Dear SOFT Families:

We made it through this hot summer and now we are right around the corner for the new season to begin. Fall is just starting to show up in the Northeast. We are hoping for a mild winter but probably won’t be that lucky for two years in a row.

Plans are under way for the 2017 SOFT Conference in Madison, Wisconsin. The hotel contract has been signed and you will be able to call the hotel to register soon. As every year there are only so many rooms reserved so make your reservations early so you don’t lose out. The hotel cost for this year will be $144 per night. The committee is very excited to welcome you to Madison and they are working hard to set up the clinics, workshops, outings and picnic. Let them know early what you would like to see, maybe they can fit it in. I hear the committee will be offering a special hotel value once we are ready to register so keep watching the web site and opening your emails so you can see what the offer is for one family! www.trisomy.org

It has been a very tough year for many of the kids this year. Respiratory issues, bowel issues it just continues on. Support to these families when they are in the hospital or when their child has passed is so important. Nobody knows better than their family of trisomy families knowing what they are going through. I know when we were in the hospital this year with Stacy I so appreciated the many prayers and words of encouragement we received. Even on those days where we thought we were not going to make it, those caring words so helped. So The VanHerreweghes send their love and prayers to each and every one of the families that are on the journey to get better, stay healthy and to those that have lost their sweet child. Know we care and we are here to support you.

Stacy is slowly regaining her strength and getting better. Less suctioning most days and she is actually down to 1/2 liter and yesterday she tested room air for a while and did well. One day at a time in her new way of life. She has lost her thick ponytail due to the lack of good nutrition as well as 4 anesthesia times. She smiles every day and is so happy every day even with her new challenges. We are working towards good health and happiness and what more can we ask for. We hope that in time she will be able to get back to her program as she so loves going out and being with her friends during the day.

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.

SOFT Headquarters:

S.O.F.T.
Support Organization For Trisomy 18, 13 and Other Related Disorders

2982 South Union St.
Rochester, NY 14624

Phone: 1-800-716-7638
(1-800-716-SOFT)
Stacy was able to attend her niece’s first birthday a couple weekends ago. Where has this year already gone? She helped Andrea get the piñata open and saw her eating her cake so Stacy joined in and enjoyed frosting from the cake and loved every minute of it. Andrea got her first Dodge Ram pick truck and loves sitting in it. Not able to drive it yet but she will get there. The girl has so much energy but we enjoy every minute watching her enjoy life and smile just like Aunt Stacy all the time.

Remember to start making your plans for the Madison conference early. Desmond Hotel is the hotel for the conference. More information from the conference coming your way.

Enjoy your fall and stay healthy to all!

The VanHerreweghes

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2016 SOFT of Utah Annual BBQ

“We didn’t realize we were making memories, we just knew we were having fun.”

- Unknown

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SOFT of Utah would like to encourage other chapters to create their own annual event to make memories with the SOFT Families in their area.

Pictures courtesy of Raquel Wagner
The Tracking Rare Incidence Syndromes (TRIS) project, as I have described in previous articles, is near and dear to me for many reasons. As a researcher, I feel so fortunate to have a “research agenda”, which keeps me excited and motivated. On a personal level, I have learned so, so much from children and families participating in the project. I feel honored to have parents seek me out with questions, ask for information and the like. I try to answer them all. If I don’t have the answers, I do my very best to locate them.

I am further honored to be a part of the September 2016 special issue of the American Journal of Medical Genetics Part C on trisomy 13 and trisomy 18. TRIS project is in stellar company with the authors of the other articles in this issue. I am also humbled that the article is based on a dissertation by a mom of a trisomy 18 angel. Again, she sought me out, after we met at a SOFT Conference several years ago. She asked me to serve on her dissertation committee and if she could use data from the TRIS project. I agreed to both. The result is our article, “Medical interventions and survival by gender of children with trisomy 18”. The abstract (summary) is below:

Research has typically shown limited aggressive medical interventions and low survival rates for children with full trisomy 18. Recent studies provide more positive results. This study examined 82 children with full trisomy 18 drawn from the Tracking Rare Incidence Syndromes (TRIS) project database. Children were classified into three groups according to the highest intervention received: “hospice or no intervention” (n = 5, 6.1%), “necessary interventions (enteral feeding, ventilator use)” (n = 46, 56.1%), and “aggressive interventions (surgery)” (n = 31, 37.8%). Seven of 14 male children (50%) and 52 of 68 female children (76.5%) were living at the time of survey completion. Additionally, information about any interventions used during the care of these children was also provided. It was found that three males (37.5%) and 28 females (48.3%) had used hospice care at some point; 12 males (85.7%) and 61 females (89.7%) received enteral feeding at some point; 7 males (58.3%) and 25 females (38.5%) had ventilator; and 7 males (50%) and 33 females (48.5%) underwent some form of surgery. These results suggest improved outcomes when given necessary and aggressive medical interventions. Implications and recommendations for further research are provided.

