Dear SOFT Families:

We are well into the Trisomy Awareness Month. Thanks to Terre for getting the State of Washington to sign a Proclamation, as well as Terra for the State of Nebraska. The more the better in recognizing our March activities to help others be aware of Trisomy.

I hope everyone was able to get their profile pics and we have shown them proudly throughout the month in raising awareness. Thanks to the committee in getting all these pics done for everyone and helping to highlight stories as the month has gone by. The awareness shirts are being printed, or you might have already received yours in the mail. They will continue to be available and I know Terre is working on changing the colors and lightening up the shirt colors for a later time. Hope you got yours and you are enjoying it. Don't forget to Follow SOFT on Twitter, Instagram and Pinterest through Raquel.

SOFT Registration for the conference in Madison, Wisconsin is now open and already moving forward. Make sure you get your hotel rooms reserved and then get your registration in. Early registrations help the committee to complete the plans they are making. This year there are several highlights: Dr. Marty McCaffrey will be joining us, as well as Rick Guidotti will be back from Positive Exposures snapping those pics of your beautiful kids. The older Sibs will be off to a water park. The workshops are coming together and so much fun will be had by all! Be there so you don't miss it! Remember there are minimal funds to assist through Joey Watson Fund. Think you can help with something at conference? Check out the Wish List and help us get this conference funded in special ways!

It has been a challenging year for many of our families. So many children sick and trying to recover from so many viruses. We have lost so many children and younger adults this year. Our prayers and thoughts are with all of them. Know we are here for you as you need the support.

March 22nd, 23rd and 24th we had a special SOFT Team representing us at the American College of Medical Genetics meeting. Debbie Dye, Kris and Hal Holladay and of course, Dr. John Carey. Thanks for getting the word out at this important conference about SOFT. Check out the picture in the newsletter.

It was a rough month of March here in NY, two hospital stays, a wind storm that crashed a tree down taking out our power and then a snow storm to top it off. Spring is supposed to be here now, and we are so ready! We are hoping for a healthy Spring and Summer for all. Hope to see you at conference in July! Madison or Bust!

The VanHerreweghes
The Erin Jorgenson Memorial Scholarship was established by the 2010 Conference Hosts, Kim and Gloria Jorgenson, of Waubay, South Dakota, in honor of their daughter Erin, who had a trisomy 18 condition. This $500 annual scholarship is awarded based on criteria explained in the application and is available to those attending college, university or trade school. Applicant families must be current SOFT members but attendance at the annual conference is not required. You can go to: http://trisomy.org/?page_id=5491 to apply for this scholarship. The deadline for applying is June 1st, each year.

Please congratulate the three 2016 recipients of the Jorgenson Memorial Scholarship:

Stacia Sherry is currently going to school for nursing; her SOFT Sibling is Elise, who has Trisomy 18.

Olivia Thompson is going to school to be a Special Education teacher; her SOFT Sibling is Karah, who has Trisomy 18 (deceased).

Grace Gilhooly is going to school for marketing or library science; her SOFT Sibling is Claire, who has Trisomy 18.

Each of these young ladies received a $500 scholarship.
Erin Jorgenson Memorial Scholarship Essay

Stacia Sherry

I was only five but can vividly remember her in the hospital those first few days after her birth. The room was sterile and cold, and she lay isolated in a plastic bassinet. She was hooked up to multiple monitors and tubes tracking her heart rate and oxygen levels. She lay motionless except for the slight pulsing of her chest as she inhaled and exhaled. I remember wanting to crawl up next to her so her frigid, frail body could feel my warmth and be assured of my presence. I reached for her little hand and wedged my way through her tightly clenched fist. It opened just wide enough to fit my finger, and quickly tightened around it with a suction-like grasp. That simple act gave her fragile, vulnerable being something and someone to hold on to. At that moment, I knew and she knew that she was not alone in this fight for survival. Thus began my journey in medicine; a journey ignited by the love of one human being to another, and transforming into the passion that fuels my pursuits for medicine today.

My younger sister Elise was born with Trisome 18, a severe chromosome disorder leading to the improper development of her heart, lungs, and body. From a young age I routinely visited hospitals and doctor’s offices with Elise. As a child, I bathed her, tube fed her, gave her the proper dosage of medicine, and learned to recognize signs of seizures. Nothing about my exposure to medicine was unnatural; it was a normal part of life. As I grew older, my care for Elise was expanded as I became more and more curious about how science connected to medicine and health. Why were so many people “normal”? How does our body function perfectly to not only keep us alive, but also healthy? And why does that system not work sometimes? These questions intrigued me throughout my adolescence. My high school chemistry and biology classes soon took on greater significance and became the means by which I could begin to answer these questions. I developed a keen interest in science which later propelled me to pursue a college degree in biochemistry and molecular biology.

