels with tie dyed wings, flowing hair and a sparkly tail, pointing outward in a determined swim, were in memory of Philina Lockwood, January 20, 1983-June 6, 2014. Philina often wore tie dyed shirts, inevitably knew where she was headed, headlong and intent, and was, if anything, sparkly. We will remember Philina’s enthusiasm, curiosity and fascination with cameras, both taking pictures of everything and everyone and being in your pictures, no matter what your intentions. She was a walking Kodak moment, long after the demise of the supremacy of Kodak, and she pulled in everyone around her. Many of us will point to shoot pictures in the conference to come and expect her big smile to come into view. Norfolk provided the mermaid design for the 2014 angels, but with no coincidences in SOFT, it turns out that Philina’s favorite movie was The Little Mermaid. She wore out three VCR tapes, requiring an eBay search in 2001, when a three month hospital stay without the tape was just not an option. Although her mom signed the movie, “little fish girl,” Philina signed it by pretending to run a brush through long mermaid hair.

Philina was a mainstay at conferences for many years. We could hear her, no matter where we were, and soon she was close by, nudging, poking, pointing and without words cajoling those around her to stop what they were doing and follow her direction. This inevitably led to being in her picture, or preferably to Philina, being in yours with a big cheesy grin. There was always a great sense of satisfaction on her part that she had managed to have her image recorded one more time. She was sadly not at the Norfolk conference, but her spirit was, and the angel each family received embodied her uniqueness. She got to be ubiquitous one more time.

Mermangels are waterborne and airborne; they drift and hover, call us from memory and fly and swim just beyond our reach. Like our children with us too short a time, so long beyond our hugs, beautiful and mysterious, they give us a heart song to carry in the waves, currents and winds that carry us forward, forever changed. Those of us who have been lucky enough to attend conferences regularly carry many angels in our hearts. Philina, who was ambulatory and without being verbal vocal, touched many. She might now have tie dyed wings, her adored sunglasses and a camera clicking away among our angels.

Pam Healey
The First Annual
Walk Run Roll.....

Any of those cities who have done a conference know that they don’t plan themselves, and they also don’t pay for themselves. There are many fundraising efforts that go into putting on a conference. I decided hosting S.O.F.T.’s first 5k would be a great way to raise funds for our Salt Lake City conference. I thought being a runner, having completed and registered for dozens of races personally that this would be a walk in the park; or in this case, a run in the park.

Numerous calls to sponsors, booking the venue, insurance applications, and timing companies were just a few of the tasks that had to be completed to get the race up and going. Not to mention, publicizing the race and getting participants. Needless to say, it was not the walk in the park I had initially thought. Thankfully, our committee really stepped up and helped pull everything together for race day and it turned out to be so successful, we’re crazy enough to do it again in May 2015.

We held the race on Saturday, August 2nd at Liberty Park in Salt Lake City, UT. We had a lot of fun and a great turn out. Thanks again to all of our “virtual” runners who donated to the cause even though they couldn’t be there. We appreciate all the great participation from members of SOFT and the community.

Submitted by Kimber Dye Walton
Soft Of Utah Committee Member

Photos Courtesy of Chloe Nguyen Photography
SOFT of UTAH Chapter Holds Its Annual Barbecue

Another summer has come and gone and the SOFT of Utah Chapter held its annual barbecue and swim party on Saturday, September 6th. Utah has one of the largest chapters in SOFT, which is probably because SOFT’s roots took start right here in Salt Lake City.  We’re very proud of our chapter and all the members who were original members of SOFT and its beginnings. We invited the SOFT board members to come from all over the country.  SOFT’s Founders, Kris and Hal Holladay, took us up on the invitation and showed up at our annual gathering, which was an great surprise for all of us! Kris and Hal visited with old friends from SOFT’s early years and made new friends as well. It was an awesome reunion. We can’t thank them enough for their presence and inspiration. The scheduled 3 hour party turned into 5 hours – because we weren’t ready to wrap it up. We are so grateful every day for our associations with all our SOFT family and this celebration is our way to thank our local chapter for their support. We’re all ready and willing to get going full force on next year’s conference. Be ready to have some good ole UTAH fun next July. We hope everyone tries their best to be here, you won’t be sorry, but that’s a SOFT conference, love and support no matter where we go. See you in Utah in July – DON’T MISS IT!!!!!