And with each new survey completion, there is more data to review and analyze. There are more questions from parents (outcomes of TPN use, puberty and children with trisomy 13), which, several times to date, have led to articles.
Many researchers hope for something like this...and I have it. I am grateful for all of you who have enrolled and support the project by completing surveys, referring parents to participate etc. I also appreciate the call outs on Facebook and followers of the project’s Facebook page. All of this combines to keep the project moving forward.

Further information about the TRIS project can be found online:
Project homepage: http://tris.siu.edu
Enrollment page: http://tris.siu.edu/survey/form/PreEnroll.php
Facebook page: 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

#SimonsLaw • Protection for Parental Decision Making Rights for All Minor Children

#SimonsLaw • Protection for Parental Decision Making Rights for All Minor Children...
There is a need for Simon's Law nationwide. In many hospitals across #America it is legal for a child to be denied life-sustaining care and for a '#DoNotResuscitate' order (#DNR) to be placed on a child's medical chart without parental knowledge or consent. Do you want a third party determining the value of your child? Should it be legal to withhold procedures, medications, food or water to hasten the death of a child without written parental consent? Should it be legal to place a 'do not resuscitate' order (DNR) in a child's medical chart without written parental consent?

If you want to protect your parental decision making rights, sign this petition. Please include the state you live in when you leave a comment (even if you don't leave your name). This will be beneficial in letting us know which areas of the US are being reached.

*Please help spread the word and raise awareness by signing this petition [ipetitions.com/petition/simons-law] and then by visiting this link and sharing. Use hashtag #SimonsLaw

Reporting: KOMU-TV News [bit.ly/2d7TWSW]
Perspectives on the Care and Advances in the Management of Children with Trisomy 13 and 18

American Journal of Medical Genetics, Part C, Seminars in Medical Genetics, September 15, 2016 (whole issue)

by Drs. John C Carey and Tomoki Kosho

On September 15 of this year, the American Journal of Medical Genetics, Part C published an entire special issue devoted to the trisomy 13 and trisomy 18 syndromes. The issue included 9 papers, consisting of an Introduction by the two Guest Editors of the issue (Carey and Kosho), two Commentaries, one Editorial, and five Original Research Articles. The main purpose of the collection of articles in this issue of the Seminars in Medical Genetics series is to continue and ideally expand the ongoing dialogue that has emerged in the medical literature in the last decade regarding the care of infants with the two conditions. This dialogue relates to the controversy that is very familiar to the readership of this newsletter: on one side is the conventional approach of initiating comfort care and holding off on intervention for the management of newborns and infants while the opposing view argues for a more balanced approach to ongoing care that offers intervention when appropriate depending on the individual child (summarized by Carey, 2012). These contrasting views have created what was referred to by one of the papers in this series (Andrews and colleagues) as "a palpable tension."

The first group of papers in this issue deals with perspectives on care and research studying interventions in children with trisomy 13 and 18. The second group of papers documents advances in the management of specific medical manifestations, i.e., seizures and tumors. In the rest of this piece we will highlight the papers in the issue. (The following summary is adapted from the Introduction by Carey & Kosho, 2016).

The opening Commentary by Dr. McCaffrey plunges immediately into the dialogue regarding the level of care in individuals with trisomy 13 and trisomy 18. He argues eloquently against the use of the terms "lethal" and "incompatible with life", still commonly applied labels after initial diagnosis. The essay summarizes the key papers in recent years regarding interventions and makes a "plea for truth, transparency, and recognition of our prejudices regarding patients" with the two syndromes.

