President's Corner

Dear SOFT Families,

We had a beautiful warm and green Christmas here in Rochester. That is unusual but as I get older I am so glad when it stays warm and we don’t have to fight the snow. This year was extra special with the addition of our granddaughter Andrea. I have to say I am a very proud grandma and I am truly enjoying every minute I get to spend with her. The girl is learning to do the shopping with her Aunt Stacy! What a team. The nice days have changed and we are now back to snowy, cold days in western New York. Hope all of you had wonderful holidays also.

It is a very tough winter on our kids this year. I am so scared every time I open Facebook. So many beautiful children who have gained their angel wings. Heaven must be overflowing with love and beautiful children running and playing with each other! What a picture that would be. Love to each and every family, we are crying with each of you. Please know how much we care.

So who is ready to travel to the west coast for a wonderful conference? Plans are coming together and so many exciting things are happening. You can make your hotel reservations anytime. Ask for the SOFT room block at the Hotel Murano. Come early and leave late, enjoy the beautiful state of Washington. There are some very special plans for the picnic this year you will not want to miss. Don’t miss it, get your reservations set and your travel plans all planned out. The clinics this year will be exceptional! They all know Krissy so this will prove to be a chance of a lifetime for families to bring their children and get expert advice from professionals. Those that have lost their angel will have special experiences to share together. This is a safe place to share your story and know your child is in your heart and with who those you share. There are more details within the newsletter, check them out and get registered. Registrations will be accepted starting in March. There will be Joey Watson Funds available so get your applications completed and sent to Barb before May 1st. Find the application on our website.

The new Embrace the Journey t-shirt came out before Christmas. They turned out great! They will be released again soon so if you didn't get yours, you can order to get in time for Trisomy Awareness month in March. We still have the bracelets, cards and bumper stickers available to let everyone know to, Embrace the Trisomy Journey. There may be bumps in the road, but what an amazing journey it is and what a wonderful family we meet on this journey. You are all wonderful and may your journey be rewarding and smooth.

Love to all, hope to see you in Tacoma, Washington!
The VanHerreweghes
Barb, Dave, Stacy, Andy, Melissa, Nicole and Andrea!
Miss Andrea VanHerreweghe, Grandma Barb & Andrea VanHerreweghe, Grandpa Dave & Andrea VanHerreweghe, and Aunt Stacy & Andrea VanHerreweghe Page 3 – Lauren, Peggy & Steve Cantrell, Nora & Steven Flores, and Hal & Kris Holladay & The Holladay Family. Pictures provided by each family.
HAL & KRIS
Best friends for 41+ years!

TRICIA & RYAN
Rayna (12 yrs), Ella (10 yrs), Joshua (6 yrs)

BRYCE & TIFFANY
Hannah (4 yrs), Callie (2 yrs), Isaac (8 months)

KARI - our angel in heaven
SAVANNAH - our earth angel

NICK & TARA
Reese (5 yrs), Nash (4 yrs), Irie (3 months)

DEVIN & MIYA
Lacey (10 months)

IT’S BEEN A GREAT YEAR!

WE WISH YOU ALL THE BEST IN THE YEAR TO COME...

WITH LOVE FROM HAL & KRIS HOLLADAY
Page 4– Jacob, Ray, Cindy, Evan & Nathan Cook, Patrick, Andrew, Leslie & John Carey and Randy, Krissy & Terre Krotzer and The Krotzer Family.

Pictures provided by each family.
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SOFT of Utah participated in the 45th Annual Festival Of Trees in Salt Lake City, Utah this past December. The Knobel Family took lead this year in tree decoration with the theme, “Heaven’s Playground.” Our members spent several weeks using their wood working, sewing, crafting, and toy gathering skills to create a fun memorial for all of the SOFT children living and past. Over 700 trees were auctioned to raise money for Primary Children’s Hospital.

Pictured below left to right- Kourtney Knobel, Debbie Dye, Tim & Kindra Watson, Lisa & Bella Hooper, and Kira & Julie Knobel.

