President's Corner

Dear SOFT Families:

What an awesome Trisomy Awareness month we had in March. The highlighted stories and pictures were wonderful. The profile pictures that were created with the children were so beautiful and just lit up the Facebook sites. The job that needed to be done was definitely a success. Showing people outside our community what Trisomy is and the community and Love we have all found together. Our kids are the teachers whether they are still alive or alive in our hearts. The Jumping 4 Trisomy videos were so creative and fun to watch. Keep them coming, Trisomy awareness is not just a month long but an everyday occurrence. We almost sold out the awareness bracelets. The cards were shared with Doctors all over the United States. It is not too late to order them and share with the hospital and Doctors in your community. Let’s make them a staple to share wherever we go.

Thanks to all the people behind the scenes who did such a wonderful job! Terre, Terra, Abir, Kelly, Stephe, Kristina, and Ann- we thank you. Of course we can’t forget Frank with the Website, he is always there to help us with whatever we need.

So now it is time to get ready for conference. Did you get your hotel room yet? Did you send in your registration yet? Did you find something on the wish list that you want to help out with? If so you can go to the website conference info and it is all waiting for you right there. Get signed up, you will not regret it. If you can’t make it but you still want a balloon released in memory of your angel you can do that also, Time is running out! SEE you in Salt Lake City!

Check out the new improvements to the website. There is now easier access to all areas. You will find that all the books are now E-books and available right online. Tell Your Doctors to check them out, they are free of charge. Make sure they get their copy of the Care Book so they know how our children can be treated for surgeries and more!

Links for the pictures by Rick Guidotti from conference last year are on the website and available to those who want to see the pics. We were able to use many of these wonderful pictures Rick did this year for highlights during March-

Birthdays are celebrated on a daily basis when we have a date and story together.
Birthdays are celebrated on a daily basis when we have a date and story together. If you want us to highlight your child’s special day go to family stories and add yours so it will be there when we get to the birthday.

For those that are considering being a chapter chair, the application is now available on the website. Fill it out.

So many new things always coming our way!

Do not forget to get on the SOFT Facebook group to talk with other families. Sharing is the key to learning.

-Off to finish planning the special wedding for Andy and Melissa. Stacy will be a bridesmaid so stay tuned for pictures. June 20th will be here for our special family celebration before we know it. Two weeks later we will meet you in SLC.

SOFTly,
The VanHerreweghes
Barb, Dave, Stacy, Andy, Melissa and Nicole

SHARING OUR SOFT STORY TO HELP EDUCATE

The Wagner Family was invited to the University of Utah this past April to speak to 2nd year Genetic Counselors. Their Trisomy Journey story was shared after Dr. John Carey made his hour presentation of Trisomy 18, Edward Syndrome. The class was relatively small, but full of questions regarding Ashton’s medical history, experiences with professionals, home life, school, therapy, support groups, etc. This was our fourth time as guest speakers and representatives of our SOFT/Trisomy families. We gave out several SOFT “business cards” with QR code that takes you directly to: www.trisomy.org for future patients. It is a privilege to speak to those who maybe be a first contact with parents of children newly diagnosed with Trisomy 18, 13, or other related disorders. We emphasize that all children are unique to their diagnosis. The children and their families rely on medical knowledge and family support. It’s important for them to be willing to assist the parents with their first steps into their Trisomy Journey.

_Pediatr Cardiol_, Jan 23, Epub.

In this article the authors examine the outcome of children with trisomy 13 and trisomy 18 who were assessed for possible heart surgery at the Children’s National Medical Center in Washington, DC in 2008-2013. Some children received heart surgery (7 of 13 with trisomy 18, 1 of 3 with trisomy 13), and others had “expectant” management. While the number having surgery was small, the results confirmed what other studies have shown: the majority of children with trisomy 18 and 13 who have heart surgery survive the operation and are discharged from the hospital. As I have summarized in other columns in the last two years, at least 80% of infants have an immediate successful outcome.

This case study represents the 7th published article (5 from Japan) that reports on the results of heart surgery in children with the 2 syndromes. All of the studies are limited by small numbers, usually less than 35 infants undergoing heart operations. In addition all lack information on the long term outcome of the surgical intervention.