The other Commentary is by Andrews and colleagues, including SOFT’s own Scott and Vivian Showalter. These authors propose a model for care in the trisomy 13 and trisomy 18 syndromes that uses "shared decision making as a foundational principle" and the pathways approach as a method. The paper reviews the chronology of the thought process that led us to the current controversy about care. The authors provide a detailed Table (we would consider to be the centerpiece of this work) that is designed to be a guide for applying the approach. (The Conference that helped lead to this article was partly funded by SOFT.)
The next three papers involve interventions, procedures, and events in children with trisomy 13 and 18. Josephsen and colleagues (including Dr. Steve Braddock) from St. Louis University perform a single center review of procedures performed in children with trisomy 13 or 18 over a 15-year period. These authors show an increasing rate of procedures per patient over this period of time. In the next article Dr. Debbie Bruns and colleagues utilize the Tracking Rare Incidence Syndrome (TRIS) database and examine medical interventions and survival rate in 82 children with full trisomy 18. The authors discuss their results and its implications for future research. The last paper in this group of studies on interventions is the questionnaire study of Drs. Janvier and Barrington and Barbara Farlow. These authors invited parents of children with trisomy 13 and 18 to answer a survey online; 261 participated. Parents demonstrated "common hopes" when they received a diagnosis of one of these conditions. The authors suggest that "rigorous transparency regarding specific interventions and outcomes may help personalize care for these children."

The last two papers discuss specific manifestations that can occur in infants and children with trisomy 18. The first of these by Matricardi and colleagues from Italy is a multicenter study of the clinical aspects, EEG features, and neuroimaging in children with full trisomy 18 and associated epilepsy. The last article is the paper by Satge and co-authors, who reviewed the literature and present the occurrence of tumors in trisomy 18. The authors show that children with the syndrome are at increased risk for a liver tumor (hepatoblastoma) and a kidney tumor (Wilms tumor). Carey and Barnes accompany this article with an Editorial that summarizes the evidence for the association of Wilms tumor in the trisomy 18 syndrome and uses the SOFT Registry, a parent-reported outcome database (created by Ann Barnes), to estimate the risk for a child with the syndrome to develop the tumor.

**The cover figure of the issue is a composite group of photographs of seven SOFT children taken by esteemed photographer, Rick Guidotti, at the recent SOFT Conference in Takoma, WA.

All of these papers mentioned above will be accessible on www.trisomy.org in early October.

REFERENCE
Vison, Light Sensitivity, Headaches and Seizures
By Steven D. Cantrell, O.D.

Special Thank You to our sponsors BluTech, Natural Ophthalmics, and OcuSoft for their very generous donations to SOFT and the workshop. BluTech for providing 50 pairs of Pediatric and Adult sized frames with their new pigment infused medical lens. Natural Ophthalmics for providing 10 dozen revenue sized bottles of Ortho K Thin and Ortho K Thick ocular drops. OcuSoft for lid scrub samples. Thanks also to everyone who shared important information during our workshop in Tacoma. Special thanks to Terre, Heidi, Diana and the entire organizing committee for an outstanding meeting.

Two recent papers linked below found that some children in the study diagnosed with Trisomy 13 also were diagnosed with Photosensitive Epilepsy. This is new information.
http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2007.01220.x/abstract;jsessionid=B394945877E9603D496369011BD5465C.f02t01

Our kids attending the first SOFT conference were in obvious pain outdoors. Since then we have improved comfort by wearing dark sunglasses and eating foods rich in Lutein and Zeaxanthin. See link below.
https://www.kemin.com/images/files/2452_FloraGLO_BR_4-Panel_V02F.pdf

Our SOFT friend Chris Donahue juiced all the veggies on this list for Mary and to our surprise reduced her light sensitivity. This means a daily diet is extremely important for Trisomy 13 and 18. Lutein and Zeaxanthin are the eyes natural filter and they do not store.

So why do these new studies linking Photosensitive Epilepsy matter? We know what triggers seizures and occasional apnea in Adults with Photosensitive Epilepsy, so it’s possible the same things effect our SOFT kids. Here is a list of visual triggers that adults tell us can cause seizures and occasional apnea.

1. Ceiling Fans
2. Sunlight through trees
3. Flashing emergency vehicle lights
4. Fireworks
5. Strobe Light
6. New Flat Screen LED TV (reduces brightness)
7. Video Games- High intensity graphics
8. All Technology Screens
9. Some retail stores with banks of fluorescent tubes. Sam’s, Walmart, Michael’s have been mentioned as trouble. SOFT kids with seizure activity should wear Photosensitive Epilepsy Sunglasses indoors and out.
10. Turning bright lights off and on in a room may cause a seizure if eyes are not protected.
Apneas observed in Trisomy 18 should be differentiated from epileptic apneas.