Pictures provided by Kira Knobel
Tracking Rare Incidence Syndromes (TRIS) project staff sends their wishes for a wonderful 2016. We look forward to the New Year and new opportunities to work with and on behalf of parents and families with a child or adult with a rare trisomy syndrome.

Much of the past few months have been spent data mining (locating data on spreadsheets based on criteria) and analyzing new data sets. This is the first step in working with data to prepare to share at (national and international) conferences and for publication in medical journals. For the former, TRIS project will present at the International Society for Early Intervention (ISEI) conference in Stockholm, Sweden. Debbie Bruns will be joined by Siri Berg and Vera Valen (both from Norway, one with a trisomy 18 angel and other with a living child with trisomy 18) to present “Lives worth living: Advocating for young children with rare trisomy conditions”. It is a symposium with information about developmental milestones, working with infants and toddlers with trisomy 18 and trisomy 13 and a problem-solving perspective. Details to follow after the conference!

An ongoing focus of the project is responding to parent questions. Over the years, parents have contacted TRIS project staff via email and phone and, more recently, rare trisomy related Facebook pages. We hear from parents just receiving a prenatal diagnosis, shortly after a child’s birth and as issues arise concerning specific medical conditions, therapy needs and the like. TRIS project staff data mines, analyzes and summarizes the results to share with the parent making the request and, as appropriate, with other audiences. Several of these queries have become published articles, often the first of its kind in specialty medical journals including *Special Care in Dentistry* and *Topics in Clinical Nutrition*.

Currently, plans are underway to conduct a study examining autoinflammatory issues in children with trisomy 8 mosaicism. This was also initiated by a parent and highlights a topic not explicitly addressed on the TRIS Survey. A survey is in development with related TRIS Survey items and items specific to autoinflammatory issues. A Fellow at the National Human Genome Research Institute housed at the National Institutes of Health (NIH) will develop the latter items. This is an exciting collaboration! More information to come!

The power of the Internet to link parents is further highlighted by TRIS project staff introducing parents to Facebook groups including the project’s page at https://www.facebook.com/TRIS.Trisomy.project for information and support. While not considered rigorous research, parents sharing their experiences are powerful and can make an impact on a child’s care. TRIS project staff will continue to assist in these efforts to share knowledge and provide hope.

Began 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.
Donations to SOFT’s General Fund
United Way of Denton County, Texas
Anonymous through United Way of Buffalo and Erie County
Anonymous through United Way of Salt Lake
Anonymous through UnitedHealth Group and Prudential Financial Inc. via The Benevity Community Impact Fund
Goodshop, earned by SOFT supporters who shopped online using Goodshop and Goodsearch
FirstGiving.com represents funds raised on SOFT’s behalf.
Martin Laird
Give With Liberty

In Memory of Ian Joseph Kihiu
The Cauthon Family
Glenda Clawson
Karah Merrell
Monkey.Lulu.Bean Clothing
Don and Barbara Bushell

In Memory of Kelsey D. Bates
Jim and Lynn Burrell

In Memory of Maggie Lynn Yost
Christina Bradner

In Memory of Grace Ann Cooper
Baptist Foundation of South Carolina

In Memory of Simon Crosier
ThereseAnn Siegle

In Memory of Lois Matetich
and her granddaughter,
Beatrice, who had Trisomy 18
Mary Pat and Bryce Peterson

SOFT APPRECIATES YOUR GENEROSITY AND 
RECOGNIZES THE LOVE AND CARE THAT THESE 
DONATIONS REPRESENT...
In Memory of  
*Gracelyn Marie Schlater*
HYP Jewelry LLC

In Memory of  
*Regan Adeline Lawson*
Joe and Laurie Hetzel
Mikuly’s

In Memory of  
*Serena Grace Pertile*
Stephanie Balazs

In Honor of  
*Emmerson Jane Gordon*
“Keep Collective”, a fundraiser hosted by Emmerson’s mother