Notably the SOFT Surgery Registry of heart surgery (overseen and managed by Ann and Frank Barnes) contains detailed information on over 90 children with complete trisomy 13 and 18 who have had cardiac surgery. In collaboration with researchers at the University of Utah, Ann and I are planning on analyzing the existing data in the heart surgery Registry. This investigation would be by far the largest case study yet documented. In order to improve upon the existing case studies, we will need to examine the long term outcome of the surgery. Thus after final approval from the appropriate review boards, we will seek follow-up information from the families of the children registered currently. We hope to report on those results at a scientific meeting in Salt Lake City this July in conjunction with the 2015 SOFT Conference.

_Every child is a different kind of flower and all together make this world a beautiful garden._
Spring came slowly to the Northeast, days remaining cool and nights cold, and neither April nor May had showers. It was explained that the remaining 25 to 30 foot snow banks that will greet June would have been smaller if not gone, if there had been rain, which penetrates the mass, bringing energy to convert solid to liquid. They are a reminder of the winter that broke records but not spirits. Spring came. Dogwoods seemed winter weary and sparse, but lilacs, magnolia and a ground cover of purple, yellow and white bulbs announce invincibility. Pollen has been fierce, but more people seem to have taken to the streets and trails after being cooped up for so long. I am walking beaches that for two months were impassible, blocked by thick ice floes stacked so high there was no evidence of tide. Elsewhere, where open ocean meets the land, dunes and cliffs eroded, trees toppled seaward and gouged concave banks changed the landscape.

A number of SOFT members have had their own emotional winters. I heard from Phyllis Gipe that in April, after a short illness, Paul passed away. She scheduled his memorial service for the day before their 30th wedding anniversary. Paul and Phyllis, parents of Lauren T-18, are longtime members of SOFT and joined us at the conferences the last two summers. A favorite memory of mine of Paul is in 2001 at the Boston conference. I had booked a hotel that was a bit more expensive than usual, which concerned me, but I had had no choice and had negotiated a greatly reduced rate. He calmed me when he shared that sitting out on his balcony looking down at the broad, calm lakes section of the Charles River with its forested banks and abundant wildlife was worth every cent. Then he smiled and said he could do without the hippies in the canoes. Paul will be missed, and we wish for Phyllis memories that will lighten the dark times as she negotiates life without Paul.

Raquel Wagner has spent recent months overseeing her mother’s health needs and facing and making decisions precipitated by her decline, then guiding her father’s understanding of what needs to be done, no easy task. Her mother’s recent passing, although anticipated, is surely painful, particularly after what must have been an exhausting half year, balancing the needs of both generations, not to mention the conference and the newsletter. We wish for Raquel the peace that comes from knowing she found the strength to do what needed to be done and made good decisions. Exhale!

This year families have joined SOFT who knew their children briefly and turned to us, people who understand. We welcome you and the memory of your precious child who we come to
This year families have joined SOFT who knew their children briefly and turned to us, people who understand. We welcome you and the memory of your precious child who we come to know through your memories and pictures. At SOFT we are family and share in the joys and the challenges and sorrows of our members. At our annual conferences, through the slideshow, on Facebook, and through the newsletter we connect through our children and with each other.

Anne Lamott, one of my favorite contemporary authors, reminds us, “You will lose someone you can’t live without, and your heart will be badly broken, and the bad news is that you never completely get over the loss of your beloved. But this is also the good news. They live forever in your broken heart that doesn’t seal back up. And you come through. It’s like having a broken leg that never heals perfectly—that still hurts when the weather gets cold, but you learn to dance with the limp.”

Two centuries ago Johann Wolfgang von Goethe realized, “The world is so empty if one thinks only of mountains, rivers & cities; but to know someone who thinks & feels with us, & who, though distant, is close to us in spirit, this makes the earth for us an inhabited garden.”

For some of us a record breaking winter has passed and with snowbanks in June blocking views and eroded beaches changing our path, remnants of what we survived, we move forward. We emerge from different kinds of winters, coming out into spring gardens to walk together.

