President's Corner

Dear SOFT Families:

The conference is over, but the wonderful time together will never be forgotten. We started out with an Ice Cream Social on Wednesday evening. Coldstone Creamery provided delicious sundaes for all to enjoy as we mingled and got to know each other! Workshops were held Thursday morning. There were a variety to choose from and all were very informative. We managed to pull in a few families to attend the conference workshop and encourage them into hosting future SOFT conferences! That evening we gathered for the Welcome Dinner at Rice Eccles Stadium. This was the site of the Opening and Closing Ceremonies for the 2002 Winter Olympics. What a beautiful sight as we looked out over the city. During the evening we enjoyed guest speaker Kara McHenry Black, from the Facebook page Prayers For Corbin, who spoke about her son and his trisomy journey. Then we honored our SOFT children with the Zion Lint Parade of Stars. What Stars and Heroes they all are, as each walked or rolled in one at a time to receive their gold medal! Thanks Lizzie for that great suggestion! We enjoyed a beautiful video of our SOFT kids and their families, created by Kris and Hal Holladay, in memory of their daughter Kari Deanne Holladay. We also honored Dr. John Carey with the SOFT Lifetime Achievement Award! Who could ever be more deserving of this award than Dr. Carey? He has attended every conference and championed the care of our children year after year! It certainly does not seem like enough to repay him for all his caring and teaching about all our kids. Congratulations, Dr. Carey!

Friday was the Remembrance Outing for the families who have lost their children. I saw beautiful rainbow ribbons hanging from the trees each with a special angel name at the garden they all visited together. Clinics were held at Primary Children’s Hospital for the SOFT kids headed by Dr. Carey and his staff of volunteers. That evening families went out on the town, as a few of us stayed behind to prepared auction items for Saturday night. Then it was time for BINGO! It was a fun activity for some SOFT families.

Saturday brought the business meeting and the election of officers. Special thanks to those who served on the Board whose terms expired; the Stockman family as well as the Wagner Family. Elected Board members are the Dyes, Nora Flores, Terra Spiels-Garst and a one year term for Chelsea Dye who is bringing in the siblings to serve. The Picnic was held that afternoon. It was filled with super heroes, a blow up slide and house, bikes from Freedom Cycles and a wonderful barbeque. There was also face painting, cotton candy, and snow cones for all who attended. We moved on to the balloon release to honor our SOFT angels that were taken from us too soon. We watched as each balloon, with it’s own tag, floated into the sky until we could no longer see it. I am sure those angels received their balloons and the messages that their family’s attached with smiling faces. Enjoy sweet ANGELS! You are forever in our hearts! Later that evening, we gathered for the auction. It proved to be a great time for making more friends or being with the friends you met over the week. There was a beautiful hand carved nativity scene, angel quilts and so many more wonderful items made with love. The competitive and generous bids brought in over $9000 for our organization that night!

That is the end of two years of planning and so much fun! What’s in store for next year? The plan is to be in Seattle Washington. More details coming soon!

Hugs and Blessings to all

The VanHerreweghes: Barb, Dave, Stacy, Andy, Melissa and Nicole
During June, the Utah Chapter of SOFT hosted the second annual Run with SOFT. It was a Walk, Run, Roll held at Liberty Park in Salt Lake City as the final fundraiser for the 2015 SOFT Conference. In all, about 80 runners participated this year and many more volunteers and spectators. It was so fun to see several of our SOFT kids participating with their families in the 3.2 mile jaunt around the park.

SOFT of Utah had many sponsors that helped to make the event possible and provided great prizes for the winners including: A Simple Truth organic foods gift basket from Kroger, a gift card from Albion Fit, a variety of gift certificates featuring yoga classes from Cardio Barre, a gift certificate for a 60 min massage session, a Doterra essential oils gift pack, and CASH prizes. Of our ten winners (top 5 men and top 5 women), four were from SOFT families. Three of the men’s prizes went to the brothers of Aaron Peterson (age 5, Trisomy 18). Congrats to David, Joseph, and Andrew! The female second place winner was Hadley Richins, the granddaughter of Grant and Emma Richins. The Richins family was one of the first SOFT families when SOFT was founded in Utah. Grant and Emma had a daughter, Kimberly, who lived into her 30’s with Trisomy 18.

Our Utah Chapter loved this event! It was a great opportunity to work together as well as share our kids and our organization with our runner friends and family. We look forward to making this an annual event and are in the process of scheduling the third annual Run with SOFT 5K for next summer.

A huge THANK YOU to all of our SOFT families who registered as “virtual runners” to help fund this years SOFT conference! If you would like to sport one of our cool Run With SOFT race shirts, please contact the Dyes at softofutah@aol.com. We have several shirts left and one just might be your size. They are $7 plus shipping and all proceeds will benefit the 2016 SOFT Conference.

Story by Debbie Dye
Photos provided by the Dye and Wagner Families

“It is when you give of yourself that you truly give.”
Kahlil Gibran

“Volunteers do not necessarily have the time; they just have the heart.”
Elizabeth Andrew

“It’s not how much we give, but how much love we put into giving.”
Mother Teresa
“Miss Ashton was my pacer and motivation to keep going! That’s what cousins are for!”
Angie White (pictured to the right)
At the conclusion of the 2015 SOFT 29th Annual Conference held in Salt Lake City, Utah, I was asked to share details of early SOFT. Thank you for the opportunity to take a stroll down memory lane and reflect on the beginning of SOFT.

I remember... Brandy Woodcox. Her name will never be forgotten to our family. It was November 1977 and Kari was just two months old. We asked everyone, including strangers on the street if there were any other families who had children with Trisomy 18. The answer I received was always the same, "No". Finally, as a passing thought, a nurse mentioned a family in Salt Lake City, but she would need to ask around for this family's name. The excitement was overwhelming and when the nurse finally called back with the name of the family, we shouted with joy! She gave me the name of the Woodcox family and their phone number. Yes, another family, another child; we were not alone! I called Debi Woodcox and she shared her story about their daughter, Brandy. Brandy was 2 years old! Brandy smiled! Brandy played! Brandy was happy! Much to our disappointment, the Woodcox family moved to Iowa the very next day so letters and picture became our life-line. But, never ever would we feel alone again!