Three of seven study patients had EEG-confirmed seizures.

Department of Pediatrics, Anjo Kosei Hospital, Aichi, Japan.

Our children diagnosed with Trisomy 18 have always been painfully light sensitive. Children diagnosed with Trisomy 13 did not appear to be ultra light sensitive until I spoke to Jamie Lint in Salt Lake City. Jamie said that Zion reacted to flash photography and lightening often followed by seizures. Zion and others diagnosed with T-13 did not exhibit the painful reaction to light as kids with T-18. The EEG study is a potential breakthrough and may explain what causes some seizures and apnea.

Seizure activity with or without apnea could be reduced with eye protection. The Triggers are everywhere. In addition to Nutrition and Protective Eye Wear Ocular Hygiene is important. Hydrating protective eye drops and lid scrubs are essential to comfort.

There are many particles in the air, like dust, mold, pollen and sand, which can get into your eyes and harm them. Eyelashes help to sweep these particles out of the way. Our kids have very long lashes that catch and hold everything and contributes to red goopy eyes. Cleansing over and around eye lashes with OcuSoft Infant Lid scrubs washes away debris. Hydrating eye drops are also needed daily. Use Natural Ophthalmics Ortho K Thin three times per day and Ortho K Thick at bedtime. No red goopy eyes- everyone sleeps better.

Blepharitis and Dry Eye Trisomy 18 and Trisomy 13
- Chronic Red Irritated Eyelids
- Comes and Goes
- Dandruff Like Appearance in Eyelashes
- One or Both Eyes Stuck Shut in the AM
- Warm Wash Cloth
- Pre Packaged OcuSoft Lid Scrubs
- Pre Packaged OcuSoft Lid Scrubs

OcuSoft Infant premoistened lid scrubs are available through Walgreen’s, CVS, and other pharmacies without prescription. Natural Ophthalmics products, Ortho K Thin eye drops and Ortho K Thick eye drops are available through a doctor’s office.

Call: Natural Ophthalmics 1-877-220-9710 for an office close to you- be sure to ask for Diann and mention SOFT.
To order Ortho K Thin and Ortho K Thick eye drops call toll free 1-877-846-7122. The Registration code is: SC970
On-Line ordering: www.DSSOrders.com/DrCantrell Save 10% code on first order: HCPC970WELCOM

One Final Warning: Before your child’s next eye exam. Tell your doctor your child might be sensitive to bright lights shined in their eyes and could cause a seizure. Mention Photosensitive Epilepsy is common to Trisomy 18 and Trisomy 13.

Best wishes to everyone and see you in Madison, Wisconsin!
The 2016 SOFT Conference...

is now in the history books but the memories created will hopefully last a lifetime. Seventy-seven families from across the country and around the world, including 29 SOFT Children (and adults!), gathered together in Tacoma, WA to celebrate our beautiful children, remembering those who have passed and honoring those who continue the journey of challenging the beliefs of medical professionals. Families came from as far away as Aruba, England and Uruguay just for the chance to meet and spend time with others who can relate to lives and understand their journey.

Our time together was kicked off by a Welcome Reception Ice Cream Social that included not only our SOFT Families but also approximately 40 medical professionals who had just attended Dr. John Carey’s “Grand Rounds” CME Presentation “Perspectives on the Care of Infants with Trisomy 18 & 13.” This evening gave families and professionals a chance to come together in a casual social setting and gave many of the attending professionals a glimpse of our children in a non-medical environment surrounded by the love of their families and see for themselves the quality of life and love our kids experience and bring to their families. The evening was capped off with the premiere of the annual Kari Holladay “SOFT Friends” video lovingly created by Kris and Hal Holladay.

Michelle and Layne Monaghan
Sara, Ron and Megan Hayes
Karson Friedmeyer
Pictures courtesy of Raquel Wagner
Thursday brought a day full of workshops by a wonderful group of presenters including Dr. John Carey’s talk on genetics, Steve Cantrell on Vision, Light Sensitivity and Seizures, Debbie Bruns’ Tris Project presentation as well as workshops on IE-P’s, Augmentative Communication, Guardianship, Grief, You’re your Story, Essential Oils and much much more. In addition, Rick Giodotti of Positive Exposures spent the morning capturing the beauty of our precious Trisomy Kids. You can see all the photos that Rick took online – go to www.trisomy.org for the link and password. Thursday afternoon we had a Vendor Fair with vendors of all types from around the Puget Sound area.