In Memory of  
*Samuel Hall*
Sheryl Crosier

In Memory of  
*Ezra Estes*
Bonnie and Danny Klein

In Memory of  
*Eisley Hope Klein Hutchinson*
Casey Lynn Klein

In Memory of  
*Lilyana Grace Hinojosa*
Lannette Garrett

In Memory of  
*Michael Dean Meador*
Jeanie Richards

In Memory of  
*Emma Lynn Brown*
The Employees of Ebert Machine Co.
Jane and Gary Horner

In Memory of  
*Aurelia Magnolia Carlson*
Carol Schofield

In Memory of  
*Magnus Carlson*
Jonas Carlson, Gothenburg, Sweden

In Memory of  
*Sarah M. Banks*
Bill and Cindy Brady

In Memory of  
*Jared Johnston*
Wendy Hogarth

In Memory of  
*Abel Conte*
Maggie and Laz
In Memory of

Angela Frances Ricker
E. David and Nancy Ricker, Angela’s grandparents
Jacqueline S. Joy-Ames
Adam Goldstein
Laura Barrett
Amanda Doster and Moti Zemelman
Gail Parsloe
David Bideau
Barbara Miles
Anonymous
Ellen Waite-Franzen
The Brooks’
Joseph and Mary Doucet
Craig Saunders
Harry, Nancy, Levy and Cecily Byrd
Jennifer Turbes
Benjamin Van Vilet and Alicia Casey
Lorelle Faith Foundation
Dartmouth College - ITS
Sheila Moran and David Millstone
Carole Dempsey and family
Blakeney Bartlett
Helga Tse
Daniel Longnecker
DeWitt Mallay
Sarah Schwaegler
Chris, Barbara and Nacio DeFeline-Levey
Hope G. Hungerford
Eva Behrens
Robert and Lisa Handel
Paul Schroeder

In Memory of Elizabeth Hilmes and her grandfather,

William C. Hilmes
James and Dolores Pierce
Kevin and Kimberly Hilmes
Steve Hilmes
Greg and Lisa Hilmes
Donald and Karen Hilmes
Scharol A. Ewest

In Memory of

Julia Elizabeth Flor
Rob and Melissa Overton
Maria Voitovich
Mary Beth, Randy and Erika Brown
Erin Dunlap on behalf of Doc Engine Team 1
Mukunthan Muthukumar
Susan and Tim Thompson
Paul and Robyn Runyan
OTHS Class of 2003 Girlfriends
Chad and Kim Luce
In Memory of Natasha Winslow
Leominster Spanish SDA Church

In Honor of John Pucci’s Aunt
Irene Lorenzo’s 100th Birthday
Susan and John Pucci

In Memory of
our granddaughter,
Jordan Arella Coulombe
Sally and Ray Boucher

In Memory of
Lynden Elsie Rose McHarry
Lambda Sisters, given with much love, Priscilla Ing

In Memory of Rachel Maurer
Anne and Wes Wallace
Vicki Price

In Memory of Gabriel McElroy
Shelley Rahill

In Memory of Sarah Marcela Poole
Joseph Meijide

In Honor of Tristan Williams
Mary Botello

In Memory of Mercy Martín
John Martin

In Honor of Zia Moore
Thea Moore and Michael Jones

In Honor of Morghan Kubena
Jonathan, Paige, Addie Grace and Reed Kaufman

In Honor of Brinley Hubright
Heather Baier

In Memory of Makena Lillian
Theresa Schmelzer

Thank You!
In Memory of Vida Elyse Mora
Elizabeth McCausland, “Vida was a beautiful child”
Fred Rodriguez, “In memory of little Angel, Vida”
Ileana Oria Veronica Medina, “Donating in the name of Vida Elyse Mora (Life Dedicated to God). On January 5, Heaven gained an angel and a beautiful baby girl who touched the hearts and lives of many in her short time with us. She will be missed more than words can describe. Praying for her family to find peace and strength during this time.”
Salvator and Cynthia Garcia, “Donating to allow Vida Elyse’s legacy to continue and touch the lives of other families with children with Trisomy.”
Rene and Rosy Rodriguez, “We hope this donation will help mommies and daddies in the future who give birth to special angels like Vida Elyse.”
Jose Requejo
Javier Ley-Soto
Cynthia Morales

In Memory of Boniface Hassan, Jr
Jose Antonio Hassan “My elder brother, Boni, would have been 80 on December 8. He and his wife Christine dedicated their lives and love to the care of Joanna, and through this, their support and shared experience with other parents of children with Trisomy.”