Pam Healey

"What seems to us bitter trials are often blessings in disguise."
- Oscar Wilde

"Climb the mountains and get their good tidings. Nature's peace will flow into you as sunshine flows into trees. The winds will blow their freshness into you, and the storms their energy, while cares will drop off like falling leaves."
- John Muir
SOFT APROCIATES YOUR GENEROSITY AND RECOGNIZES THE LOVE AND CARE THAT THESE DONATIONS REPRESENT

Donations to SOFT's General Fund
Kristin Ward
Bryan and Colleen Sibthorp through Deere & Company and United Way Combined Campaign
Martin Laird
Anonymous through Local Independent Charities of America
Teespringo
United Health Group through The Benevity Community Impact Fund
Sarah Majino

Donations to the Joey Watson Fund, established to help families attend the annual SOFT conference
Trisomy 18 Foundation
In Memory of Zoe Karmis
Christos and Anna Karmis
In Memory of Sarah Kathryn Evans
Jessica Porterfield
Avia Dimattia
The Eldreds
Diane Webb
Liah Wiedenfeld
Mike and Anna Whittenbarger: “In loving memory of Sarah Kathryn, a cherished child”.
Louis and Rosie Avallone
Sam and Nancy Cimino
Louis and Colleen Avallone
Thomas Avallone
Allissa Pietrowski
In Memory of Caitlin Schrock
Suzanne and Larry Montague
In Memory of Rowan Sibthorp
Courtney Huber
In Memory of Gabriel Henderson
Dana and Lori Poling
William and Sharon O’Brien

Thank You!
In Memory of Samuel Reese White  
Patrick G Hagen  
Paula T. Langteau  
UW-BSC Agency  
Patricia L. Stuhr

In Memory of Baby Boy Severson  
Genesis Reliability Group

In Memory of Micah Krupinski  
Enterprise Rent A Car, Dulles, VA

In Memory of Marge Gallagher  
Michael and Linda Murray

In Memory of Nicholas Wright  
Shannon K. MacMaster

In Honor of Stacy VanHerreweghe  
Jack and Judie Laird

In Memory of Mercy Martin  
Jean Hayes

In Memory of Brody Alexander Franklin  
Erica (Brody’s aunt), Ken, Ian, Victoria and Ryan Jaslow

In Memory of Gabriel Blaha  
Dave Blaha’s Co-workers

In Memory of Noah Nicholas Armstrong  
Carol and Danny Tong

In Honor of Sam Jackson  
Max and Barbara Omar

In Memory of Lilly Faith Deese  

In Memory of Jillian Kate Walker  
Janice, Meghan and Alison Walker: “Alison lost her twin, Jillian, to Trisomy 13. We three girls wanted to make a donation to SOFT as part of Meghan’s bridal shower. Alison is Meghan’s maid of honor. Jillian is truly always in our hearts.”

In Memory of Grace Marie Goodpaster  
Dan and Sarah Bugbee

In Memory of Ethan Shale  
Bryony Brookes

In Honor of Kaitlin Pickett  
Debora Szymski
Our daughter Ella was born on July 31, 2002. She was our first child and our 20 week ultrasound conducted in a Dr.’s office (since moved out of the office) provided no indication that something could be awry. Our first indication came from the Neonatologist as he informed us that she had some markers that he wanted to investigate further. What was supposed to be one of the happiest days of our lives, suddenly took a different path, filled with apprehension, hundreds of questions and entry into the Trisomy 18 “club”.

After 5 days, we took Ella home at 3 1/2 pounds as she continued to beat the doctor’s expectations. We did have very supportive doctors that tried to be as informative as possible, but also were realistic in the odds that faced our little girl. At home, we tried to experience as much of Ella’s life in the days that we were blessed to have her. One occasion consisted of an overnight stay in Chicago where she was our dinner table’s centerpiece, where the entire restaurant staff sang Happy Birthday (it was her 6 week birthday). We continued to be cautiously optimistic as we celebrated her weekly birthdays, but still grounded in the fact that we were hoping not for a cure, but as much time as possible with her.

The weekly birthdays soon gave away to monthly birthdays as Ella turned one (and our waistlines continued to grow with weekly cakes). We all just looked at one another and relished the presence of our little girl. Ella was born with several heart defects, the most severe being a large VSD. Even as curve balls were thrown our way (developing primary pulmonary hypertension, difficulty in getting pounds on her) we still knew how precious Ella was to still be in our lives and we shared her with anyone that wanted to take notice. A phrase we quickly learned to describe our situation was, “It’s Ella” when doctor’s looked at us with a “don’t have a clue what will happen next” look. However, even if we didn’t know what to expect, we and Ella’s doctors agreed that we would do what we needed for her to enjoy life to the fullest for as long as she was here with us. One of the more daunting days was her first day of school as we raced after the bus like crazy paparazzi stalking a celebrity. She loved school and while she couldn’t talk to tell us, her mood definitely darkened when she was on breaks from school.