In college, my fascination of science led me to world of research. At UC Davis, I worked as an undergraduate research intern in a biochemistry and molecular cell biology lab for two years. It was here that my innate passion for research fully surfaced. My lab became a space where I could test out ideas, explore scientific journals, and
collaborate with mentors, colleagues, and other scientists. It was here where I witnessed and practiced the initial stages of medicine; including experimental trials, multiple failures, and the mental stamina and fortitude that is required. I found that research was a critical component necessary to bridge the gap between scientific innovation and helping those in need of medical care.

Apart from working in lab and attending class, I was able to maintain my role and passion as a caretaker by volunteering for Team Davis, the Davis community’s Special Olympics team. I was an assistant track coach for children and adults with physical, cognitive, and/or developmental disabilities. This volunteer experience brought balance to my life as a student by providing an outlet for me to do what I had grown up doing: caring for and serving people in the medical community. My research and educational experience proved to further enhance this quality in me by providing a basis of knowledge for what was occurring at a biochemical level in the bodies and minds of these individuals.

Following graduation, I continued on this path by shadowing physicians and volunteering in hospitals. I became a Respite Care Provider and an In-Home-Support-Services Provider for peoples with disabilities. I worked for a year as an assistant teacher in a special education classroom for severely handicapped children. Tending to the needs of medically fragile students in this environment was daily routine. Throughout my life, I have been exposed to a broad spectrum of illnesses and disorders, ranging from individuals with learning disabilities, to those dependent on feeding pumps and seizure medication. It is not uncomfortable for me to be around those who are sick, dying, or physically deformed. Being able to utilize my scientific background to educate and care for those in the medical community energizes and fulfills me.

Though my pursuit of science began as a love for my sister and a dedication to keep her alive, it has evolved into a deeper desire to spread healing, wellness, and hope to all those in the medical community. I am dedicated to the science and practice of medicine because I have the abilities to succeed. Medicine is to me, more than sterile hospital rooms, prescribing medication, and executing protocols. It is a tangible way for me to use my passion and my skills to give those in the medical community something to hold on to; even if at first, it is simply a finger to grasp.
My name is Olivia Thompson and I am applying for the Erin Jorgenson Memorial SOFT-SIB Scholarship. I am the younger sister of Karah Thompson.

When I think of my sister Karah I think of sunshine. My sister hated the feeling of the sun’s glare against her pale skin. She disliked the direct light in her blue eyes. Karah could only tolerate the sunlight for minutes at a time. Despite this Karah continues to be the sunshine of my life. Karah is my sunshine because she brings out the ability in me to stay strong when the going gets rough. She taught me that struggle and pain exists in life, no one is immune. But Karah showed me that overcoming difficulties is a worthwhile battle.

I witnessed my sister go through many painful illnesses, and medical procedures. But I never saw spite in her eyes. I only saw bright beautiful eyes full of hope and promise. Karah taught me that. She taught me that the worth of one’s life is not determined by wealth or fame. But, the value of life is determined by how you live your life. Karah lived her life by inspiring her family, and friends to realize that life is a gift and to make the best of the time that you have been given.

Karah has inspired me to pursue a vocation in Special Education. When I reflect upon what my teaching practice will look like. I know that Karah will be at the heart of my practice. I know that families of special needs children need strong advocates who are willing to make every service and learning opportunity available for their child. Growing up I witnessed my parents do this for my sister. I know that not every child have strong parents to advocate for them. I know that because of Karah I will be determined to provide a strong voice for my students and their families as they journey through the educational system.

Next year at Augustana University I will be employed as the co-chair of the academic program for students with disabilities who are enrolled at the Augustana University Campus Learning Center. My job will be to serve as an advocate and mentor to students with disabilities. Since the students will be enrolled in college classes part of my job will be to oversee class schedules. Another part of my job will be to get the students involved in campus life activities such as attending games, dances, and movie nights. I know that I was asked to serve in this position because my professors knew my sister Karah. They saw me growing up with her and know that because of her I can be an effective advocate and voice for the program.

In conclusion when my parents were picking out Karah’s gravestone they asked my brother Spencer and me what we would like to have on the stone. We thought and cried and finally we both knew that we wanted these words inscribed on Karah’s stone “Karah you have been our greatest teacher.” Karah continues to teach me. Daily I am reminded of her wisdom. Under Karah’s love, I feel warm and safe. Under Karah’s love I know that I can be a successful
special education teacher. It is awesome to think that all of this comes from a girl who doctors said would have a poor quality of life yet the reality was that Karah enhanced the quality of our family. To me Karah was a sister, a teacher, a friend and a safety blanket. To me Karah was sunshine.