It took two more years before another family came our way. Out of the blue, I received a phone call from a mother, also living in Salt Lake City. She said, "I think we are going to be friends." I thought she was rather bold until she told me that she and her husband had a daughter with Trisomy 18. She was right, we would be forever friends. Pam & Tim Watson had also been looking for another family with a child with Trisomy 18. Pam recalls the day a stranger noticed her daughter, Rachael. The stranger said that she looked a lot like a little girl she knows named Kari. To this day, we do not know who this stranger was, but she brought us together in nothing short of a miracle! Rachael & Kari were the same age yet no one had ever thought to introduce us! How sad to have lived for two years so close to each other, and yet be so far away. (The Holladay's lived in a small town, Tooele, about 45 minutes from the Watson's who were living in Salt Lake City!) The meeting of our two families left an impression never to be forgotten and a promise was made to create a way for others to meet and share their stories.

Within a few weeks, I was told by our geneticist, Dr. Bruce Buehler, that a new, young and very handsome doctor had just accepted a position at the University of Utah Medical Center. This doctor had just completed his work in San Francisco. And, not so coincidentally, he had expressed concern for families whose children were born with Trisomy 18 and Trisomy 13. As I recall, Dr. Buehler said that this young doctor expressed the predicament for these families and expressed it much like being "caught between a rock and a hard place." Yes, that young doctor is our very own Dr. John Carey! The day we met Dr. John Carey was memorable. His compassionate blue eyes and warm conversation were exactly what we needed. In September 1979, Pam, John and I decided to get busy and get organized! Dr. John Carey, Pam Watson, and Kris Holladay were going to become an "official" parent support group!

Pam & I made an appointment with Legal Services for the Handicapped. The meeting was encouraging and productive. The lawyer explained our responsibilities and recommended we first decide on a name for our new organization. Now, that sounded like fun! Hal and I decided that an acronym would work best and would leave a good impression without having to repeat the longer name of the organization. What we didn't know

Kari Holladay
then, but came to understand in time, the name of the organization grew longer and longer as the days and months went by as more families came into SOFT with numerous genetic conditions. We tried all sorts of combinations of words only to end up with a senseless word we couldn’t pronounce. Then Hal said he had figured it out! He said to write down the first letter of each word as he said the “new” name. It went like this—Families And Relatives of Trisomy. Oh no! I just couldn’t visualize letterhead with the acronym F.A.R.T.! He laughed and I crossed it out and we started over again! Somewhere in the combination of words we finally found the perfect acronym and S.O.F.T. was created. On September 10, 1980 we officially became SUPPORT ORGANIZATION FOR TRISOMY 18/13 (S.O.F.T.), INC. Our first governing board was President: Kris Holladay; Vice-President: Dr. John Carey; Treasurer: Pam Watson. The sound of SOFT warmed our hearts and we knew it would stay with us. John, Pam and I signed all the necessary legal papers and we were incorporated through the State of Utah. (Note: The original name was changed for accuracy at the Philadelphia Conference in 1988. The “/” was replaced with a comma. Later, "and Related Disorders" was added to the organization’s name.)

Now that we were official, it seemed like a good idea to find some members! We had articles put in the newspaper, Dr. Carey told his friends about the group, and we talked to anyone and everyone who would stop and listen! When Pam received a call from a family in Henefer, Utah with a daughter with Trisomy 18 who was 11 years old, we were stunned and amazed. The Grant & Emma Richins family along with their daughter, Kimberly, soon became our fellow “pioneers” as we ventured into unknown territory!

During this time of reaching out, we decided to print a SOFT newsletter and the first one was created by my sister, Karen. The newsletter still brings understanding, information, and connections. The original format is carried on today with the family’s letters linking us through the miles. For the first edition, we printed 25 copies even though we only had 14 names on our address list (which included grandparents, aunts, uncles, and friends)!

At last, we had a few members and we held our first “Gathering” on May 31, 1980 in Salt Lake City, UT. The meeting of new friends was memorable! We took pictures and shared stories. The second “Gathering” was held on February 21, 1981 and the family that traveled the longest was Pat Farmer and her family! She drove 3 hours and their family received a standing ovation for their sacrifice. Again, we shared pictures, stories, memories and more! We had more “Gatherings” and our address list grew longer and longer and we started to hear from families all around Utah and in California, Arizona, Montana, Idaho. Our growing bigger meant growing pains. I appreciated the referrals from medical professionals, but couldn’t believe the mail and phone calls it generated! SOFT continued to grow and we applied for a bulk rate mailing permit. I spent so much time at the Post Office that I think the local Post Master thought I had a crush on him!

By 1981, growing bigger was our biggest obstacle for our new organization! Once the word was out that there was a parent support group, medical and educational professionals trustingly referred families to SOFT. Phone calls and letters shared heartfelt stories of new families. The familiarity bonded us together, yet each story was unique! It truly felt as if we were “old friends who had just met.” The newsletter remained our link of friendship and we tried to distribute an issue every other month. (I still have a copy of every newsletter from the first one to the present!)

Our hearts would break whenever we were notified of the death of a precious child; it was felt deeply by everyone reading the newsletter. Through the thoughtfulness and generosity of families, SOFT often received memorial donations from families and friends. Sadly, without this financial support, SOFT could not have continued. I always felt a sad irony that through the memorials of a cherished child, SOFT continued to survive. With every memorial check I cashed, I shed a tear. “Thank you” never felt adequate when expressing appreciation for donations when given by a grieving family! How grateful I was and still am for your kindness and generosity! (continued on page 6)

All Photos provided by Kris Holladay, Pam Watson, and Emma Richins
SOFT always enjoyed hearing from a new family and appreciated the medical and educational professionals contacting us. However, I found responding to the vast amount of mail was becoming overwhelming and each time I would “catch up”, it generated more mail and more phone calls. Through this period of time, our daughter, Kari began a struggle with seizures, especially status seizures which often lasted for hours. She would be hospitalized and when released, we would begin rebuilding her lost skills. When Kari was six years old she suffered a stroke which left her the diminished use of her right side. Kari continued to smile and play with her same enthusiasm and these setbacks didn’t diminish her spunky personality! The Holladay’s were a busy young family with Tricia, Kari, and Bryce. Then in 1983, our family welcomed a newborn son, Nicholas. Kari was fascinated by this new “doll” that made sounds and she would roll, or scoot towards the new baby and watch with fascination.