While Ella couldn’t “talk” she could convey a lot with her actions – especially her eyes. An example was how she stared daggers at her new brother when he came home
While Ella couldn’t “talk” she could convey a lot with her actions – especially her eyes. An example was how she stared daggers at her new brother when he came home three years later. Ella was hard of hearing, but she somehow still had the ability to cry at a moment’s notice when our son decided it was time to alert us to feeding time or when he had too much fun in her bath (how dare he)! One of the best experiences out of having another child was for her to show emotion, even if it was jealousy and not really being able to tolerate her brother (take that Mr. Geneticist who said she wouldn’t amount to anything but a blob of unsmiling flesh)!!

After five years of working continuously with a nutritionist and our GI doctor, we decided that we need to get a G-tube as Ella was starting to lose weight (she did have a sucking reflex from the first few days onward, so we had the extra blessing of being able to bottle feed – although we did create a little monster as it had to be precisely the right temperature or she wouldn’t take it – talk about logistical nightmares on road trips). As Ella came out of the successful operation, we quickly were reminded of her fragility as her numbers dropped and she needed to be put on a vent. However, true to Ella form, she fought her way off the vent and we looked forward to our new chapter. The day we were dressing her to take her home, she had another attack (seizure or heart) and she decided that her fight was over. She came into the world on her terms and left it as well. She passed away just 13 days past her 5th birthday.

After nearly 8 years from her passing (and another son – yes, life does go on), Ella continues to be a big part of our lives. The boys kiss her good night each evening and we talk freely to those that want to understand what Ella was all about. Ella was too precious not to share while on earth, but also continue to enrich people’s lives still today with talks at hospitals and Northwestern’s genetic counseling master’s program on Ella and Trisomy 18. We still have a long way to go in educating people, especially the medical community, that while our children’s lives may not be “normal”, they are still our children and probably end up providing more benefits in their short lives than a lot of other people do in an entire lifetime.

Ella, we while we miss you terribly, and we are reminded of your gift to us on a daily basis and couldn’t be prouder parents!

Eric Marohn
Began in 2007, the mission of the Tracking Rare Incidence Syndromes (TRIS) project is to increase the knowledge base on rare incidence trisomy conditions, and to make this information available to families and interested educational, medical and therapeutic professionals. Related outcomes will be the development of appropriate services, advance treatment options, and supports during the prenatal, newborn and subsequent developmental periods. Children affected by trisomy 18, trisomy 13, trisomy 9 and other rare syndromes possess unique needs requiring education of those involved in their daily, educational and medical care (see http://www.coehs.siu.edu/tris/).

To these ends, several versions of the TRIS Survey have been developed to collect data. The Full Survey collects initial (baseline) data for children aged two months and older. The Follow-up Survey is completed on the anniversary of the Full Survey and provides annual updates. Finally, parents whose child was either stillborn or lived less than 60 days complete the Modified Survey. Each version includes questions asking about pregnancy, labor and delivery, medical issues and treatment, family support and developmental progress.

Due to the worldwide reach of the project, participating families represent five continents and over 20 countries. Overall, approximately 750 children and adults with rare trisomy conditions are enrolled in the project. Through April 1, 2015, 350 Full Surveys have been completed as well as approximately 200 Modified Surveys. Data is available for Year 1 to Year 7 Follow-up Surveys. Importantly, TRIS project data points to extended longevity in contrast to the “incompatible with life” view of many medical professionals.

TRIS Survey data is analyzed and shared through research articles (many in the American Journal of Medical Genetics, the premier journal in its field; see list below for recent publications), presentations at national and international medical conferences as well as at the annual SOFT Conference and online such as in a series of blog posts for the Global Genes project (see http://globalgenes.org/raredaily/giving-a-face-to-trisomy-18-debbie-elaborates-on-this-rare-condition/ for an example). Current data analyses focus on cardiac surgery in children with trisomy 18 and oral health and dental needs across trisomy 18, trisomy 13 and trisomy 9 groups.