Grace Gilhooly

**Erin Jorgenson Memorial SOFT-Sib Scholarship Essay**

01/16/2016

Money. Power. Fame. We are told that these are the things that will determine our happiness and worth. But I have found that this is far from the truth.

My little sister, Claire, has a genetic disorder called Trisomy 18 or Edward’s Syndrome. It is similar to Down’s Syndrome except that it is more rare and is extremely disabling, both mentally and physically. When she was born, no one knew what was wrong with her. When it was discovered that she had Trisomy 18, the doctors found that medical journals labeled the syndrome as “incompatible with life.” The doctors told my parents she would live only a few hours. Claire is now fifteen years old and despite numerous illnesses and surgeries, she is a very happy girl. She has inspired me to challenge the idea that you have to be rich and successful to have value.

I was only five years old when Claire was born, so it is hard to imagine life without her. Her constant joy and peacefulness despite her severe limitations, have helped me to be thankful for my abilities and not to take them for granted. I know that if she was not in my life, I would be far less patient and empathetic. She has taught me from a young age that everyone deserves love and respect regardless of their differences.

Living with Claire has shown me that having special needs does not diminish someone’s value. In America today, many children like Claire are unwanted because people fail to see their value as human beings. These children are often disposed of before they are born through abortion. The lives of these children are precious and should be treated with dignity regardless of the opinions of their parents or doctors. The value of these children lies in the fact that each of them is a person and that value needs to be recognized and protected. I have become involved in pro-life work to help unborn children with disabilities receive the dignity they deserve.
When I was fourteen, I decided that I had to become active in the pro-life movement. I attended my first pro-life camp where I learned to effectively defend human life in all its stages. I have been attending this camp for five years and have been involved as a pro-life leader for four years. I also am involved with Forty Days for Life which is an organization that encourages people to pray silently outside abortion facilities. Working at the pro-life booth at the New York State Fair gave me the opportunity to share my knowledge of pro-life issues with others. I have never regretted my involvement with the pro-life movement because I know that I am helping to make a positive change in the world.

Being actively pro-life has never been more important because the truth about the dignity of all life is so little-known and largely ignored. Witnessing Claire’s happiness and contentment in her life has motivated me to defend the dignity of every child. Each life has an impact on the world and we all lose when even one is lost. Everyone has the right to life and I hope to see the day when that right is protected.

Holladay Grandbabies in lieu of SOFTly Spoken

Hal & I have 12 beautiful and delightful grandchildren! Being grandparents is the best!

Our son, Bryce and his wife, Tiffany had their 4th child, August Arthur Holladay.

Our son, Devin and his wife, Miya had their 2nd child, Graham Halburt Holladay.
March is Trisomy Awareness Month and it was a busy month. The theme for this year was “Shine a Light on Trisomy” and our SOFT Families have truly Shine the Light through the sharing of their stories and spreading awareness.

While SOFT promotes Trisomy Awareness all year long, it is during March that we ask the entire trisomy community to take part in spreading awareness throughout your local neighborhoods, schools, friends, families and medical communities. This year our Trisomy Awareness Month Declaration was created and signed by Washington State Governor Jay Inslee.

We made profile and cover images that you could be use on Facebook, Twitter, Instagram, Google+ or even your blog to help promote Trisomy Awareness. If you haven’t seen them, this is what this year’s TAM profile and cover images look like: (Pardon the shameless promotion of my daughter Krissy – her photos were handy, she’s so darned cute and she just turned 17 years old on March 25! Go Krissy!)

Many thanks to our entire SOFT Trisomy Community for your participation in our Trisomy Awareness month activities. Thanks to our TAM team for your creativity and dedication. Also, a very special thank you to Kelly Hernandez who designed this year’s profile and cover photos, created hundreds of personalized profiles and covers for our Trisomy Community and pretty much single handedly ran this year Trisomy Month campaign. We love you Kelly!
WHEREAS, “Trisomy Awareness Month” is observed during the month of March to encourage residents to increase their awareness of Trisomy, a genetic disorder that deeply affects families; and

WHEREAS, trisomy is the presence of extra chromosome material within a person’s cells, yielding a total of three chromosomes instead of a pair, and as a type of aneuploidy, trisomy can occur with any of the 23 pairs of chromosomes individuals have; and

WHEREAS, the most common trisomies in newborns are trisomy 21 (Down syndrome), trisomy 18 (Edward syndrome), and trisomy 13 (Patau syndrome); and

WHEREAS, local support groups, medical professionals and online communities offer education, encouragement, and counseling for those managing trisomy pregnancies or raising trisomy-affected children; and

WHEREAS, Trisomy Awareness Month is a time for all Washingtonians to educate themselves on all forms of trisomy, support families currently experiencing trisomy and participate in helping people with developmental disabilities achieve their full potential;

NOW, THEREFORE, I, Jay Inslee, Governor of the state of Washington, do hereby proclaim March, 2017, as

Trisomy Awareness Month

in Washington and I encourage all people in our state to join me in this special observance.