Changes were on the horizon. During this period of SOFT’s history, Dr. John Carey and the University of Utah were my lifeline and sanity. John could see I needed help in sharing the responsibilities of this growing organization. In 1985, Debbi Stutz was hired to assist with SOFT’s growing needs. We slowly transitioned the paper work and communication for SOFT to her home. Each week, I would drive an hour into Salt Lake City and meet with Debbi to bring her stacks of mail and talk about SOFT “stuff”. She had a fancy new computer and was able to bring SOFT into the digital age. Although Debbi didn’t have a child with a chromosome disorder, she was compassionate and felt an immediate love for our children and families. She worked long and hard for SOFT. Through this time, Debbi began to form an amazing dream for SOFT.

From 1979 to 1985, SOFT members were “long-distance” friends sharing stories through the newsletter and phone calls. Our only personal contact was through our “Gatherings”, which was convenient for only the few families living in Utah and Idaho. Knowing how desperately families wanted to see another family or child, Debbi began to not only dream, but to actually make plans to bring families together from all over the United States for a family conference. Dr. Carey had started the idea by sharing his experiences with other support groups having national conferences. This gave us the confidence to believe we could really “pull it off”! Debbi plotted and planned, talked and thought, searched and screened, worked and worried until her dream began a reality. Plans for the first SOFT FAMILY CONFERENCE was set for the “Summer of 1987”. Planning for the conference was made more difficult when the Holladay family moved from Tooele, Utah to Mesa, Arizona in July 1986. Debbi continued to oversee SOFT even after I left Utah. We kept in constant touch through letters and calls and she met regularly with Dr. Carey. I did my best from Arizona, but the logistics of the conference fell to Debbi and John. Pam & Tim Watson, and the incredible families in the Utah Chapter were the planning committee that put special touches on the conference.

Debbi would call to update me on the progress of the conference. And, with great excitement she would tell me that another family just signed up to attend! We were actually shocked! Their hard work brought the first ever SOFT Conference to go from a dream to a reality!

Opening day of conference was a terrifying day for everyone! Families from the east coast to the west coast, boarded planes, trains, and cars with only a hope that other families were coming too! In Utah, we all waited at the front doors at the Little America Hotel & Conference Center. We actually wondered if these families would show up!

History was unfolding before our eyes! Parents brought their precious children either in their arms or in their hearts. Photo albums were carefully carried and shared openly. Tears came first, then smiles and laughter. When it was all over, we shed tears again. Everyone’s dreams were realized in just a few short days. No matter what your situation, someone understood, cared and shared. We were no longer alone! We found a safe place with each other! We felt “at home” with each other!

During the business meeting, we held an official election and elected a President and a Board of Directors. (Contrary to rumor, we did not force anyone onto the board. We may have begged and pleaded, but never force!) Our first board meeting was held in the hallway next to the hotel’s kitchen. The membership voted to have a SOFT Conference each year, which is a tradition that continues to the present time. Thank you to all those “early pioneers” in SOFT’s history!

Today, SOFT continues to be a source of support by offering information to families and professionals, connecting families, providing opportunities for research, organizing annual conferences, and providing opportunities to honor our children whether in our arms or in our hearts. SOFT values and respects children and families. We feel grateful for professionals who continue to offer support and expertise.

And finally, a profound thank you to SOFT’s President, Barb VanHerreweghe, for her unfailing commitment to SOFT and her unwavering devotion to all children born with genetic disorders and to their families. She has made it possible for SOFT to proudly say, "Families serving families for over 35 years!"
A final note: Our precious Kari celebrated the first conference with us in 1987 in Salt Lake City. But much to our sadness, she died just 8 weeks before the 1988 conference in Philadelphia. She was 10 years and 9 months old when she died. If we could “see” with our hearts, I believe that Kari and Rachael and all their angel-SOFT friends are with us in spirit. We are truly watched over by angels!

The Holladay Family is eternally grateful for this extraordinary journey we share with each and every one of you!

Holladay Family: Hal & Kris, Tricia & Ryan (Rayna, Ella, Joshua), Kari (our angel), Bryce & Tiffany (Hannah, Callie, Isaac), Nick & Tara (Reese, Nash), Devin & Mya (Lacey), and Savannah.

I’m surrounded by great friends and family. I don’t know what I would do without them.

Emma Roberts

The bond that links your true family is not one of blood, but of respect and joy in each other’s life.

Richard Bach

It’s not what we have in life, but who we have in our life that matters.

Unknown

The Infamous Holladay Family!
This year’s conference welcome dinner was held at Rice-Eccles Stadium Tower on the campus of the University of Utah. This stadium was home to the opening and closing ceremonies of the 2002 Olympic Winter Games. It was an amazing venue for a wonderful event. The evening began with a walk through the silent art auction to benefit the Joey Watson Fund. The art was done primarily by our SOFT kids and their siblings, and their siblings’ children. This was the first time we have held this event and we raised over $800 to help bring families to conference next year!! Thank you to all who donated art. It was so fun to see the creativity of our cute kids.

The meal at this year’s dinner was also amazing. We had the pleasure of being fed by best of state caterer, Culinary Crafts. The buffet of tasty salads and sides ended in a carving station with roast beef. There was even a kid’s buffet that was just their size. During dinner, we had the “Walk of Stars” or as we called it, the “Walk of Heroes” to present the SOFT kids with gold medals. As this was the location of the 2002 Olympic events, the children’s names were read and they were strolled or walked across the floor and all of our SOFT Kids (Heroes) were presented with their gold medals around their necks, just like the athletes at the Olympics. Thank you, Lizzie Bona-Cohen for such a fantastic idea!