TRIS project has also prepared and uploaded 12 case studies to the website (http://www.coehs.siu.edu/tris/casestudies.html). Discussion is underway to publish the case studies to reach a larger audience. In addition, the TRIS project Facebook page is located at https://www.facebook.com/TRIS.Trisomy.project and provides project announcements, updates and resources. TRIS project staff also participate in rare trisomy related Facebook groups and offer responses to parent queries on topics including incidence and treatment of reflux in children with trisomy 18, and communication development in individuals with trisomy 9p.
The enrollment form for the TRIS project is located at http://web3.coehs.siu.edu/tris/PreEnroll.php and questions can be emailed to tris@siu.edu - please join us to continue raising awareness and building the knowledge base for this unique group of children and adults.

Recent TRIS project publications:


### 2015 ACMG Meeting in Salt Lake City, Utah

SOFT National was among 150 exhibits at the American Clinical Genetics Meeting sponsored by the American College of Medical Genetics and Genomes in Salt Lake City, Utah March 25-27th. Over 2,200 professionals attended the meeting consisting of 40 plus sessions, workshops, and forums. Board members Debbie Dye and Raquel Wagner (with daughter Ashton who is fifteen and has Full Trisomy 18) represented the SOFT organization by handing out Trisomy Awareness cards, SOFT brochures, and business cards with a QR code which directs the user straight to www.trisomy.org. They meet with several of the attending Genetics Counselors, Geneticist, and other professionals from around the country - many were already familiar with Dr. Carey and/or SOFT which was very exciting!

Dr. John Carey had a busy schedule as well. He had the opportunity to host the research meeting for the 4p group, educate trainees about writing and publishing medical articles, and speak during a presentation entitled: Community Conversation addressing helping with undiagnosed conditions and rare disorders. Overall it was a great experience. Thank you, Barb for allowing us to represent SOFT National at this special event. Go to: www.acmgmeeting.net for more information about the ACMG.
2015 SOFT Conference Update:

July is fast approaching which means the SOFT Conference is almost here. SOFT of Utah welcomes you to Salt Lake City and the amazing views of the University of Utah Campus. The conference will be held at the University Guest House. Book your rooms as soon as possible by calling 1-888-416-4075. The room block will be released on June 1st.

Registration has also begun on www.trisomy.org and will continue until Midnight Sunday June 7th. (A late fee of $25 will be added to registrations received after June 7th.) The registration form includes the opportunity to register for conference, select workshops and clinics, and purchase SOFT-wear.

June 1st is also the deadline to include pictures in Kris Holladay’s annual SOFT video. Pictures can be uploaded at www.softannualvideo.com.

This year’s schedule is designed to allow us to maximize our time together including all meals from Thursday through Saturday (except dinner on Friday) being provided. Our activities commence Wednesday night with an Ice Cream Social catered by Cold Stone Creamery. It will be a wonderful opportunity to visit old friends and meet new ones.

Thursday will begin with a collection of workshops on varying topics that will appeal to trisomy families, no matter where you are on your journey. Thursday will culminate with a Welcome Dinner not to be missed, held in the Stadium Tower on the University of Utah Campus. It was home to the opening and closing ceremonies of the 2002 Winter Olympic Games. The view is amazing as will be the food with the stadium’s new exclusive caterer, Culinary Crafts, 11 time best of state caterer. Thursday night dinner also includes a children’s art auction that will benefit the Joey Watson fund. Feel free to bring your art created by the SOFT kids and sibs to be included or mail them ahead. 8x10 size preferred. The dinner will include the viewing of Kris Holladay’s annual video and special guest speaker, Kara McHenry, founder of Prayers for Corbin.

Friday will begin with a special guest speaker on palliative care arranged by Dr. John Carey. The siblings (ages 5 and up) are invited to register for the sibling outings. Parents of SOFT angels are encouraged to register for a Remembrance Outing to the beautiful Red Butte Gardens where we will have opportunity for a special program, tours of the gardens, and lunch. Friday will also include clinics for our kids at the world-renowned Primary Children’s Hospital in a brand new clinic building. Primary Children’s is the professional home of own Dr. John Carey and he has an impressive collection of professionals arranged for the clinics.

Friday night is family night out on your own. Daycare will be provided and you can take the train from just outside the hotel into the city for dinner and an opportunity for shopping and exploring the sites.