Signed this 28th day of February, 2017

[Signature]

Governor Jay Inslee
**Trisomy Awareness Wear** - This year we relaunched our ever popular “Trisomy Strong” shirt which features uplifting and empowering words in the shape of a heart. If you have not yet ordered yours, you can do so at this link: [https://teespring.com/stores/trisomy-awareness](https://teespring.com/stores/trisomy-awareness) We have t-shirts and hoodies in a variety of styles, sizes and colors to fit everyone. (Even a Onesie for your favorite “Little!”) Order yours today – they are a great way to start a conversation and help you spread awareness.

SOFT focuses on Trisomy Awareness all year long! Window decals, wristbands and postcards are some of the promotional items available at: [http://trisomy.org/?page_id=9808](http://trisomy.org/?page_id=9808)
THIS IS THE DAY! Today we celebrate World Trisomy 9 Awareness Day! Wear purple to show your support for my Bethany and all of her friends! And post photos of you or your special ones wearing purple. I will use them to make an album for Bethany. Thank you all so much for appreciating my girl! Use the hashtag #WearPurple-ForTrisomy9 #WT9D (world trisomy 9 day)
Jamie, Kristie, Zion (who has Trisomy 13), Mariah and Olivia Lint wearing yellow for World Patau Syndrome Day!

*Zion left this world and became an angel in 2010

Both pics courtesy of Kristie Lint

Olivia wore her yellow uniform to school today in honor of Trisomy 13 Awareness and for her brother.

Facebook
Kristie Lint/ March 13, 2017

Trisomy 13 Day!!!! Better known as Patau Syndrome Awareness Day.... Today we celebrate how lucky we are to have had such a special person in our family. He came into our lives and totally rocked our world.... happy days, hard days, fun smiles and lots of traveling to conference.... nurses who became part of our family, doctors who either loved us for advocating for him or hated us because we wouldn't give up.... but never a burden.... Zion was and still is our blessing!!!! And although most people wouldn't see any good in a "trisomy" day, we have a huge reason to see today as a great day to celebrate. He may be gone from this earth but we will always celebrate him!!! We are forever changed because of Zion and because of trisomy. So, let it be said...Happy Trisomy 13 Day!!! To all of our SOFT family who have reason to see today as a special day too.... WE LOVE YOU AND COULDN'T HAVE MADE IT WITHOUT YOU!!!!! WE LOVE AND MISS YOU ZION!!! (Posting our yellow picture from 2006 for today)
Kristen Guptill (who has Trisomy 18) wearing her blue for World Trisomy 18 Awareness Day!

*Kristen recently turned 27 – Happy Birthday to You!

Both Pics courtesy of Diana Guptill

Facebook

Diana Guptill/ March 18, 2017

Today is Trisomy 18 Awareness Day for March 18th. Kirsten wore her 'Blue' - the color for Trisomy 18. The picture on the left: She loves her carrot rattle! The picture on the right, got to love her 'look'. Kirsten: 'Mom, you know I do not enjoy having you take so many pictures!' Love it! Love her! Kirsten has great motor skills with her hands. She also has a tight grasp! Just take that carrot away when I tell her it's time for bed and the carrot also needs to go to bed. She really 'grrrippps' that carrot! I have to pry her fingers off of it! I get the carrots from the Dollar Store around Easter. I add two jingle bells and seal the carrot with scotch tape. Brings her hours of enjoyment!
Greetings from Wisconsin!

We have had some very cold weather, but are eagerly planning our 31st SOFT conference! As you know the dates are July 19th - 23rd. We are anticipating a great experience for those choosing to attend conference.

The hotel we have booked is The Madison Concourse (www.concoursehotel.com). The location of the hotel, as well as the amenities offered are sure to make this a prime component of the conference experience. If you are a history buff, the capitol building as well as the Wisconsin Historical Museum and the Wisconsin Veterans Museum are all within a stone's throw of the front door. If this sounds like a snooze to you, then perhaps one of the restaurants, eclectic shops, or piano bar would be more up your alley. Complimentary shuttles within a couple mile radius are available for those that don’t want to go by foot.