We then had the pleasure of hearing from Kara McHenry Black. Kara is the mother of Corbin Alfred McHenry. He was born in 2012 with Trisomy 13. Kara and Corbin’s story is not unlike many of the stories of other SOFT families, but through a social media wildfire, Corbin’s Facebook page was eventually followed by over a half a million people. The day he was born, a family member created the “Prayers for Corbin” Facebook page. His parents documented his first day of life with a picture of him and a sign that read “I am one day old, Team Corbin.” By day two, three thousand people had “liked” and read Corbin’s story. By day twenty, 20,000. They continued to celebrate each day and share his life and progress. Every day had a new picture, a new update, and a sign that read a quote of inspiration for Corbin and anyone that read it. His days turned into months and he was able to go outside, have visitors, make a NICU best friend, make a TV appearance, and take a plane ride to a new hospital near his parents’ home in North Carolina. Corbin lived for 135 days. We appreciated the opportunity to hear from Kara and the awareness her page brought to people who knew nothing about trisomy.

Our evening then continued with the presentation of a Lifetime Achievement Award, which was given to Dr. John Carey. Dr. Carey has served as the medical advisor for SOFT since our founding and was even the Vice-President on the original incorporation filing. Founder Kris Holladay has said on numerous occasions that Dr. Carey coming on board made all of the difference in what they were trying to do with the organization. It gave us credibility. He did so at great professional sacrifice. It was fitting to give this award to Dr. Carey at his own professional institution in a year where he was able to show his trisomy family to his professional colleagues at Primary Children’s Hospital. We were then pleased to see the annual SOFT Friends Video presented by Kris and Hal Holladay. It was uplifting to see the adorable faces of our trisomy friends who are still with us and those that have gone. Thank you to all the families that send photos and to the Holladays for the time that goes into making the video.

The evening ended with music and dancing across the checkered dance floor to the view of the sun setting across the west windows of the stadium tower. It was picturesque and will not soon be forgotten by anyone in attendance.

*Story by Debbie Dye*
*Pictures provided by Nora Brady Flores and Kari Brockman Adamson*
Preparing the next generation: An (un)intended outcome of the TRIS project
July 2015  Debbie Bruns
Photos provided by Kelly Hernandez and Kari Brockman Adamson

My family knows all about my passion for children with rare trisomy conditions. My husband, Bill, was there when I first encountered three preschoolers with trisomy 18. He was with me when I searched the fledgling Internet and only found autopsy photos. He was there when I went on (and on) about “my girls” and what a joy they were to be around. My daughter, Marlie, accompanied me to the SOFT Conference in St. Louis several years ago. It was incredible to watch the children go to her, want to be held by her and interact with her. Have to give shout outs to Jill Berta, Michelle Mangan and Gina Vera for sharing their children!! Finally, Will, my son, also attended the picnic that year in St. Louis. He was weary and kept a distance. Imagine my surprise when he came to me last fall and asked for ideas for his Science Fair project.

Long story short, after discussion and some reading including the SOFT Carebook, he settled on an experiment, which incorporated raising awareness of trisomy 18. I’ve included parts of his final report here to share with all of you. It wasn’t the easiest process, research never is, but he followed through and learned a great deal. He has also mentioned an interest in continuing to pursue this topic this coming fall. I’ll keep everyone updated!!

Verbal versus video: Which method helps Unity Point School students learn more about trisomy conditions?

The purpose of this project is to determine the knowledge of 7th and 8th grade students at Unity Point School about trisomy 21 and trisomy 18. Specifically, how the use of verbal information or verbal information with videos affects pre-post test scores.

It was hypothesized that the students who are informed using video and verbal information from fact sheets will demonstrate a greater increase in test scores compared with students given only verbal information from fact sheets about two trisomy conditions (trisomy 21 and trisomy 18). Some test items confirmed while others rejected the hypothesis statement. Seventh grade students provided with verbal information and videos showed some variability in the number of correct pre and post-test responses with most increasing. The verbal information only class demonstrated greater decline in correct responses especially for multiple-choice items. The two eighth grade classes who received verbal information and videos exhibited larger gains in True/False and fill in the blanks items. The verbal information only class showed gains across 12 of 15 test items.

The results represent 46 7th grade students and 58 8th grade students at Unity Point School. There were 15 students in [homeroom] 7-1, 15 in 7-2 and 16 in 7-3. For 8th grade, 20 students in 8-1 and 8-2 and 18 in 8-3. There were four students in 7th grade and three in 8th grade who did not complete both the pre and post-test. As such, their completed tests were not included in the analyses.

Pre-test was conducted during the week of December 1st as well as sharing verbal information only (7-3, 8-3) or with videos (7-1, 7-2, 8-1, 8-2). Post-tests were completed during the week of December 8th. All data was entered in Excel spreadsheets and printed for visual inspection. Analyses were completed by December 28, 2014.

Due to greater familiarity with trisomy 21, only videos with children with trisomy 18 were used in the experimental condition. Parent made videos were used as well as news stories providing factual information. Responses to the videos were positive with emotional responses from students (smiles, sad facial expressions) but gaining factual information about the characteristics and medical conditions of children with trisomy 18 was limited.

There were a number of controls in place to reduce experimental error during this study. First, all 7th and 8th grade students were provided with the verbal information on the same day and had the same amount of time between pre and post-test (one week). Second, when videos were shared with two of three classes at each grade level, they were shown in the same order and with the same introductions. Videos were also consistently shown prior to the verbal information. In addition, students were not assisted during the post-test.
Future plans for further study on this topic include replicating this study with the six and seventh graders of the 2015-2016 school year and retesting the current seventh graders next year. In addition, a similar study can be conducted with only trisomy 18 as the focus. Finally, a video of a parent of a child with trisomy 18 could also be included to more specifically address the items on the test. Information to raise awareness of trisomy 13 could also be conducted.