In Memory of Julia Grace Childress
Steve and Neva Martin “Our precious granddaughter Julia would be 5 years old November 30, 2015. We love and miss her very much!”

If you or someone you know would like to make a donation to The SOFT National organization, go to: www.trisomy.org for further information.
The big news for us is this past October I was the keynote speaker for the Schenectady, New York State Right to Life chapter's annual meeting. I was able to share Alexander's story, as well as our experiences when facing the medical community in a battle for rights to care and life. I shared the stage with the local bishop, a local rabbi, and the 90 year old chapter president. It was a lovely evening. Happily the group consisted of several medical professionals, and I hope the message gets out that our children are worth every single bit of care as any other. I have developed a relationship with Lori, the NYS RTL president, and it is a pleasure to get to share the trisomy experience with such a large audience. Barb VanHerreweghe was also speaking at the meeting in western New York around the same time. The next item on my agenda is to try to organize a conference here in New York. I am working with the major medical center in Albany, where I still moonlight. I have the pleasure of calling the pediatric palliative care doctor my friend, and she is like an instant pass to all those specialties we want our families to get to see. Dr. Natasha Shur is also the pediatric geneticist, and has been involved in SOFT before with Dr. Carey, so I say we have a good "in"! Personally, I am getting settled into my new role of family nurse practitioner, and all the responsibility that holds....including 20 hours a day between clinic seeing 20+ patients and then managing care after hours, such as responding to prescription refills, x ray and CT reports, calls for consults, and simply catching up on charting. It is a great experience, but....I mourn what I recall was a normal life! But what a great opportunity to share the trisomy experience with professionals (my clinic medical director is an OB GYN), as well as patients. I recently had my first counseling appointment with a woman to review her positive AFP and T18 screening, as I see OB patients up to 28 weeks. But I was able to refer her to SOFT, our own Alexander's Awareness, and show her photos of how amazing our babies are, born alive or still. It was a moving experience!

Nora and Steven Flores pictured above
Story and pic by Nora Flores
Our son, Caleb Nathaniel Adamyk, was born in March of 2009. Caleb was diagnosed with having Full Trisomy 18. We were incredibly blessed to have a wonderful team of doctors at the UF Health Shands Hospital in Gainsville, Florida. Caleb lived for 2 ½ amazing years. During this time we had been asked by our Genetics Counselor if we would be interested in doing a lecture for their 1st year medical students. We were honored to be asked to share Caleb’s journey and to bring more awareness to trisomy 18. We have done seven lectures in total. The first couple of years Caleb was able to be by our side. After Caleb passed away, a video documentary of his life has been shown. We also have display boards of Caleb and many of his friends. We include children that were stillborn, infants, toddlers, older children and young adults. Our goal is to help students understand that it isn’t about the length of time our children are with us, but the quality of life that they can have while they are here. Most of all, that each of their lives matter even if they never take their first breath. The majority of the medical students have only seen a child with trisomy 18 in text books. So to see and learn how amazing their lives can be on a personal side is so incredible for them. And to see how receptive they are in learning more and asking questions is what motivates us to continue speaking. It gives them the opportunity to learn more about our children, and how they as doctors can help make a difference in our children’s lives. Especially the family as a whole. We tell them that the greatest gift they can give us is to treat our children with respect and dignity; to help them through whatever illness or issue(s) they are having at that moment….not to look at them as a diagnosis, but as a precious person.