As in recent conference tradition, our conference will start with an Ice Cream Social on Wednesday evening. This is a great time to catch up with old friends and meet new ones. This is a fun and relaxing way to kick off the conference. We will be premiering the Kari Holladay SOFT Friends Video during the evening – a must see for all attendees. Kris Holladay needs your photos for the video! Click this link to find out how to send your photos to Kris.
Thursday features a variety of workshops to include: Planning for Older Kids, Music Therapy, Hippotherapy, CPR Training, A Sibling Panel and the Mom’s and Dad’s Forums. The Welcome Dinner, which will include Zion’s Parade of Stars, our keynote speaker, and dance will be held in the evening. We are excited to announce that Dr. Marty McCaffrey, clinical professor in neonatal-perinatal medicine at UNC Chapel Hill will be our keynote speaker! Dr. Marty is a strong advocate for families facing difficult perinatal diagnoses. He also serves on the International Trisomy Alliance and Be Not Afraid boards. He has been a huge support to many families and we are so excited to have him join us!

The Jonathan Cook Stroll of Hope will be held Friday morning. This is a great fundraiser for SOFT! Decorate your wheelchairs and wear your best outfits as we enjoy this “awareness” event.

The American Family Children’s Hospital, which will serve as the hosting medical facility for Clinics, are a very trisomy friendly hospital and are located three miles from the hotel. The medical clinics being offered this year will be: Cardiology, Neurology, Genetics, Occupational Therapy, Developmental Pediatrics, Pulmonary, Orthopedics, Feeding/Nutrition, GI, Communication Aids and Systems, Audiology, ENT and PT.

The Remembrance Outing, for families who have lost children, will be at Olbrich Botanical Gardens. In addition to the usual summer exhibitions, the Blooming Butterflies exhibit will be available in the Conservatory.

Older Siblings (age 8+) Outing at Little Americka Amusement Park. This is a 1950s-style amusement park with restored classic rides, a wooden roller coaster & a kiddieland for tots. Younger Siblings (age 5 – 7) Outing, Madison Children’s Museum and Babcock Creamery. The Children’s Museum contains exhibits on the arts, sciences, history, culture, health, and civic engagement. The Babcock Creamery is part of the University of Wisconsin.
Our Friday night out will be spectacular opportunities to families to reconnect with familiar faces and plant the seeds for new friendships. We will be providing daycare for all children in hopes of allowing parents a quiet night out on the town, or perhaps a raucous evening depending on your tastes. We will have a full list of options available for conference attendees in the welcome packet at check-in.

Our picnic will be held at Warner Park Community Recreation Center. This large space will allow for a diverse set of options sure to tap into the demands of all attendees both young and old. Located a convenient five miles away, the facility is close enough for those who choose to drive themselves.

Our auction will be Saturday night as usual. Please start thinking about any items you can donate or solicit from your area business! We could use your help! We would like to do a table of creative baskets from represents your state or country! WI is easy, beer and cheese! We think this could bring a new, fun element to the auction!

We would also like to encourage everyone to think about making a donation to our conference in memory or honor of their child. No amount is too small! It all adds up. Some families in the past have purchased our binders, conference bags, pens, lanyards, etc. If you would like to donate something and would like it earmarked for a specific item or activity, please let us know. We appreciate all donations and they will be acknowledged!

We are so excited to welcome you back to the Midwest, and for the first time to Wisconsin! If you have any suggestions, questions, comments, anything we need to know or can do to make this conference a better experience for you, please let us know! We want to hear from you! See you in July!!!
## 2017 SOFT CONFERENCE WISH LIST

**ANY AMOUNT CAN BE DONATED FOR ANY PURPOSE. IT'S NOT NECESSARY TO COMPLETELY FUND AN ITEM.**

**CLICK THIS BLUE LINK TO MAKE A DONATION. YOU CAN APPLY YOUR DONATION TO ONE OF THE ITEMS BELOW OR TO BE USED AS NEEDED BY THE CONFERENCE COMMITTEE.**

THANK YOU TO THOSE WHO HAVE ALREADY DONATED MAKING THIS LIST SHORT AND SHORTER!