Awareness should start early, potentially in junior high or middle school, so that individuals recognize the conditions along with the children’s strengths and needs. Articles, resource materials from organizations and websites are a place to begin. There is also a need to provide additional information through media such as videos. This type of presentation has the potential to be especially relevant to 7th and 8th graders as they are avid users of technology.

Beginning in 2007, the Tracking Rare Incidence Syndromes (TRIS) project seeks to increase the knowledge base on rare incidence trisomy conditions including trisomy 18, trisomy 13 and trisomy 9 mosaic through data collection, analysis and sharing the results with various audiences. The three forms of the TRIS Survey collect data focusing on common medical conditions, developmental milestones, therapeutic needs, family-related concerns and demographic data of families with a child (living as well as deceased) with rare trisomy conditions. The resulting information is shared through publications and presentations to raise awareness, increase treatment choices and enhance child and family outcomes.

Further information about the TRIS project can be found online:

Project homepage: http://www.coehs.siu.edu/tris/
Enrollment page: http://web3.coehs.siu.edu/tris/PreEnroll.php
Facebook page: https://www.facebook.com/TRIS.Trisomy.project?fref=ts

Any questions, please send an email to the TRIS project at tris@siu.edu or dabruns@siu.edu

The more that you read, the more things you will know. The more that you learn, the more places you’ll go.

Dr. Seuss

Life is a series of experiences, each one of which makes us bigger, even though sometimes it is hard to realize this. For the world was built to develop character, and we must learn that the setbacks and grieves which we endure help us in our marching onward.

Henry Ford

Tell me and I forget. Teach me and I remember. Involve me and I learn.

Benjamin Franklin
This year an old favorite was added to the conference agenda. The sibling panel was brought back, after missing from the workshop choices for a few years. The panel this year consisted of: Kira Knobel, Mariah Lint, Olivia Lint, Noah Jackson, Jordan Stockman, Ashlyn Jorgenson, Deborah Petersen, David Petersen, and Michael Petersen. It is a special group to put together because we tried to represent a variety of ages, within different parts of the Trisomy journey. Some of the sibs have a Trisomy brother or sister at home and some within their heart.

I had the honor of facilitating this workshop and I must admit that I was slightly anxious when initially asked. Having worked with in the public schools for over 20 years, I know from experience that panels can be difficult, at times, to run smoothly. There are participants who don’t elaborate on answers and give “yes or no” responses. Sometimes participants’ have so much to say, that the others cannot get their feelings across. I was also concerned about the content, talking about deeply personal feelings regarding a sibling in front of an audience. I went in apprehensive and walked out with a deep appreciation and understanding of life with a sibling with special needs. These “kids” blew me away.

What I walked away with most, was the level of influence the Trisomy sib had on each of their lives. Each told of some level of difficulty they overcame and the greater sense of joy that their sibling gave them. When they spoke, it was as if their faces lit up. I was overcome with emotion more than once. As they told their stories, they told of good times and of good people, however they also told of confronting difficult times, difficult people and deeply difficult feelings.

When they were done, the audience was able to ask questions, anonymously. They wrote down questions, which were then read to the panel. The questions varied, however the last one stood out. The question read “If you could go back in time and take away your brother or sisters Trisomy condition, would you”? I opened it up to everyone, thinking maybe only a few would answer. What happened instead was a statement from each sib! “No”, “Absolutely not”, “No but I wish he was still here”, “No way, he changed my life” were just few statements. As I sat there, listening in awe really. I was struck with the level of wisdom, faith and gratitude each sibling had developed. I listened to them talk about their Trisomy sibling changing lives and I thought, no kids you are wrong, YOU are changing lives.

This workshop could not have turned our more perfect. My only hope for the session was that more people would have attended it. We had a variety of siblings in the audience and parents. I am not sure if there was confusion as to the target audience? I believe, this session would be beneficial to all audience, siblings, and parents. Siblings are living the Trisomy Journey too. How powerful their words are. I am forever inspired by this experience. It gave me a deeper understanding of the journey my own boys are going through. Thank you sibs, you are braver, wiser and unconditionally kinder than people so much older than you.
From Left to Right: Kira Knobel, Mariah Lint, Olivia Lint, Noah Jackson, Jordan Stockman, Ashlyn Jorgenson, Deborah Petersen, David Petersen, and Michael Petersen. (Photo provided by Cindy Cook)

Bottom Left: A group of SOFT Sibs on the Sibling Outing to Lagoon. (Photo provided by Kira Knobel)

Bottom Right: A very sleepy SOFT Sib, Chevelle Wagner, on her way back from Lagoon. (Photo provided by Kira Knobel)

Brother and sister, together as friends, ready to face whatever life sends.
Robert Brault

There can be no companion better than a Brother & There can be no friend better than a Sister!
Shobhna RJ

The greatest gift parents can give their children is siblings.
Unknown
ICYMI: Clinics at Primary Children’s Hospital was a Hit!

The 2015 S.O.F.T. Clinics made the local media- Check it out!


https://www.facebook.com/primarychildrens

A special Thank You to the young women of Bethel 13, JDI who volunteered to assist our SOFT Families during the clinics.

Photo provided by Aubrey Valdez

SOFT of Utah would also like to Thank the many Doctors, Nurses, Specialists, Assistances, Child Life Volunteers and all others at Primary Children’s Hospital for their time and care of our SOFT Families.
Here is an exchange of e-mail between Dr. John Carey and Katy Welkie, CEO of PCH:

Dear Colleagues,

I cannot express my gratitude in simple words for your contributions to the SOFT Clinic. We received many Kudos and compliments for the visits and for our hospital. Several families at the Conference came up to me and thanked us for the Clinic. Again your time and kindness were greatly appreciated!

John

John,
I am so pleased it was a success, and happy that you received the media coverage for your great work. Thanks for your leadership and compassion for the patients and their families. You are truly loved for your dedication.