Submitted by Debbie Dye

— SOFT OF UTAH Chapter Co-Chair

Photos Courtesy of  Debbie Dye
Kinder Than Necessary

By Pam Healey

Be a little kinder than necessary. What does that mean? Aesop reminds us across the centuries, “No act of kindness however small is ever wasted.” George Sand, the French author who told us that “There is only one happiness in life, to love and be loved,” also understood the necessity of kindness, insisting we must “Guard well that treasure within yourself, kindness. Know how to give without hesitation, how to lose without regret, how to acquire without meanness.” She understood the breadth of kind acts and their necessity. Mark Twain saw kindness as a universal language that everyone understands, explaining that, “Kindness is the language which the deaf can hear and the blind can see.” For all there is a necessity to act kindly in small and large ways to make the journey easier for those we meet along the way. Kindness abounds in SOFT and glues us together.

Kindness requires thinking in terms of the other at home, at work, on the road and just going about the business of the day. It involves having the imagination to consider being in the other person’s shoes. It involves understanding probable feelings from what has transpired. It involves stepping away from one’s own needs. It means stepping away from control. It should mean doing something natural, heartfelt and satisfying. It involves words, looks and actions that make a difference.

I think back at over forty years of bosses: deans, department heads and principals, and I count myself lucky. I was in a school system with national standing, and it succeeded because of the level of cooperation, respect and support that was expected. It succeeded because people there were a little bit kinder than necessary. There were a few insecure leaders who required some ducking, but contact was infrequent, sentiments shared among colleagues, and tenure for the nasty brigade thankfully short. Nothing is gained by attacking; everything is gained by a kind word or quick deed. I remember an administrator explaining that we are all busy and sometimes our help is needed when time is short. She told us to reply, “I am hurrying to class (or a meeting) but I can give you a minute or you can walk with me and I can give you three minutes.” Good advice that I took to heart. I think of those of kindness minutes. I learned and grew from the kindness I was shown and passed it forward. Kindness at work: a word in passing about a good idea, a valuable comment, or a spontaneous deed that added to our community. Kindness engenders the same in others in the days and
maybe hours ahead and ripples outward. Be a little kinder than necessary: wrap a request, change, charge or constructive criticism in the appreciation of what went well, took effort and time or was creative. Stop and admire or assure, or slow to help. Everything is to be gained from a smile and a nod, a hand of reassurance and a minute to smooth the path for someone else. Random kindness can right an otherwise wrong day. Be a little bit kinder than necessary: slow down, listen, bend down, and speak gently. Be a little kinder than necessary: do not override what may be important to someone else for well-considered reasons. Shelve your own agenda and listen. Kindness is not overrated. Kindness creates what we want to build. It carries understanding, hope and connection. Kindness carries the day. Kindness carries SOFT.

In SOFT, kindness makes us grow in understanding, caring and membership. It is seen in everyday interactions of listening and appreciating someone’s story. It is seen in sharing the burden. It is seen in spontaneous connections, in ready smiles and through tacit understanding that comes from shared anxieties and experiences. Kindness requires time, empathy and respect. Kindness is the willingness to share someone else’s task, if even for a few minutes, to think as they do, to enter their world with a smile. Kindness like love cannot be used up, maybe needs to be expressed to develop fully. At every conference people step up and step in to do what needs to be done, not just the old timers but new folks who quickly feel at home with their new SOFT family. A few minutes of time to shorten a task for someone else, quiet reassurance for someone trying to manage grief, a bit of respite, are all acts of kindness. I suspect SOFT has grown nurtured by kindness as well as hugs. Its absence turns people away, even when kindness may not have been expected, because the kindness void too often is filled with power needs, us and them thinking, and difficult attitudes. Kindness keeps negative approaches at bay. Kindness keeps us together and growing.

Think about acts of kindness that made a difference to you along the way. Think about opportunities to be kind that meant slowing a bit, and might have been missed. Think of your own spontaneous acts of kindness that made you feel better as well as the recipient. The Dalai Lama explained that kindness is the philosophy of his simple religion. He saw opportunities for kindness everywhere, making such a religion easy to practice. At every conference, in communications in many ways during the year kindness keeps SOFT going, because so many are kinder necessary, kinder than expected.
Meet The Wheat Family!