<table>
<thead>
<tr>
<th>CONFERENCE NEED:</th>
<th>ITEM STATUS</th>
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<tbody>
<tr>
<td>Keynote Speaker Travel Expense: $1200, Lodging $750</td>
<td>$100 generously donated by Jennifer Childress in memory of Julia Childress. $120 generously donated by Christine Kowalski and Alicia Parks in honor of Gavin Kowalski and Leita Parks.</td>
</tr>
<tr>
<td>Welcome &amp; Conference Materials Bags, lanyards, name tags, etc ($1500)</td>
<td>$1500 needed.</td>
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<tr>
<td>Gifts for SOFT Children $500</td>
<td>$500 needed.</td>
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<tr>
<td>Medical Director's Hotel Cost $750</td>
<td>$340 generously donated by three anonymous donors.</td>
</tr>
<tr>
<td>Bottled Water expense $300</td>
<td>$300 needed</td>
</tr>
<tr>
<td>Child Care Supplies – $300</td>
<td>$300 needed</td>
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<tr>
<td>Welcome Dinner Decorations – $250</td>
<td>$250 needed</td>
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<tr>
<td>Welcome Dinner Band/DJ – $TBD</td>
<td>$TBD</td>
</tr>
<tr>
<td>Hotel Audio/Visual Costs – $1000</td>
<td>$1,000 needed</td>
</tr>
<tr>
<td>Hotel Meeting Room Expense – $3500</td>
<td>$3,010 needed: $25 donated by Scott Campbell in memory of Mary Donohue. $25 donated by William Campbell in memory of Mary Donohue. $140 donated by Angela Maliszewski in memory of her son Hayes Kallahan Maliszewski. $250 donated by Dianne Mann in memory of Hayes Kallahan Maliszewski. $50 donated by Ellen Adam in memory of Ellen Roma Nelson.</td>
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<tr>
<td>Transportation to Clinics – $700</td>
<td>$700 needed</td>
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<td>Transportation to Remembrance Outing Estimate: $300</td>
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<tr>
<td>Transportation to Picnic – $1000</td>
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<td>Grand Rounds food &amp; drink – $3,000</td>
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<td>Workshop Snacks – $600</td>
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<td>Remembrance Outing Bags &amp; Gifts – $300</td>
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<tr>
<td>Food &amp; Drink – $400</td>
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<td>Auction Refreshments – $2,500</td>
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In an emotional ceremony, Kansas Gov. Sam Brownback signed legislation named for Simon Crosier into law. Simon’s law is the first of its kind in the nation.

Brownback told a crowd of Simon’s family, friends, and legislators that he was pleased and honored to sign legislation that prevents doctors from putting do-not-resuscitate orders in children’s medical charts without parental notification.

“Simon’s law will insure families can secure the full support of the medical community as they fight for the lives of loved ones,” Brownback said. “...Simon’s story is tragic and short. This law ensures that no parent again experiences this injustice.”

Simon Crosier was born in 2010 to Sheryl and Scott Crosier. He was diagnosed with Trisomy 18, a genetic disorder, three days after his birth in a Missouri hospital.

Throughout Simon’s stay in a neonatal intensive care unit, Sheryl Crosier fought with medical staff who shut off his heart monitors, refused to give him breathing treatments, and begged to give Simon breast milk. She later learned medical staff were reluctant to give Simon breast milk, because his chart only allowed comfort feeds. Comfort feeding isn’t enough sustenance for nutrition or to sustain life.

“After three months of tenaciously fighting for his life, Simon’s life was cut short,” Brownback said before signing the landmark legislation.

The Crosiers learned later that Simon’s care was limited, because a physician placed a DNR in his chart. Sheryl hugged Brownback and addressed the crowd through tears.

Justice and joy, I’m feeling right now,” she said. “We know that every life has meaning, and every life has purpose and dignity. We feel like this is a restoration, so to speak.”
The law also requires hospitals to give parents and prospective patients access to its denial of care policies, sometimes referred to as futility policies.

Scott said he hopes other states will follow Kansas’ lead. Prior to attempting to get the law passed in Kansas, the Crosiers fought for Simon’s law in Missouri, the state where Simon was born.

“All other state needs to get on board and follow Kansas,” he said. “Our neighbor to the east, which is currently my home state, needs to get off their high horse, and the doctors need to quit blocking this bill.”

Sheryl thanked Kansans for Life, a pro-life lobbying group, and several Kansas legislators for their efforts on the bill. Mary Kay Culp, executive director for Kansans for Life, said it’s a misnomer that babies born with Trisomy 18 always die.

“That’s not true,” she said. “…A frightening number of children with chromosomal disorders are denied life-saving medical treatment.”

Despite its failure in Missouri, Kansas lawmakers overwhelmingly approved the legislation. Only three legislators voted against it in the Kansas House. In the Senate, it passed 29-9.

“Raising awareness about trisomy Through Simon’s Story and others. Sharing the “specialness” of special needs.” For more information and updated news on Simon’s Law, go to simonismyname.com. You can also find them on Facebook (Simon’s Law) and on Twitter (@Simons_Law.)
The more things change, the more they stay the same.