Katy

Katy Welkie | CEO
Primary Children’s Hospital
100 North Mario Capecchi Drive | Salt Lake City, UT 84113
Office: 801.662.6225 | Fax: 801.662.6202
katy.welkie@imail.org

We make a living by what we get. We make a life by what we give.
Winston Churchill

Not everybody can be famous, but everybody can be great because greatness is determined by service.
Martin Luther King, Jr

There’s nothing stronger than the heart of a volunteer.
James Doolittle
Eye Protection from the Inside Out

Lutein (LOO-teen) and its sister molecule zeaxanthin (zee-uh-zan'-thin) work like internal sunglasses inside your eyes, protecting them from damaging light. These powerful antioxidants keep your eyes healthy, improve visual performance and help reduce the risk of certain eye conditions as you age. Although you are born with protective lutein pigment in your eye, these levels generally decrease with age. Since your body can’t produce lutein, it’s important to replenish your lutein levels through diet and eye vitamins. Your eyes are exposed to high-energy blue light every day from sources indoors, like light bulbs and even computer screens, as well as from sunlight outside. Lutein keeps your eyes protected 24/7.

Nearly half of all Americans aren’t getting enough lutein each day— an essential nutrient critical to maintaining healthy vision. Just 10 mg a day helps protect your eyes.

Keep Your Eyes Healthy

- Maintain healthy levels of lutein in your eyes through diet and supplementation
- Wear sunglasses and hats when in sunlight
- Get an eye exam at least every two years
- Do not smoke
- Watch your weight
- Limit alcohol intake

Are You Getting It?

The newest clinical research indicates that you should get at least 10 mg of lutein daily to protect your eyes and keep them healthy. Eating green, leafy vegetables like spinach and kale provides the best dietary sources of lutein, but it’s difficult to get the lutein your eyes need from diet alone. If you’re like most Americans, your daily diet only provides about 1-2 mg of lutein.

How Does Your Diet Measure Up?**

<table>
<thead>
<tr>
<th>food serving</th>
<th>lutein</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kale - cooked 1 cup</td>
<td>23.8 mg</td>
</tr>
<tr>
<td>Spinach - cooked 1 cup</td>
<td>20.4 mg</td>
</tr>
<tr>
<td>Turnip Greens - cooked 1 cup</td>
<td>12.2 mg</td>
</tr>
<tr>
<td>Collards - cooked 1 cup</td>
<td>11.8 mg</td>
</tr>
<tr>
<td>Spinach - raw 1 cup</td>
<td>3.7 mg</td>
</tr>
<tr>
<td>Broccoli - cooked 1 cup</td>
<td>1.7 mg</td>
</tr>
<tr>
<td>Corn - cooked or canned 1 cup</td>
<td>1.4 mg</td>
</tr>
<tr>
<td>Green Beans - canned 1 cup</td>
<td>1.2 mg</td>
</tr>
<tr>
<td>Romaine Lettuce - raw 1 cup</td>
<td>1.1 mg</td>
</tr>
<tr>
<td>Green Beans - cooked 1 cup</td>
<td>0.9 mg</td>
</tr>
<tr>
<td>Eggs 2 large</td>
<td>0.3 mg</td>
</tr>
<tr>
<td>Orange 1 medium</td>
<td>0.2 mg</td>
</tr>
</tbody>
</table>

*Based on the results of the National Disease and Therapeutic Index syndicated report among physicians who recommend a dietary supplement with lutein for eye health – June 2012 – June 2013 (USA data)


Ashton Troi Wagner is wearing a new pair of Junior JBanZ with UV400 Polarized polycarbonate lenses. Thank you to Steve Cantrell for finding companies to donate fun and protective sunglasses to our SOFT kids each year!
2015 Recipient of the Erin Jorgenson Scholarship:

Megan Roozeboom

My brother, David, has had a special impact on my life. He has a partial trisomy 3q, which scientifically means that he has an extra bit of the 3 chromosome attached to his 13th chromosome. It also means that he has experienced a lot of medical problems, most of them at a young age. He doesn’t see, he doesn’t talk, he eats through a g-tube, and his mind hasn’t advanced past the 2-4 year old age, even though he is now 30 years old. But he’s inspired me to follow my dreams. I grew up with him, he lived in the next room over for more than a decade, and while most doctors think of him as a medical anomaly, one who shouldn’t have survived past his first or second year of life, I just think of him as my brother. I’ve seen him go through so many surgeries, spent so much time in the hospital room in Iowa City, and watched him come out of all of the, and recover. He has inspired me to help people, and that above all else is what I want to do when I grow up.

Growing up with David has also caused me to look at disabilities and the people who have them in a different light. I know that people who have disabilities face many challenges in life, but I also know that these disabilities do not define them. The things that they can do are sometimes limited, but the person on the inside does not simply go away because of a medical condition. I don’t know if I would have figured this out without David. If I hadn’t grown up living with a person who I thought of first as my brother, friend, and playmate, I definitely would not have been able to see past the disabilities of others as well as I do now.

All of the impact that David has had on my life has come from the unconditional love that we have for each other. The sibling bond that we share is unbreakable. Taking care of somebody who is completely dependent on me ignited my sense of caring years before anything else did. David enjoys having someone around who will care and look out for him, but what he really wants is a companion, someone to lay around and enjoy anything with. Whether it’s playing with toys, listening to music, or just walking around at the store, I will always be that companion for David.
What started out in Chicago as a simple gathering and fundraiser has turned into quite a social event at our conference. This year’s Stroll was no exception! Families come out and “stroll” over the grounds of the conference, visiting with each other and in some cases, showing the outfits they created. Prizes are awarded in SOFT dollars that can be used at the auction for goodies! This year’s winners were Dominic, for individual theme and the Peterson family for “Best Decorated Wheelchair or Stroller”! It is always a difficult decision to pick a winner as everyone who participates has such creativity.