In 2002, Katie and I found out that our first child, Abigail Renee, had full Trisomy 18. Like so many others, we were instructed by the medical community to terminate the pregnancy as our daughter's diagnosis was "incompatible with life" and she couldn't possibly survive. We decided to trust God and wait to see what He had in store for our family. Unfortunately, Abigail was born still at 30 weeks. However, God still had plans for us.

A year after Abigail's birth, Katie and I founded a nonprofit organization called, A Butterfly's Touch, to provide support to parents whose lives have been impacted by the heartbreaking loss of a child to early pregnancy loss, stillbirth, or newborn death. We accomplish this by providing memory boxes and remembrances for the parents, providing information and support through our free lending library and helping to lessen financial burdens through a fund to help with funeral and burial expenses.

During our research about Trisomy 18 and grieving, we met Terre and Krissy Krotzer through the online listservs that were around at that time. Krissy was 3 years old at the time and living with Full Trisomy 18. We were living in Portland, OR and the Krotzers lived in WA. Throughout the next several years, we stayed in contact with the Krotzers. We all finally met in 2007. Since that time, we have met many other families touched by trisomy disorders. Many times we have heard stories about other parents who were also told to terminate pregnancies because of this diagnosis. Sadly, some have because they just didn't know there were other options or chances.

In early 2013, I (now stationed at Ft Sam Houston, TX) had this idea that Krissy and I could participate in running events in an effort to raise awareness about Trisomy. Krissy is now 14 years old with full T18! We met and ran our first half marathon, the Portland Marathon half in Portland, OR in October 2013. We ran using a jogging stroller adorned with ribbons bearing the names of other children who were living or had passed with Trisomy. It was an amazing experience for all involved, and we decided to keep doing it. In March 2014, Krissy, along with her parents Terre and Randy Krotzer traveled to San Antonio, TX for the Alamo 13.1.

This summer, our family was able to attend our first SOFT conference in Norfolk, Va. During that time, we met new people, made new friends, and discussed future ideas. The first of these has become a reality now in the form of another nonprofit organization called Running4Trisomy. It's purpose is to spread awareness through running activities and to raise funds to provide running/jogging strollers for other families with children with Trisomy. The goal is to help other families to get outdoors, run, and be active with their children just as any other child.

Krissy and I are running the Portland Marathon Half again this year on October 5th. We will be running with the new hot pink and lime green pushchair that we debuted at the SOFT conference this year, again adorned with name ribbons. Our goal is to raise $1000 by race day to provide our first stroller donation to another SOFT family.

If you would like to help, please visit our fundraiser page at www.gofundme.org/dko9qw
If you would like to read more about our story, you can visit our webpage www.running4trisomy.org

There is also a video on the website that tells a lot about what Krissy and I are doing. Thank you all for your help and support.

Larry Wheat
www.abutterflystouch.org
www.runningwithkrissy.org

Larry, Katie, Mara, and Baleigh
On a beautiful autumn day October 8, 1998, my life was forever changed. I had just started high school and would shortly be celebrating my own sixteenth birthday. We had been anxiously awaiting the arrival of the youngest Dye daughter. In the week before her birth, we learned that she had Trisomy 18. We had very little idea what that would mean but the professionals were telling us that her life would be incredibly brief and that we should prepare to spend minutes or hours with her.

My sister, Morganne Jayme, was delivered via C-section that autumn morning by an incredible doctor who did everything he could to get her here safely. We savored each moment while the minutes turned into hours which turned into days. We were able to take her home at 5 days old and at just over three pounds. She was already defying the odds. The days then turned to weeks and we learned things we never thought we would need to know. As the weeks turned to months, our family began to imagine the future. Although unspoken, this was a fear each of us shared. Looking beyond “today” meant imagining life with our baby sister but it also meant facing the possibility of life without her. It was in these months that we began to meet other families with amazing trisomy children. Thus began our journey with SOFT.

Morganne passed away after a brief seven months in our home. As a teenager, I don’t think I could fully comprehend the feelings I had about her life and her passing. I knew that the grief was like nothing I had ever experienced but I had little idea how that tiny baby would change so much about my life.

Thirteen years after my sister was born, I became a mother. The morning my son, James, was born, I repeatedly had one sentence run through my head. It was something my father had said at my sister’s funeral. He looked down at his daughters from the podium, grief stricken that one was no longer among us, and said, “Now you know how much we really love you.” At 16, I thought I knew what that meant. I didn’t. The morning I became a mother I had a much better idea the grief my parents must have felt and the depth of love a parent has for a child as well as a greater concept of how my sister had changed my life.