I find a great deal of truth in that statement. There’s a positive aspect to it and a not so positive aspect. The former highlights that change is possible while the latter emphasizes the potential limits of change.

In the past few months, there have been new articles published focusing on aggressive interventions for children with rare trisomy conditions as well as concrete ways to encourage parental decision-making (references are below). What makes this even more exciting is these new articles appear in the Journal of the American Medical Association, the leading journal in the medical field. These articles need to be read and shared. Not everyone will agree but the growing evidence including these articles with empirical (research-based) results, cannot be ignored. These articles also promote the belief that conditions described as “incompatible with life” in the very recent past are, in some circles at least, viewed as lives with worth.


This brings me to thanking everyone, again, for enrolling and participating in the Tracking Rare Incidence Syndromes (TRIS) project. The information you share about your children and adults with rare conditions allows additions to be made to the literature, additions calling attention to the range of needs and outcomes rather than decision-making based on a diagnosis. I discussed this in an article published a few years ago and continue to reiterate the need to look at each child individually rather than assuming what should or should not be done based on number of chromosomes.

During Trisomy Awareness month (and beyond), it is critical to offer factual information as well as anecdotes describing the range of needs and outcomes. There is a corresponding need to be vocal and persistent whether that means changing one or more professionals on your child’s medical team, requesting more therapy sessions and/or seeking out others with similar experiences. We can communicate in many ways that were only an idea a generation ago but should remain aware of how information is presented. What I refer to here is I’ve had exchanges with both professionals and parents who do not agree with my perspective. I don’t argue or criticize. I provide data and recommendations from TRIS project data, the SOFT Care books and similar sources. I haven’t changed everyone’s mind but know the information touched their hearts.

We need to see Trisomy Awareness month as an opportunity to continue to put these wonderful children and adults at the forefront, to talk about the joys and the hardships. No one will understand what it’s like without hearing experiences of both the best and darkest times. We must wear t-shirts with rare trisomy related humor, post videos of accomplishments, and tell the naysayers of the worth of each child and adult. We can do no less today and every day.

Thank you for your continued support.

Further information about the TRIS project can be found online:
Project homepage: [http://tris.siu.edu](http://tris.siu.edu)
Enrollment page: [http://tris.siu.edu/survey/form/PreEnroll.php](http://tris.siu.edu/survey/form/PreEnroll.php)
Facebook page: [https://www.facebook.com/TRIS.Trisomy.project](https://www.facebook.com/TRIS.Trisomy.project)
If you have any questions please send an email to the TRIS project at tris@siu.edu or dabruns@siu.edu
Two seminal papers addressing care in children with trisomy 13 and 18 appeared in the prestigious journal, the *Journal of the American Medical Association*, in the last 6 months. The fact that these articles were published in this particular Journal is monumental in and of itself. The papers support the suggestion that there is now an emerging and rich dialogue about care in trisomy 13 and 18 that basically did not exist the medical literature 10 years ago. At this point, in the discourse, I would assert that the dialogue is no longer “emerging”: it has arrived front and center. The importance of the publication of these two recent papers is that they support parental involvement in decision making around care of children with the syndromes and suggest that intervention improves outcome. The idea that "no matter what we do there is no difference in the survival of infants with trisomy 13 and 18" is something that I had heard for decades in medical circles. These two papers as well as other important papers that they cite in the references say otherwise. In the Professional Viewpoint column in the Summer of 2016 (www.trisomy.org), I made the point that there is evidence that intervention does improve outcome in infants with the syndromes.

The paper by Nelson and colleagues demonstrates the highest one-year survival for both trisomy 13 and 18 than any previous study. This article also includes 5-year survival figures and stresses that if an infant with either syndrome lives past one year, the majority celebrate their 5th birthday.

The second paper is also published by *JAMA*, but in their Pediatrics edition. This article is a review and what is most important is that they are advocating for a "patient-centered care approach" in the treatment of infants with the syndromes. The authors close their paper with mentioning that the use of "shared decision making" had been advocated in the past by Andrews and colleagues in the paper highlighted in the Professional Viewpoint.
point, September 2016. The Andrews paper was one of the featured articles in the September issue of the American Journal of Medical Genetics, Seminars of Medical Genetics, which was devoted to management issues in children with trisomy 13 and 18. This paper by Andrews and colleagues (which included Dr. Scott Showalter and Vivian Showalter, who are members of SOFT, as coauthors) represented the summary of a Bioethics Conference held in Denver at the University of Colorado that was attended by SOFT members and cosponsored by SOFT. I was particularly pleased to see that they had cited this paper in regards to shared decision making. The paper by Haug also emphasizes the importance of parent support groups in their care model, and they refer to SOFT in particular.