In addition, families create a Stroll page and gather pledges from family and friends. It is a great way to create awareness for our children and raise some extra dollars for SOFT. All funds received for the Stroll are divided equally between the conference committee and SOFT National. Over $3000.00 was raised in this year’s Stroll!!! To date the Stroll has raised over $25,000!! The top fundraisers this year were: 1st Place- the Stockman Family, 2nd Place- the Dennis Family, 3rd Place - Team Lizzie Bona-Cohen! A special Thank you to all families who made a page and contributed to our overall Stroll total.

Finally, the Cook Family sponsors The Stroll each year. We wanted a special place/event to organize and develop for SOFT in memory of our beautiful boy Jonathan. Jonathan had Partial Trisomy 3,5,13. He was the joy of our lives and we were blessed with for 10 years. Jonathan had a smile that could light up a room and a giggle that was contagious. He was the strongest, bravest, most inspirational person that I have ever known. There is not a day that goes by that I don’t long to hold him, stroke his hair, or give him a kiss just one more time. Jonathan has 3 brothers; Jacob, Evan, and Nathan. We look forward to taking this piece of the conference each year and giving it a special “Jonathan sparkle.” Keeping this tradition in Jonathan’s memory gives us great joy. Thank you again for all your support for The Stroll and especially for SOFT. Until next year.......Stroll On!!!
Top Left – The Petersen Family
Top Right – Artwork by Lizzie Bona-Cohen
Bottom—SOFT Families at the Finish line!
Donald Robert Heaton is one of God’s special creations. He was not created the way we, as humans, consider normal, but nevertheless Donnie was made in God’s image. When he came into this world on September 10th, 1992, he came with a disorder labeled Trisomy 18. The medical team declared gloom and doom, but instead Donnie took the medical world by storm and for 22 years, 9 months, and 3 weeks he continued to amaze all who know him and even those who had only heard his story.

His story - Each day Donnie wrote a new page and sometimes a whole chapter. He overcame several operations and countless stays in the hospital. Many times over the past three years he would be on the verge of death and God restored him to his Mom and all others who also dearly loved him. Each time praises were given to God for another miracle on behalf of Donnie.

September 2010, Donnie turned 18 and there was a big celebration of life. Donnie’s circle of influence had grown bigger and bigger over the years, as was evident by the number of people who came to rejoice over Donnie’s life. God had always been and would always be with Donnie. God had Donnie’s days in His hands.

Donnie’s personality was sweet, gentle, and loving. He was most always smiling, loved to giggle, and do high-fives. His love was genuine and radiated to all who know him. Because of the Trisomy 18, Donnie could not walk nor talk, BUT even without words his spirit spoke loud and clear and without taking a step, he walked right in and captured the hearts of all who knew him. God definitely followed through on what He said the night Donnie was born, “I caused Donald Robert to be born alive. He is my child and I have a special plan for his life.” God used Donnie to touch a multitude of lives, who might otherwise never have recognized the love of God. Donnie is tangible proof that GOD IS.

After turning 18, Donnie continued to enjoy life. Although interrupted more often with hospital stays. It was uncertain if he would see his 21st birthday. Once again, God gave the answer of YES and September 2013 there was another celebration of life. Again thanking and praising God for His faithfulness in Donnie’s life. In the three years since his 18th birthday, his influence had expanded even further. It was like ripples in the water that keep getting wider and wider never really stopping.

Donnie loved to attend worship and praised God as only he could. School was also an important part of his life. On June 1, 2015, despite another hospital stay, Donnie graduated from Nina Harris School. There was another celebration, as always praising God for His faithfulness in Donnie’s life. The doctors had said he would not survive 24 hours after he was born. And now, almost 23 years later, we were witnessing his graduation.
Man had their thoughts about Donnie, but God over ruled. “For My thoughts are not your thoughts. Neither are your ways My ways,” declared the LORD. “For the heavens are higher than the earth, so are My ways higher than your ways, and my thoughts than your thoughts.” Isaiah 54:17

A week after graduation, Donnie was again hospitalized. This time with a severe gallbladder issue. Surgery was not an option due to his complex body and trisomy issues. God, in His abundant grace and mercy set Donnie free and call him home early Sunday morning, June 21, 2015 on Father's Day. What an appropriate time. Donnie was able to celebrate with his earthly father, who had passed away.

Donnie will be greatly missed, but now he is running, jumping, talking, and doing all the other things that he could never do here on earth. Even though he is physically absent, his story will continue to live on and influence people's lives. At the time Donnie was born, God said He had a special plan for him and now he is resting in the loving arms of Jesus. While here on earth, Donnie had a pure sweet relationship with Jesus that we can't begin to comprehend. Now he sees Jesus face to face and I am sure that Donnie heard these words, “Well done, thy good and faithful servant.”

Donnie had physical limitations, but nevertheless he was a missionary, an ambassador of God. His life was not a mistake. Donnie was born with a purpose and he ran the race well. Donnie’s life verse remains, Psalms 139:14, “I will praise You, for I am fearfully and wonderfully made; Marvelous are Your works, And that my soul knows it very well.” No one could have known Donnie and not realized that there is a God. For knowing Donnie, is experiencing God’s love. How blessed are we who knew and loved him. Our lives are the richer because of Donnie’s life. Thank you, Lord!!!
SOFT APPRECIATES YOUR GENEROSITY AND RECOGNIZES THE LOVE AND CARE THAT THESE DONATIONS REPRESENT

Donations to SOFT’s General Fund:
Anonymous
The Ability Experience on behalf of Pi Kappa Phi at Christopher Newport University.
National Junior Honor Society Members/South Seneca Middle School, Ovid, NY
United Way of Greater Atlanta
United Way of Denton County, Texas
United Way of Greater Philadelphia and Southern New Jersey
United Way of the National Capital Area

Donations to the Joey Watson Fund, established to help families attend the annual SOFT conference:
In Honor of Samuel Jackson
Faculty, Staff and Students purchased shirts and participated in “Gene” Friday during Trisomy Awareness Month:
Milan Elementary
Milan Middle School
Milan High School
Jim and Pat Farmer in behalf of Dr. Carol Stenson
In Memory of Nona Evelyn Brown
Spencer and Janelle Brown