On this side of the journey it gives us great peace in knowing our son Caleb was treated with such care, love and respect. It is crucial that medical staff, caregivers and families work together in making the best decisions for a child, whatever that may be. Approximately four years ago, the UF College of Medicine decided to integrate basic and clinical training. The new Genetics course integrated basic science lectures with clinical presentations. One “block” of the new course focuses on trisomy conditions. This course is the first course that UF medical students undertake during their training. We feel so blessed that our son can make a difference for future children with the same diagnosis. It only takes making an impact in one person’s life.
If anyone is interested in learning more about the lectures that we have done please feel free to contact us, Jeannette and Steven Adamyk. Many thanks to Brian Harfe, Ph.D., Associate Professor, Molecular Genetics and Microbiology College of Medicine AND Associate Dean College of Liberal Arts and Sciences AND Assistant Provost and Jennifer Mueller, M.Sc., C.G.C., Genetic Counselor, Dept. of Pediatrics at UF, for giving us the amazing opportunity to share our story to their medical students.

Part 2...

In December of 2013 my husband and I welcomed our first child, Payton Jewel Thompson. The happiness of having our first child was very short lived as we knew immediately when she was born something wasn’t right. The next day we were told that she had Full Trisomy 18. I stayed up late trying to find answers about this. I got a response to one of the many emails I sent that night from Alex Hauber. He quickly got me in contact with Jeanette who lives about 45 minutes from us. Jeanette was so important because she had lived this just a few years prior to us. Her son Caleb saw the doctors my daughter would be seeing. She told me EVERYTHING to look out for and what to be prepared for while going to appointments at Shands Hospital at the University of Florida. I was terrified as I knew that many children were refused treatment, but at Shands the majority of doctors there were open minded and most where willing to help. There are of course a few bad apples in every group.

I like to think that Jeannette, Steven and Caleb paved the way for Payton and other children with Trisomy 18. Amazing parents like the Adamyk’s are what makes it even easier for the doctors to love our children even more. Many people Jeannette set us up with remembered Caleb, which is such an amazing tribute to truly how amazing he was.

Throughout my life I have always been a person to get involved. I wanted to get more involved in spreading awareness for Trisomy 18, but with having a newly diagnosed child it was very difficult to find the time. Jeannette called me and told me about this talk that she and Steven did every year for the first year medical students. She asked if I would like to join her. I was so happy! That first class we went to was amazing! I got to hear Caleb’s story and see the videos the local news had done about him. I got to hear how Jeannette and Steven responded to some very difficult questions. They answered the questions with such poise and elegance, I was impressed. After the formal lecture the students crowded around us and Payton. They was so interested and asked so many questions. They also crowded around the Adamyk’s wanting to know more about Caleb.

“Teaching creates all other professions.”
–Unknown Author

“A teacher affects eternity; he can never tell where his influence stops.”
–Henry Brooks Adams

“Tell me and I forget. Teach me and I remember. Involve me and I learn.”
–Benjamin Franklin

“Those who know, do. Those that understand, teach.”
–Aristotle
This was our second year attending. Payton was so excited this year, unlike last year which she slept through, she babbled through the entire lecture, as that is what she does when excited. Again Jeannette and Steven shared their story and again answered some pretty tough questions. This year we got to share a little of our story. My emphasis to these future doctors was that one of the most important things they can do is to connect parents. Help parents, with children who have similar conditions, get in contact with each other. I believe to this day that Payton would not be here if it wasn’t for Jeanette and even Caleb. Jeanette guided me through, and Caleb paved the path for the doctors to accept Payton. Getting involved in these lectures with these first year medical students has been so fulfilling. I believe that they are learning about all rare and “hopeless” conditions when they see children like Payton and Caleb who were not supposed to even be born, thrive. It teaches them that miracles are possible.

March is Trisomy Awareness Month

Trisomy Awareness Month is right around the corner and preparations are already underway. The theme for this year is “Embrace the Journey.” 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. Once again we will have profile and cover images that you can use on Facebook, Twitter, Instagram, Google+ or even your blog to help promote Trisomy Awareness. You will be able to start requesting this year’s images in early February. Look for an announcement at www.trisomy.org or on the SOFT Facebook page: https://www.facebook.com/Trisomy18.Trisomy13.Awareness.SOFTrelatedDisorders/

Our 2016 Trisomy Awareness shirt has been relaunched and if you have not yet ordered yours, you can do so at this link: https://teespring.com/etj-2016-trisomy-awareness We have hoodies and t-shirts in styles, sizes and colors to fit everyone. Shirts will be printed and shipped to arrive in time for Trisomy Awareness Month. Additional Trisomy Awareness promotional items are available at: http://trisomy.org/?s=trisomy+awareness+month

“Embrace the Journey” and help us help others get the information they need to avoid feeling alone and hopeless on their Trisomy Journey. More information and details about Trisomy Awareness Month will be available as we get closer.
Another year has come to a close and a new one begins. Time marches on from days to weeks to months and years. And on difficult days, it is seconds to minutes to hours!