Thursday was capped off with our Annual Welcome Dinner featuring the Zion Lint Parade of Stars and a Candle Ceremony in honor of our children who were there in spirit. We had the pleasure of hearing from our keynote speaker, Brandon Bosma who received a standing ovation for the fabulous job he did sharing his unique perspective on the Trisomy Journey. The remainder of the evening was spent in dancing and celebration. Friday brought our Annual SOFT Business Meeting where new board members were elected. Kari & James Adamson and Larry & Katie Wheat were
-newly elected to the SOFT board of directors taking the place of Sheryl & Scott Crosseir and Chelsea Dye who are stepping down. Faye Kaufman and Mark Kubena were reelected back to their position on the SOFT Board. Friday afternoon our SOFT Children attended clinics at Mary Bridge Health Center while other families took part in a Remembrance lunch and outing in the beautiful setting of Point Defiance Park. Our SOFT Sibs took a trip to Enchanted Village Wild Waves park.

Friday night families had a chance to take a night on the town or try their hand at painting at our first ever Paint and Sip. Those attending created beautiful paintings of the Northern Lights, learned a few new skills, perhaps discovered a hidden talent and absolutely had fun spending a relaxed time with their SOFT Family.

Saturday morning brought the annual Jonathan Cook Stroll for Hope, raising funds for both the conference and the SOFT National General Fund. Late morning families loaded buses and were off to Cheney Stadium, home of the Tacoma Rainiers for the Annual Ryan Cantrell Memorial Picnic. In addition to more food than we could possibly eat, kids of all ages had the opportunity to hone their skills at batting practice with a member of the Rainiers’ staff, play Whiffle Ball (a Washington tradition!) and other field games and even meet Rhubarb, the Rainiers’ mascot.
The highlight of the day however was the Annual Ryan Cantrell memorial balloon ceremony. This year balloons were released without strings to the accompaniment of a photo slide show of our beautiful Angels on the stadium’s jumbotron. The ceremony was a loving tribute to our beloved SOFT Angels. It was clear that their energy could be felt as they watched lovingly over their families and friends.

Saturday night was our Annual SOFT Auction led by Steve Wagner and Scott Crosier. Families enjoyed spending a fun and competitive evening together raising money for a cause that is near and dear to all of our hearts – SOFT!

Sunday morning families enjoyed one last breakfast together and said their goodbyes. You could feel the energy and love that had filled the Pavilion from the start of the event begin to fade as one by one our families headed out to begin their trek back home.

The 2016 Tacoma SOFT Conference Committee thanks all those who came to our beautiful city and helped make this conference a success. Without you, your families and the love you brought the event would not have been the same. As we pass the torch to Wisconsin and 2017 Conference Committee we encourage SOFT members everywhere to make the decision to join us in Madison, WI to meet new friends, connect with old friends and be part of what will be yet another incredible SOFT Family Reunion.

Until we meet again...SOFT of Washington
**30th Annual SOFT Conference Donors and Sponsors**

**Thank you to all of our Generous Sponsors and Donors for your contributions to the 2016 SOFT Conference!**

*Please note that this list may not include last minute donations or auction item donations*

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A special Thank You to The 2016 CONFERENCE COMMITTEE:

Terre Krotzer, Heidi Estes, Diana Guptill, Christine Kowalski, Todd Merry, Alicia Parks, Sheryl Crosier, Debbie Dye, Chelsea Dye, Patti Lawson, Satinder Sahota, Steve Wagner, Raquel Wagner, Katie Wheat and all of the SOFT members who volunteered to help make the conference a big success!
Dear Mom and Dad:

The day they told you, the day they said those words — “an extra chromosome” — is the day our world changed forever. This is the day you said “Move!” to the mountain and graciously said “No!” to the sentence they pronounced on my life. I knew you were special then, so very rare and so very precious to me. Feeling timid, weak, frail and scared, we held on to each other for dear life. Somehow we bravely moved into this new world, as though refugees running from a world that would not have me.

I remember understanding I was different, in a way that frightened you. I remember the expressions, the voices with hard edges, eyes cold, eyes pitying, faces quickly turning away. I remember you were so scared then — and I was scared for you. I wished then I could give you this “ordinary” they were talking about, this “normal”. I saw the emotion drain from your faces when their words stole your hopes and dreams. I wanted to hold you then. I wanted to tell you it would be okay; we WILL have our world.