While there is still a large amount of work to be done in changing the stereotype that can surround trisomy 18 and 13, these recent papers suggest that the balance is tipping in favor of shared decision making in the care of children with trisomy 13 and 18.

Founded in 1991, the American College of Medical Genetics and Genomics advances the practice of medical genetics and genomics by providing education, resources and a voice for more than 1,750 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals committed to the practice of medical genetics. ACMG’s activities include the development of laboratory and practice standards and guidelines, advocating for quality genetic services in healthcare and in public health, and promoting the development of methods to diagnose, treat and prevent genetic disease
SOFT Appreciates your generosity and recognizes the love and care that these donations represent

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In Honor of Ella Grace Revere
Suzanne and Mike Revere, a.k.a Grammy and Gramps

In Memory of Jace McBride Gonzalez to Fund Medical Research
Melissa and Courtney Wicks

In Memory of Angel Children and In Honor of Living Children
On Angel’s Wings Photographers, Springfield, MO

In Memory of Mia Marie Mack
Emily Carlson
In Memory of Regan Adeline Lawson
Uncle Joe and Auntie Laurie Hetzel: “Our precious niece would be 6 years old. We would like to thank this perfect little angel for working her miracles for those of us left on earth.”
Aunt Chris, Uncle Craig and Cousin Carlie: “On the 6th Anniversary of our little angel’s birth. Always in our prayers.”

In Honor of Ben J
Keith Hachey

In Honor of Living Children
Kara Schoeffel, prenatal genetic counselor

In Honor of a Living Child
Brennan Quenneville
John Kemp

In Memory of Christopher Freeman
Marrissa Dean

In Honor of Ben Thomas
Sabrina Delisle-LCA

In Memory of Josephine Annabelle Walpole
Beckie Miller

In Honor of Ivy Maupin
Amanda, Seth, Nicholas and Lucas Goodrum

In Memory of Caroline Boggs
The Grosse Pointe Moms’ Club
A heartfelt THANK YOU to those who contributed to this issue of The SOFT Times. If you have an article, story, pictures, etc that you would like to provide for the newsletter, please send your items to: softnewsletter80@gmail.com. Please note the deadline and publishing dates for future issues.

Thank you, The Newsletter Committee

Deadline Date/ Publish Date
June 15, 2017  June 30, 2017  Pre Conference Issue
Dec 15, 2017  Dec 30, 2017  Holiday Issue

Earlier this year, Dr. John Carey (Top Right Pic) spoke on Trisomy 18 to a class of First Year Genetic Counselors and a few Genetics Fellows at the University of Utah School of Medicine in Salt Lake City, UT. Guest speakers were Liandha Rijksen-Garcia & Jurrie Rijksen, parents to Lunah (Lower Mid-Right Pic), who has Full Trisomy 18 and is awaiting ruling from the Aruba government for a heart surgery, and Raquel & Steve Wagner, parents to Ashton, who is 17 years old and has Full Trisomy 18. Ashton is pictured with Dr. Dave Viskochil, who led the second half of class.

You can now follow SOFT on Facebook (SOFT—Support Organization for Trisomy 18, 13, and Related Disorders), Instagram (@trisomy_soft), Pinterest (SOFT Trisomy 18 & 13) and Twitter (Trisomy_SOFT)
Jonathan was our world. Our lives revolved around his health, the weather (if it was too hot or cold for him); his therapies; doctor appointments; whether places were handicapped accessible, etc. We were Jonathan's parents and we were so incredibly proud. When Jonathan passed, besides the obvious devastation, there was a profound sense of loss and confusion about - what now? What do we do? Who are we?

Shortly after Jonathan passed, I ran into someone I know at a grocery store. They asked how I was and I said "as well as I know to be". "I could never do it" they said. I said nothing. Just weakly smiled and walked away. My head however was screaming- Really? What am I supposed to do? I could stay home in a fetal position, believe me I wanted to or I could try and find our new "normal". A way to carry on without physical Jonathan but rather Jonathan in our hearts.

Our "way" came to be living in the spirit of Jonathan. Spreading Jonathan's love. Giving back with joyful and grateful hearts. We started with SOFT, then Easter Seals with our team Jonathan's Fans, animal shelters, church, nursing homes, hospice, Hope Children’s Hospital and more. We give back because it helps our broken hearts. It keeps Jonathan's love alive, in all we do in his loving spirit. Want to spread some Jonathan love too?

There are homeless shelters, food pantries, animal shelters, schools, hospitals, nursing homes, children's centers, they all need help! Spread some love and tell'em, “Jonathan sent you!”