Now, sixteen years after Morganne’s birth, I came to an even greater understanding as I became a mother for a second time. Mid-pregnancy, the ultrasound revealed that our daughter had an irregular heart rate. It was something that would have to be treated in-utero so that her heart would not fail. At our first fetal echo, I had so many feelings come back of that time we had Morganne. We were being treated in the same hospital and in the same cardiology department as Morganne had been. Early on a spring morning in late May, our daughter was delivered safely by the same kind doctor that had gone to great lengths to safely deliver Morganne. We named our precious daughter Madelyn Morganne.

As we have now passed the point at which Morganne has been a part of our lives longer than she wasn’t I have found that I may never fully comprehend her impact...and that’s a good thing. A small child with a brief life continues to teach me lessons that make me a better person and a better mother. The opportunity for my own children to interact and appreciate our SOFT kids will teach them far more life lessons than I could.

Happy Sweet Sixteen Morganne Jayme. As said in one of my favorite musicals, Wicked, “Because I knew you, I have been changed for good.”
SOFT CONFERENCE 2015 IN SALT LAKE CITY UTAH

SOFT HEROES - JULY 8-12

Soft of Utah is excited to once again welcome our SOFT family to Salt Lake City! The conference events will be held at the University of Utah Guesthouse, Rice– Eccles Stadium, Primary Children’s Hospital, and Ft. Douglas. All locations are easily accessible and within walking distance of each other, with exception of the stadium that will require transportation. The Guesthouse has offered rooms for just $109 a night to our SOFT members. Reservations can be made now until June 1st. After that date, the rooms will be released other patrons. Please call 801-587-1000 and let them know that you are with the SOFT conference to receive the special rate.

Here are some things we have in the works for the 2015 conference……

· Wednesday evening July 8th – Welcome Reception and Ice Cream Social

· Thursday July 9th – WORKSHOPS *this is different than previous SOFT conferences –be sure to get here on Wednesday so you won’t miss out on any of the great workshops we have in the works*

· Thursday evening July 9th – Welcome Dinner at Rice–Eccels Stadium

· Friday morning July 10th – Soft Stroll for Hope

· Friday afternoon July 10th – Clinics at Primary Children’s Hospital hosted by Dr. John Carey

· Friday afternoon July 10th – Grief Outing for those who have lost their children at Red Butte Gardens located just East of the University Campus

· Friday night July 10th – Family Outing possible baseball game by our triple A team the Salt Lake Bees (parent Team – Angels) if they’re in town or the City Creek shopping center

· Saturday July 11th – Annual Picnic and Balloon Release held at Soldier’s Circle – ½ block from the hotel.

· Saturday evening July 11th – SOFT Auction an event that can’t be missed!
The SOFT of Utah Conference Committee is committed to making the 2015 conference memorable and fun for all. We are working on some really great workshops, offering a variety of informative clinics, scheduling outings, planning conference traditions, and providing good food! We have tried to schedule the conference events in close proximity to give our SOFT families a more interment setting and less time travel time. The Welcome Dinner and Family Outing are the only activities that will require a means of transportation. The University of Utah Campus provides several beautiful and calming opportunity for social gatherings during your stay. Down town Salt Lake City is minutes away, where you can find the most popular restaurants, shopping, site seeing, and entertainment. Salt Lake City was the home for the Winter Olympics venue in 2002. The Closing Ceremonies were held at Rice– Eccles Stadium, where the torch and archway still stand. There are several other Olympic and historical sites to visit in our great city. We are thrilled to host the 2015 SOFT conference and are looking forward to seeing our SOFT family again. We will provide detailed updates and finalized schedule changes in the next few newsletters.

See you in Salt Lake City!!!

Utah Conference Committee

We also wanted to welcome and show off our newest committee member...

Miss Madelyn Morganne Woolley!!!

Congratulations to Spencer, Chelsea, and big brother James!!!

On a beautiful spring day at 3:01 in the morning, on 05.29.2014, they placed a 7lb, 11oz miracle in our arms. Four weeks early, only 7 hours after arriving at the hospital and She was perfect. We named her Madelyn. Welcomed by Parents Chelsea Dye Woolley and Spencer Woolley and Big Brother James.
I returned home from the conference and began work in a nearby middle school summer program for kids with special needs. Everyone who attends the middle school, kids in all three grades and adults working with them, is expected to arrive back in the fall having read *Wonder* by R.J. Palacio. The past few weeks we focused on the book during reading lessons. One of my students read orally daily from the book, and we discussed it, looked up information on-line and applied what he had learned to his own life and school. We have a few days and fifty pages to go, and I, who have finished the book, know I will not complete the book with him dry eyed.