In Memory of Silas Edison Gast
Jessica Snapp

In Memory of Nathan Patrick O’Maley
Clint, Amanda and Mallory Wilson

In Memory of Brielle Zawalick
Eileen Kramek

In Memory of Mercy Martin
Kalli and John Martin

In Memory of Christopher K.B. Freeman
Theta Delta Alpha SL Sorority

In Memory of Blake Ted-John Majkut
Michelle Parkes

In Memory of Jordan Gabriel Sadaka
FAS Prevention Team

In Memory of Joey Rosenberg
Jim and Melissa Rosenberg
In Memory of Nathan Patrick O’Maley
Clint, Amanda and Mallory Wilson

In Memory of Brielle Zawalick
Eileen Kramek

In Memory of Mercy Martin
Kalli and John Martin

In Memory of Christopher K.B. Freeman
Theta Delta Alpha SL Sorority

In Memory of Blake Ted-John Majkut
Michelle Parkes

In Memory of Jordan Gabriel Sadaka
FAS Prevention Team

In Memory of Abigail Emmanuel Long
Angela McGrath
Rachel Long

In Memory of Jacqueline Grace Saget-Walker
Jana Walker

In Memory of Mark Csontos
Gina Csontos

In Honor of Kaitlin Pickett
Pamela Johnson

In Honor of Alexis Wade
Bridget Becker

In Honor of Morgan McCormick
Holly McCormick
Deb Ruberg

In Memory of Alaina Anne Campbell
Capt. Jeremy and Maribeth Campbell
Brandy Grant
James and Catalina Loveman
Julie and James Crittenden
Diane Tyndall and Career Programs, Craven Community College
Oliver and Christine Moore
The Foradori Family
Carly Ford

In Honor of John Tate Bottoms
Leadership Cobb 2015

In Memory of Abigail Emmanuel Long
Angela McGrath
Rachel Long
In Honor of John Tate Bottoms
Leadership Cobb 2015

In Memory of Joey Rosenberg
Jim and Melissa Rosenberg

In Memory of London Mann
Steve and Elizabeth Kontos

In Memory of Raymond Hippenstiel
Joe and Sandy Gribbin

In Memory of Michael Dean Meador
Kelly Singleton

In Memory of Samuel Michael Rundell
South Seneca Teachers Association

In Memory of Chelsea Gertino
The Wheeler Foundation

In Memory of Lilly Grace Freda
Mary Ann and John Benton

In Honor of Maggy DeSalvio’s college graduation
In Honor of Matt DeSalvio’s 21st Birthday
Doug and Maryanne Niethold

In Memory of Jace Woldstad
Vince, Sherry, Conor and Gia Devlin and Eric and Kelly Henkel

In Honor of Addalyn Grace Froehner &
In Honor of Jay Froehner’s Birthday
Vicky and Kelly Green

In Memory of Noah Nicholas Armstrong
Associated Bank Retirement Plan Services Support

Thank You
This year our picnic was held on the historic grounds of Ft. Douglas – walking distance from the hotel. We looked out over the grounds from the large white gazebo style bandstand before the picnic began – and what a scene it was. There was a blow up bounce house and a giant slide for the kids on one side, and a huge white picnic tent filled with tables and chairs on the other side. Our awesome DJ Courtney Andersen set up his equipment on the band stand and began playing upbeat music. Everybody started walking over and the place became filled with our SOFT family – and the energy just popped. There were face painters, cotton candy makers, snow cone machines, a picture station, bubbles for the kids, and lots of wonderful Dutch oven cooking from Meier’s Catering – barbecued boneless ribs, chicken, macaroni salad, green salad and “AWESOME” Dutch oven cobbler.

The weather cooperated with sunshine and light fluffy clouds. The huge tent and surrounding trees provided large areas of shade which actually kept things pretty comfortable. Some even chose to sit on the grass with their SOFT HEROES picnic blankets. Everyone was eating, visiting, and enjoying the time together. We also had some special guests – Superman and a family of X-men came to spend time with our SOFT Kids and pose for pictures. There were super heroes of all ages. Even a cute little Wolverine – how adorable was he? What a great end to a SOFT HEROES picnic.

Story by Debbie Dye
Photos for both stories were provided by Kari Brockman Adamson, Julie T Massey, Lisa Hooper, Raquel Wagner, and Naiyah Angel on Earth Photography (Stephi Anyaibe)
The Ryan Cantrell Memorial Balloon Release

At 2:30 we started to gather the original parade ground on the other side of the road - where the trees would not hamper the flight of our balloons releasing to heaven in memory of our SOFT angels. This year we had over 200 names read, which were let go one by one as music played. It took 5 songs to release all the balloons, and every eye was moist. There was a slight breeze blowing towards the East that carried our balloons towards a picturesque mountain view. What a fitting tribute to honor the memory of our sweet angels. How blessed we were to have them in our lives. Our lives have been forever changed by their presence. This day we celebrated those lives and honored them in the best way we could. 

Story by Debbie Dye
NOTICE to our SOFT Families...

If you have a story, article, event, photos, etc. that you would like featured in the SOFT Times, please send your information to the newsletter committee.

Go to:  www.trisomy.org
>"About SOFT" >
“Contact SOFT” and select Newsletter Committee to send us an e-mail.

The next deadline to submit articles to the SOFT Times will be September 5, 2015. A new issue will be published on September 15, 2015 and will include a "Back To School" theme. We would love to see those first day of school photos of our SOFT kids and their sibs!

Thank you for reading!

Fundraiser for soft’s conference in Washington

Simon Dominic Crosier
Memorial Golf Tournament
Date: Saturday, August 8th
When: 9:00 Shotgun Start
Where: Spring Creek Golf Course
Seneca, Kansas
Cost: $50 PER Person/$200 Per Team
Includes Lunch!
Flight & Hole Prizes!
Can’t make it: donation of any amount appreciated
Please contact
sheryl Crosier at 314-443-3770
"Hello My Name is Simon" by Sheryl Crosier

This book is about a very special relationship among three brothers. Even though...

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