The final day of conference will begin with the Annual Stroll for Hope where we will have a “stroll” around the campus grounds. Start a fundraiser page for your child now at trisomy.org. Be thinking of how you will honor your kids with family shirts, decorate your child’s wheelchair- or whatever creative thing you can think of. Prizes of “SOFT” bucks to spend at auction will be awarded for most money raised, best decorated wheelchair, and other awards presented by the Cook family in memory of their Jonathan.
Often the most anticipated event of conference is our annual picnic and balloon release. This event will be held a short distance from the hotel, allowing the opportunity to come and go as necessary during an exciting afternoon of activities, visiting, and a Dutch oven picnic with all the fixings. This will be a wonderful opportunity to spend a few hours with each other and to remember our precious children that have left us too soon.

Conference will end with our Annual SOFT Auction. It is always an event not to be missed. Bring your auction items to conference or mail them ahead. Popular items donated in the past included handmade items such as quilts, sports memorabilia, and gift baskets with items from your state.

There are many events and sites in the area should you decide to come early or stay late. The SOFT rate at the hotel is available for several days before and after conference. The Salt Lake Bees will be in town on Monday and Tuesday night before Conference. With the Wasatch Mountains as a backdrop, the Smith’s ballpark where the bees play is considered one of most beautiful settings in professional baseball. Monday night is even family night with tickets and hotdogs for 4 for only $20.

Finally, there are still many sponsorship opportunities available where you can sponsor whole or part of an item/event in honor or memory of your child. As the costs of hosting a conference far exceed the registration fees, sponsorships are an important part of making conference successful. Please see the “wish list” on the SOFT website to view items that are available for sponsorship.

We are excited to see you in July.

Please contact softofutah@aol.com or smwrew@aol.com with any conference questions.
RUN WITH SOFT

For the second year in a row, SOFT of Utah is hosting “Run with SOFT.” Run with SOFT was a run, walk, roll designed as a fundraiser for the 2015 Conference and will continue as such this year. Future years will fund other SOFT projects. Last year, we had almost 100 participants and are expecting an even better turn out this year. The Second Annual Run with SOFT will be held in Salt Lake City on June 13th. In addition to local participants, we would love to have a national participation. Please consider registering as a “virtual runner” to support the 2015 Conference. Virtual runners will also receive the run t-shirt and “race number.” Other opportunities to help with Run with SOFT include sponsorship. If you would like more information about being a named sponsor (with your logo on the t-shirt and business information in the race bag), please email runwithsoft@gmail.com. Think how fun it would be to have a Run with SOFT t-shirt to wear at conference and even better – have your logo on the back!!! Register for the race at http://runwithsoft.itsyourrace.com
ART WORK WANTED!

The SOFT of Utah Conference Committee requests the talents of our young members: All SOFT Kids and SOFT Sibs can submit their original creations on canvas, art board, watercolor pad, etc. Preferably an 8x10 or 11x14; able to fit into a suitcase. These master pieces will be matted and displayed for a silent auction at the Welcome Dinner. All proceeds go to the Joey Watson Fund. Please limit one art edition per child. No mailing necessary. Simply bring their work with you and turn them into Registration upon arrival. If you are unable to attend the 2015 SOFT Conference, but would still like to submit your child’s art, you can mail them to: SOFT of Utah 2696 E. Verona Circle Holladay, UT 84117. Be sure that your son or daughter dates and signs their craft. We can’t wait to see what your child’s imagination can inspire!
Trisomy Awareness Month: Celebration and Success!
By Terre Krotzer

March is Trisomy Awareness Month and this year's Trisomy Awareness Month was very successful. We had a great team of committed folks who pulled together and took "Trisomy Awareness" to a whole new level.

As they say, it takes a village... We made great progress this year and expanded our efforts well beyond our community. The membership in our SOFT Facebook group has grown dramatically, and as a result, so have all of our related pages. We welcome all of our new members who have found us because of Trisomy Awareness Month.

As with previous years we offered Facebook Profile photos promoting Trisomy Awareness month. This year requests were filled for more than 320 Trisomy Awareness Profile Photos and more than 300 Trisomy Awareness Cover Photos.

The TAM committee created several Trisomy Awareness Month promotional items to help our families share "Trisomy" information with their community. One of those items was a TAM Postcard for our families to share with their child’s care providers and any other medical professionals that they meet along the way (In my experience physicians have been very receptive to the postcard.) In addition we designed "Trisomy Awareness Month" wristbands and also SOFT rear window decals. We bought in bulk and passed the savings on to our members who are able to order the items by simply making a donation to SOFT.