The book, as well as the child at its center, is a wonder. Every SOFT parent and sibling older than nine or ten must read this book, because it speaks of courage, assumptions, perception, growing understanding, kindness and dignity related to a devastating genetic disorder. Ten year old Auggie Pullman has been home schooled because public school has not been an option with his physical challenges and more than two dozen surgeries to correct his craniofacial anomalies. He has been in the hospital or recovering at home too often to be in school. By ten he has time to lead a more normal life, but that is a naive hope. Going to school brings him new challenges.

Auggie’s rare condition was determined by a frame shift of one nucleotide which changes the polypeptide, then protein, then gene. This is not an entire extra chromosome with so much extra DNA, this is one nucleobase (A,C, G or T) being deleted, shifting subsequent three base codons, which reduces the production of rRNA, which is necessary for cell production, and without enough, there is cell death, and the facial bone and tissue do not develop. What does develop is terribly distorted. A simple error, a seeming glitch, which is complicated and devastating, rare, and both unexpected and shocking determines one child’s fate. Auggie’s young doctor fainted at his birth. Children think he is an alien. Those with Treacher Collins syndrome exhibit a range of facial anomalies, but Auggie inherits both the recessive form of the condition and a secondary condition that makes it worse. A one in 50,000 syndrome becomes a one in four million condition with the second genetic blow. His parents love him unconditionally, live their lives out in hospitals, orchestrate some limited friendships for him, and consider painfully difficult decisions they believe to be in the best interest of a child who is bright, curious, funny, sociable and resilient but understandably reluctant to expand his world.

Auggie’s mother decides the time has come for her son to be with kids his own age, and although cognizant of difficulties he will face with peers, she has him enroll as a fifth grade student at Beecher Prep, a small private school near his home. Students are soon selected by the headmaster to be his friends initially, but not surprisingly, that does not go as expected, or maybe it does. One politely abandons him, one turns on him cruelly and publicly, and the third does not know what to do. Auggie’s first day is one of stares, gasps, shock, unkind comments and isolation. Summer, a sweet girl able to take another’s perspective, sees Auggie and joins him for lunch, so he is not alone. An act of kindness gives way to genuine friendship when she engages with him, laughs, relates, and realizes how openly she can speak with him. She alone looks beyond what repels others.
The kindness Summer shows is not characteristic of her classmates, who not only ostracize Auggie but start a game they call The Plague in which accidentally touching him must be followed by washing hands within 30 seconds. Such cruelty is only the beginning, and soon the fifth grade class aligns by “teams” consisting of those who befriend Auggie, a few clueless nerds who remain neutral, and the bulk of students who bully those who do not agree with them. A parent, the same one who photoshops him out of the class picture and distributes the new version, lobbies to have Auggie, one of a few students on the high honor role, removed from school, because Beecher is not a special needs school. Ultimately, it is an outside force that creates new sides, new awareness and a call for spontaneous action. Heroes emerge, alliances shift, and what Auggie brings to every child and adult at that school is not only recognized but celebrated.

Auggie’s face has features that are both distorted and misplaced, and surgeries allowed him to eat, breathe and speak better, but improvements to his looks are limited. At one point in the book Auggie’s friend, Jack, asks why he does not have surgery to help his situation. Auggie replies that his current face is the result of more than two dozen surgeries in his ten years. Without thinking, his friend blurts out that he should find a new doctor. The book is also a series of social surgeries, painful and sometimes prolonged, that improve the face of a community. The book is a chronicle of kids coming to terms with a peer who makes them uncomfortable and forces them to examine what is important and what must be done. His classmates appraise their own lives and many find challenges more hidden than Auggie’s that they must confront and accept.