Every January, I am reminded of a moment in time when Kari was six years old and was doing well. She was the healthiest “sick kid” around and was progressing slow but sure. Our family had found a comfortable routine and I was content. Each moment was a blessing and every day a pleasure. The challenges of a young family were familiar to us, but it was exactly how I wanted to spend my time! Then it happened! Kari had a seizure; not an “ordinary” seizure, but a seizure that wouldn’t stop called a “status seizure”. Hours passed before the doctors could control the seizure and only then by following a regiment of medications. Kari was in a hospital bed where she lay motionless except for her quiet breathing. I pulled up a chair and sat next to her, stroking her hair and wondering how everything had changed in a split second of time!

As I looked at this wonderful child, I started telling her why this would not be a good time to die! I explained to her that she couldn’t leave me in January because this is when the new year begins and I couldn’t start each year missing her desperately. But February would never be good because it’s Valentine’s Day and it would truly break my heart if she were gone. Of course, March was kite flying month and the daffodils were starting to bloom & she loves the park. And, April brought Easter and new dresses and new life. I told Kari that May was out of the question because it was the end of school and the beginning of summer and we would play all day. June was too beautiful and the sky so blue and we love to go for rides. July had the 4th with parades & picnics and I told her that she loves the fireworks because they are so loud and bright and I couldn’t look at them without her. August was the end of summer and we always played in the back yard and it was more fun with her there. September was a new school year and that would mean new clothes and pictures on the first day of school. Of course, October brings Halloween and she always looks so cute in her costume. Then there is November and Thanksgiving and I was sure I could not be grateful without her in my arms. And certainly December was not a good month because of all the celebrations and I knew I would never enjoy them if she were to leave me then! No, there just wasn’t a good time for her to die!

She didn’t leave me then, but she did four years later. Oh how I worried that time would take away the things that were so dear to me! But, I know now what I didn’t know then. Kari’s lessons of love are TIMELESS! The memories I carry are TIMELESS! My love for Kari is TIMELESS!

“Sometimes you will never know the value of a moment until it becomes a memory.”

-- Dr. Seuss --

Hugs…Kris
The 30th Annual SOFT Conference

The 2016 Conference Committee is very excited to bring this year’s SOFT Conference to Washington and we are busy planning, organizing and getting things ready to welcome our SOFT Family to Tacoma July 20 – 24th. While July seems a long way off it will be here before we know it so NOW is the time to start planning for your trip to Conference.

This year will be the 30th Annual SOFT Conference, (can you even believe it?) and what a celebration it will be! Our home away from home will be the Hotel Murano which is right in the heart of downtown Tacoma, the perfect place for our SOFT Family reunion!

There are many attractions, restaurants and activities within walking or trolley distance to the hotel: The Chihuly Glass Museum, The Chihuly Bridge of Glass (totally cool!), America’s Car Museum, and waterfront restaurants just to name a few. You will definitely want to either come in a day or two early or stay a day or two after just to take it all in! The conference will include many of the annual traditions you’ve come to love and expect: a Welcome Dinner Gala complete with music and dancing, workshops that will include something for everyone, Sibs Outing, a Remembrance outing, clinics at Mary Bridge Children’s hospital, the annual “SOFT Friends” video premiere and more...