We wanted to come up with a "challenge" of sorts to create some fun and perhaps gain some attention and from that the Jump4Trisomy was created. Families were asked to shoot a video of themselves doing "Jumping Jacks" or some other method of jumping for Trisomy and then challenge their friends and family to do the same. We had a lot of great submissions - you can check them out online. Go to either Facebook or YouTube and search for Jump4Trisomy Challenge.

Once again this year we did some give aways. This year the qualification to be in the drawing was to create a Jump4Trisomy video. During the month of March we gave away books and SOFT bags and our grand prize: 1 adult registration to the SOFT Conference. The first winner had to pass as they were not able to make it to this year’s conference so after multiple draws our grand prize winner was Terra Garst.

The Jump4Trisomy was a huge success and we look forward to continuing it through the year and especially next March.
Special thanks to:

Terra Spiehs-Garst who was the one who came up with and ran the Jump4Trisomy. She, with some help from her sister, created all of the images used for the Jump4Trisomy. Great idea and lots of fun Terra!

Kelly Hernandez who almost single-handedly created over 320 Trisomy Awareness Month profile photos and over 300 Trisomy Strong covers! This was up from the 170 total profiles and covers I created last year. Kelly, your efforts are very much appreciated and I think it goes without saying that you are my hero!

Stephi Anyai who made sure that covers and profiles were changed and updated multiple times a day throughout the month of March so that the beautiful “Faces of Trisomy” were very much in the spotlight. In addition Stephi helped out in many other ways as well as gentle reminders to me when I dropped various balls along the way!

Kristina Haynes who helped with many things included the creation and design of our Trisomy Awareness postcard and wristbands as well as uploading all of the Jump4Trisomy videos to our new Jump4Trisomy YouTube channel. Check it out here: https://www.youtube.com/channel/UCdJdn7ILNNvGyPpN2Drl4Xw/

AB Schmidt (Abir) who helped with the planning as well as by sharing our spotlight photos across our community pages as well as anything else we asked of her through the month.

Raquel Edmonds Wagner, representing the 2015 SOFT Conference committee kept the conference front of mind by sharing Conference info and details across our community pages.

Ann Barnes, Barb Blossom VanHerreweghe, Katie Doyle Paliotta, Holly Parker Hubbell, Debbie Saunders Bruns in addition to many others (I know I’m leaving some people out and I love you and apologize) helped with various things all of which added up to a very successful Awareness Campaign.

Remember, Trisomy Awareness does not end with March - it is not an event, it is truly more of a lifestyle! And as always, United We Stand Trisomy Strong!

#TrisomyAwareness #TrisomyStrong #Jump4Trisomy #SOFTFamiliesRock!
THE ANNUAL SOFT STROLL...

The SOFT Stroll began in Chicago as an addition to the conference agenda, with the "hope" of making it on the conference program permanently. The Stroll was designed to raise funds and awareness for SOFT and the conference that year. The plan was, for the Stroll to take place around Hope Children’s Hospital, which was about a city block around. Everything was falling into place, the media was contacted, friends, family, nurses and even doctors were going to go outside and cheer on the strollers as they passed by. Balloons and water bottles were ordered for the participants, even medals were waiting for all. The only detail, which was not able to be controlled was the weather. That particular summer, and most importantly, that particular day, was the hottest on record that year!! It was record breaking heat and humidity. Not a very good combination with our kids. The committee had to change plans and change plans fast!! We had days to figure it out! Fortunately, one of our members was friends with a superintendent a local school district. The district donated the use of their high school gym and all was well. We did not raise awareness outside as planned but we created a bond and a tradition that was to continue on.

The Stroll, now called The SOFT Stroll in memory of Jonathan Cook, remains a new and constant part of our conferences. The Stroll takes place, usually the morning of medical clinics, before conference attendees follow their individual schedules. Prizes are awarded to: The best dressed family, the best decorated wheelchair or stroller, and the most money raised by a family. Each year a webpage is posted and families can make individual pages for their SOFT child/family. The link to the page can be sent out and donors can contribute directly to the page, raising money for SOFT. All proceeds from the Stroll go directly to the SOFT National budget and the Conference Committee for that year (evenly). To date, the Stroll has generated over 20,000 of extra revenue for SOFT!!! Quite remarkable!!