Auggie’s condition must be understood, not so much over time, as from different perspectives. His story is told first by himself, objectively, without pity, then by Via, his older sister, who has learned to get by without adequate parental attention and with heightened vigilance to scan for those who deny her brother some sense of humanity. She emerges as his greatest defender, often to his annoyance. Later chapters are told by Auggie’s and Via’s friends. The changing perspectives, often covering the same situations are like puzzle pieces that come together. There are adults in the book: parents, teachers, doctors, and relatives, but the story is told by fifth grade and ninth grade children in authentic voices, giving the tale a special honesty and poignancy. They speak not only of Auggie but of classwork, school activities, their own challenges, often with parents more remote than Auggie’s, and the difficult search for friendship and identity that elude even the beautiful.

Throughout the book a monthly precept is given to Auggie’s English class: wise words to live by. Over the summer Auggie and his classmates are expected to create or find and share their own, and all are found in the appendix. Each addresses understanding one’s role with others and doing what is right. At the fifth grade graduation the headmaster speaks of kindness and shares James Barrie’s advice: “Shall we make a new rule of life…. always to try to be a little bit kinder than is necessary.” He continues with an example of kindness in a book by Christopher Nolan who has a character recognize in a student who helps him, “the face of God.” In Auggie’s face, so ugly that throughout his life people have a visceral response, is both the face of God and the face that inspires some to act in a way that allows others to see in them the face of God. As a child Auggie for two years wore a space helmet that covered his face, later relied on hoodies and long hair to cover what he could of a face that frightened others. He stooped, facing down to further hide his features. At Beecher he cuts his hair and stands as tall as his short stature allows. He also enables others to stand a bit taller.

Auggie does not have a disability, although others assume he must. He and his family have struggled through a cascade of medical emergencies and decisions. He has differences that prompt stares, comments, exclusion and cruelty. He brings out the worst in some strangers and classmates and the best in family members and classmates willing to risk their reputation and be kind. Auggie is fully aware of what others think. He sees their stares and watches them turn away. He does not have the protection of cognitive deficits that protect most SOFT kids from knowing how different they are and how people who do not get to know them, judge them. Via adores her brother, defends him heroically, realizes any problem she may have is minuscule compared to what he endures daily, but sometimes she wants more attention from her parents, although she knows it is unfair and unrealistic to expect that. At times she wants some space, so she does not have to ex
plain or defend her brother. She carries the anger her brother steps away from and her own guilt. He learns to manage the stares, screams and comments better than she. Justin, her boyfriend, sees in her both a fragility and a strength born of her sibling role. Both open him to new understanding.

Two days after Labor Day teachers, staff and students will return for a new school year. Most will have read a book told chapter by chapter by kids trying to understand not just Auggie’s challenges but bigger questions of why one among them must be so different. There is meanness, anguish and depth to what is conveyed by those whose lives have been changed by someone with a visible genetic disorder. Miranda, Via’s friend, concludes, “The universe was not kind to Auggie Pullman.” Justin, contemplates this and considers life a lottery with some “getting a bad ticket.” He cannot accept this, and decides if life is so random, “the universe would abandon us completely, and the universe doesn’t.” He is sure, “it takes care of its most fragile creations in ways we cannot see.” He decides “the universe makes it all even out in the end.”

Expecting everyone to read the same book builds community, and this year in one school there is the possibility that the focus will expand that sense of community to those who in some way stand outside the mainstream, those who in some way are not as expected, and those that make others uncomfortable. The wisdom of children who confront difference in others and evaluate their response immediately and over months will stay with the reader, particularly those who held a ticket that may have seemed at one time to have less value and is still judged so by others. Get angry, nod knowingly, cheer, laugh and get choked up as you read a novel that will speak to aspects of your own life and your heart. Embrace Auggie, as you embrace your own child and those of your SOFT friends. Encourage others to read this book, so they will examine what it means to be different and to be human, to be kinder than necessary and to be changed by wonder. Maybe there is a group in your community, perhaps a school, church, social or service group, that would be changed by reading Wonder and addressing what it means to be physically or cognitively different and what is required to live being kinder than necessary.

Pam Healey

Kind words can be short and easy to speak but their echoes are truly endless.

~Mother Teresa~
SOFT APPRECIATES YOUR GENEROSITY...

WE RECOGNIZE THE LOVE & CARE THAT THESE DONATIONS REPRESENT

Donations to SOFT’s General Funds

Doug Crandell: “I was at the Sheraton Hotel during the annual conference, and the children and families really touched my heart. God bless your work.”