Our picnic will be held at Cheney Stadium where the Tacoma Rainiers play baseball and you’ll have an opportunity for a short ballgame or batting practice on the very same field they play on!
Registration for the conference will begin March 1st. In the meantime here are some things you can do to prepare. First of all, decide today that you and your family will be there. From there is it easy:

1. **Book your room(s) at our hotel:**
   Hotel Murano  
   1320 Broadway Plaza  
   Tacoma, WA 98402  
   United States  
   For Reservations call: 888-862-3255  
   or go online: [https://bookings.ihotelier.com/bookings.jsp?groupId=1507727&hotelId=15048](https://bookings.ihotelier.com/bookings.jsp?groupId=1507727&hotelId=15048)  
   Be sure to request the SOFT Conference Rate of $139 per night.

2. **Start checking airfares or begin planning your family road trip:**
   There are lots of great sights and experiences to be had as you travel west! Tip: if you are traveling by air often the best rates can be found on Tuesday.

3. **Choose your favorite photo(s) of your SOFT Child.**
   Please submit your picture(s) for the Annual “SOFT Friends” video created in memory of Kari Holladay at [http://www.softannualvideo.com/](http://www.softannualvideo.com/).

4. **Consider making a donation or hosting a fundraiser to support the Conference Fund:**
   Conference Registration fees cover only the meals that we provide. (we won’t be providing every meal but trust me you won’t go hungry!) Every other part of conference: outings, activities, buses to and from activities, facility rentals, entertainment - just to name a few things – are funded by your generous donations to the Conference Fund.

   We will have a complete “Wish List” ready to publish very soon. In the meantime please consider making a donation to the SOFT Conference Fund. If there is something in particular you would like your donation to sponsor please let us know.

   There are more details to follow. In the meantime any questions can be directed to Terre Krotzer at [terre@trisomytalk.com](mailto:terre@trisomytalk.com). We look forward to seeing you in Tacoma this summer!
The most challenging and difficult issue to discuss in the care of a child with trisomy 13 and trisomy 18 is the well-known newborn and infant mortality figures. I can readily recall my opening presentation at the first SOFT Conference in 1987 when I struggled with how to frame this issue in my talk to the parents who attended that inaugural conference. At that time they were only two studies in the medical literature addressing the topic of trisomy 18 outcome, and only one was a population-based investigation, the preferred method for determining accurate figures of survival. Since the 1990s over 10 population studies have been published on survival of infants with trisomy 13 and 18 in different parts of the world, including four from the UK. The findings of these studies have led to the widely used estimate of 1st-year survival in both conditions of 5 to 8%. I suspect most readers have heard or seen these figures.

Discussions of these numbers is important and timely because I can attest that the terms “lethal” and “incompatible with life” are still used in medical circles—something that’s startles me. This deliberation leads me to talk about the recently published paper in the American Journal of Medical Genetics by Dr. Robert Meyer and his colleagues cited above and the topic of this “Journal Club”. This nine-state study examined data obtained on live born infants during 1999-2007. The article not only reports on what is the highest 1-year survival for trisomy 13 (11.5%) and trisomy 18 (13.4%), but also on 5-year figures, i.e., 9.7% for trisomy 13 and 12.3% for trisomy 18. What is particularly important is that the number of children included in the research is almost 4 times any prior population investigation, 1,113 infants with trisomy 18 and 693 with trisomy 13. The fact that median survival for both conditions was similar to other published studies suggests that the overall study is accurate.

The authors raised the question that the “somewhat higher figures” are “consistent with recent studies reporting improved survival following more aggressive medical intervention for these children”. They close with “these conditions should no longer be regarded as uniformly lethal malformations.”

This landmark research represents another step in the ongoing and continuous journey to remove the “lethal” and incompatible” labels from the medical community for good.
A Birth Announcement?
A Wedding Announcement?
A Graduation Announcement?
A Fund Raiser Event?
A Chapter Chair Event?
A Celebrated Event?
An Inspiring Story?
An Amazing Story?
An Enriching Story?

Do you have an announcement, event, or story about our:

SOFT Kids? SOFT Families? SOFT Sibs? Please submit your article and/or pictures to our Newsletter Committee at www.trisomy.org no later than March 13, 2016. The next SOFT Times is scheduled to be published by Sunday, the 20th of March 2016.

We look forward to seeing YOU in the next issue!