The Stroll is sponsored by the family of Jonathan Cook. Jonathan was born with Partial Trisomy 3,5,13. Jonathan was a gift to his family for 10 beautiful years. The Cooks were on the original conference committee when the Stroll began and really wanted to continue nurturing this particular program. The wanted a "home" for Jonathan's name within SOFT and chosen the Stroll to give back in his memory. Each year a gift is provided to participants as well as refreshments in Jonathan's name.

This year, the Stroll will take place at the University of Utah’s Guest House and Conference Center, Salt Lake City, Utah on 7/11/15

The web address to set up your personal Stroll page is http://www.firstgiving.com/softstrollforhope/2015

Please set up a page for your child. In doing so, you can help SOFT raise awareness and funds for this conference and future endeavors. In addition, you just may win one of many fabulous prizes!! Then join us on 7/11/15 in Utah as we STROLL for SOFT this year!!

Softly,
Cindy Cook (Jonathan's mom)
OUR MISSION STATEMENT:
SOFT is a network of families and professionals dedicated to providing support and understanding to families involved in the issues and decisions surrounding the diagnosis and care in Trisomy 18, 13 and other related chromosomal disorders. Support can be provided during prenatal diagnosis, the child’s life and after the child’s passing. SOFT is committed to respect a family’s personal decision and to the notion of parent-professional relationships.

SOFTLY SPOKEN
By Kris Holladay
“Hang On”

“I can conquer the world with one hand as long as you are holding the other.”

Although this happened 15 years ago, it is a forever family memory. Our family drove to California with our three sons, Bryce, Nick, and Devin. We were excited to spend the day at the Six Flags amusement park featuring a variety of roller coasters. When we first arrived, we looked with awe at the loops, corkscrews, ups, downs, splashes, and noise! Some of the rides looked fairly calm, but most looked to have bumps and turns every which way. Excitement and enthusiasm was the emotion felt by our sons, but Hal and I looked at each other with some hesitation. Bryce and Nick talked me into going on the first ride. As we were sitting down in the “suspension roller coaster” (your feet hang out and ride is held from the top), Nick leaned over and said, “Hang on – it’s going to be quite the ride!” I took his advice and held on tight and shut my eyes until we came to a stop. Much to my surprise, I survived. And, more surprising, it was fun! Off to the next ride we ran. The whole family joined in on the water ride and we laughed at each other being completely soaked by the splashes. With each ride, our courage grew and by the end of the day, we were ready to ride the biggest, highest, fastest ride at the park. As we waited in anticipation, we talked about what we would be doing on the ride such as how we were going to hold on, what we would look at while at the top, and if we would scream. Finally, we were ready to roll. I had decided to enjoy the ups and scream on the downs, watch with my eyes wide open, lean into the turns and hang on! When the roller coaster came to a stop, we shared “high fives” all around because we took the “biggest ride” together and we were proud of it!

Sixteen years before the day of the roller coasters, Hal and I were young parents with two little daughters, Tricia was 2 years old and Kari (T18) was just a few months old. We fed Kari every three hours by gavage (tube feeding), day and night. In the beginning, it took both of us to feed her. I would pass the tube and then comfort her. Hal would hold the syringe and pour in the formula. Each feeding would take us about an hour to complete. One memorable night, we were sitting on the couch at 2:30am. We had just finished feeding Kari. She was fussy and I was trying to soothe her and rock her back to sleep. After quite some time, Kari finally settled down and slept peacefully. Only then did Hal lean over and whisper in my ear, “Hang on – it’s going to be quite the ride!”

Not so unlike the roller coaster ride, we decided we would enjoy the ups, scream at the downs, watch with our eyes wide open, lean into the turns and hang on. Yes, we enjoyed watching Kari learn to smile, reach for toys and learn how to roll over and sit up. We cried when she suffered from seizures or illness. We wept with profound sadness when her little body lost the fight to chicken pox. Through it all, our family held on to each other. We shared it all together and we were and still are proud of our family.

Life is life a roller coaster ride. It has ups and downs, twists and turns, fast and slow, and it can be scary and fun! Regardless of the ride, remember …

“Love is -- no matter what life brings you, you’ll still stand side by side holding hands.”

(Kari Deann Holladay is the daughter of Kris & Hal Holladay. They serve on the SOFT Board of Directors as founding parents.)

~ Revision of article in SOFT NL May/June 2000 ~