SOFT friends who donated through FirstGiving.com

Anonymous through AT&T Employee Giving Campaign
Anonymous through United Way of Denton County Texas
Anonymous through Sabre Holdings Give Together Campaign
Epenisa Paongo
Carmen Asteinza

Elliott and Patty Lawson with matching gift from BP Fabric of America Fund

Donations to the Joey Watson Fund, dedicated to helping families come to the annual SOFT conference

Janice and John Hertig

Faculty, Students and Staff of Milan (TN) Elementary School and Milan High School, in honor of Samuel Jackson

Jack and Judie Laird in memory of Zion Lint
Dave and Barb VanHerreweghe in memory of Zion Lint
Georgia Heat Rage in memory of Oliver Wyatt Quilter

In Honor of Megan Hayes’ 34th Birthday
Ron and Sara Hayes

In Memory of Kari Holladay
Wilson and Wendy Martin

In Memory of Olivia Knight
Carmen Axley
In Memory of Zion Lint (T13), who celebrated his 13th Birthday in Heaven
Laura, Austin and Isabelle Gillespie
The Baumgardners
Zach and Jacinda Conroy, and in Memory of Cash Conroy

In Honor of Mary Donohue’s 18th Birthday
Lisa Aftel
Susan Pucci
The Gerstein Family
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Rosita Escobar
Alan Devlin

In Memory of Nida Anela-Mary Baltrusaitis
Michele and Steve Kapinus
Kristi and Brad White
University Pediatrics, FL
Jill and Brian Brames
In Honor of Stacy VanHerreweghe’s 33rd Birthday
Jack and Judie Laird
Carol A. LaRosa

In Memory of Helen Ahillen and Jason Seilnacht
John and Terry Bowles
Jack and Linda Goldkamp
Joan and Randy Oliver

In Honor of Karson Friedmeyer Casey and Joe Friedmeyer
Cassie Schwarzen: “Keep staying strong, Karson!”

In Memory of Abigail Long
Mary Cottingham

In Memory of Antonio (Tono) Elias Figueroa
George and Brenda Morse

In Memory of Glennon Lamprecht, grandfather of Jason Seilnacht
Ruth A. Brooks
Vera Lamprecht

In Memory of Simon Adam
Amy and Hugh Roberts: “This donation honors the most amazing family we know. Sending so much love and many prayers to Amy, Adam, Teddy and Simon. God bless you.”

In Memory of Christopher K. B. Freeman
Yvonne Brown, Christopher’s cousin

In Memory of Ryan Evan Peoples
Allison Granstedt: “Ryan Evan was a beautiful child, eagerly anticipated by his parents. May the Lord comfort them and may Ryan Evan be wrapped in His loving arms.”
Christine and Theodore Yang
Susan and Joe Rissing

In Honor of Mylah Perkins
Sanaa and Morgan Archer and “Operation Lil Hearts”
In Memory of Jordan Villatoro
Rosa Cavazos, Jordan’s mother: “SOFT helped me SO much when my son passed away fifteen years ago. I had never heard of Trisomy 13, and suddenly it entered my life forever. Jordan passed away before he was born, but I was left with so many questions. Thank you for being there for me. God bless.”

In Honor of Milika Hartas
Kirt Hartas

In Memory of CopperRose Keona Wetzler Harai
John A. Rogers: “CopperRose, the Pineapple Princess, lived for only 18 months, but made years of impact on many. She brought her mom and dad so much joy.”
Robert and Angela Grutko
The Kuromoto Family
Steve and Rena Krause
The Kawasaki Family
Liana Shanes
Andrea and Phillip Shea
Rena Krause
Letitia Boardman
Jean Tipton
DCP Family

In Memory of Anna Lis
Melanie Lis
Jay Ostrich

In Memory of Carey Ann Donaldson
Marie Donaldson’s Quilting Club

In Memory of Lily Faith Tarr
Brittney Caravaglia
In Memory of Mercy Martin
John and Kalli Martin: “Thanks so much to SOFT and its extended support team of advisers and doctors. Cindy Cook (Illinois advocate) was instrumental in connecting us with an excellent care team in DuPage County (OB Dr. Elaine Carroll and Palliative Care Drs. Ileana Leyva and Erin Flanagan at Central DuPage Hospital.)”
The Dewitt Family
The Lane Family
Kristin Case
Priscilla Lane
Cindy Harrigan
Jim and Katy Harrigan
Jason, Holly, Mya, Lily and Ella Hulett
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In Honor of Angela Ricker
Wayne and Joyce Crouch