I remember them talking about “quality of life”. I have seen the butterflies floating amidst the flowers, while I struggle earthbound as a caterpillar, winning victories over these peculiar milestones. A pebble here is a boulder, a small puddle an ocean. And getting around it is often a week’s journey. Yes, it’s true — my body feels like it’s fighting me every day. That is what they see in those rooms that scare you. What is quality? I have special parents who sing love into me with their life every day. Mercy, I know, when your soothing calm voice speaks to me and your gentle touch puts out the fires raging inside of me. Courage and faith, I know, when we return to those scary rooms with beeping machines, and tubes running from me. I look into your eyes and hear your heart say “we got this.” Perseverance, I know firsthand, as I watch you hold vigil over another endless, sleepless night. Or sheer joy as we reach milestones that only we can share.

I am so proud of you. Do you know how I wish I could tell you that every day as I have watched you grow? In our world, time is not measured in days, or weeks, or years, but in moments that linger with an eternal weight about them. Through seasons we labor and we struggle — as if birthing courage, hope, faith, mercy, honor, perseverance and joy — only to discover and rediscover them again and again. In that other world, people pass through these doors so quickly and hold on to the weight of those moments now gone, or they read about it to understand what it means. We live it. Mom, Dad — these are my flowers, treasures you used to build our home, to give me shade, to give me shelter in our world.

Ordinary? No, it’s complicated. When you hear a symphony, it’s singing those words, it’s our song. When you see a masterpiece, look at all the delicate shadings of light, and see all of our seasons and moments of our hope shared. My parents are superheroes. They don’t always know it and it’s tough to explain. Yes, it’s complicated. I believe I am special, and I believe I am precious, because you were given as a gift to me. Mom, Dad — with all of my heart — I love you.

Your Blessed Child &

© 2016 Christine Warner from Letters by Andrew Siebert, Sam Sansalone, Terry Krahn, Jennifer Thenhauss

This is the love letter that Brandon Bosma shared during the Welcome Dinner at the 2016 SOFT Conference, which was written by his cousin Christine Warner. Letter and Pictures courtesy of Gloria Bosma
Hello! Our names are James and Kari Adamson. We reside in Fond du Lac, Wisconsin, where we are both educators in the public school system. Kari teaches K-5 general music, and James teaches intermediate grades (4th or 5th grade). We are the proud parents of four children; Kirsten who is 24, Braeden who is 18, Madelyn who is 7, and Leila (T18) who is 4.

We became SOFT members shortly after the birth of Leila, December 28, 2011. We hoping to attend our first conference when it was held in St. Louis, but it was prior to Leila’s heart repair and she wasn’t stable enough to travel yet. The summer of 2014 we finally attended our first SOFT conference when it was held in Norfolk, Virginia. We were addicted after about five minutes, and attended the next two conferences in Salt Lake City and Tacoma.

We first joined SOFT in hopes of building our network of parents and families who have walked the same path. Upon reflection, this has been just a small portion of what we have actually taken away from being involved in SOFT. We have established amazing friendships with fellow members, gotten to know medical professionals from literally one coast to the other, and most importantly showed a multitude of people that children with trisomy are “compatible with life”.

Our favorite part of attending the SOFT conference is the “family reunion” that occurs annually, regardless of the host city. An outsider would never understand the magic that happens at a conference, but there truly is something special about being surrounded by other people who “get it”. For five days each year we can enter a room, eat at a restaurant, go for a walk; without the judgmental eyes of others questioning the decisions we have made for Leila and our entire family.

After traveling from the east coast to the west coast for conferences, we are excited to bring the conference back to the Midwest for 2017! We are looking forward to hosting the SOFT Conference, July 19-23, 2017 in Madison, WI. Our goal is to set a new record for attendance! We really hope you’ll consider joining us.

Story and picture courtesy of Kari Adamson
September 8, 2016 marked the 39th birthday for our daughter, Kari Deann Holladay.

Kari was born on September 8, 1977 with the genetic condition, Trisomy 18. Learning of Kari’s condition at her birth was devastating. It was explained that she would have profound limitations, both mentally and physically, and her chances of survival were less than 10%, at best. Oh, how our hearts ached! At first I was frightened of Kari. She seemed more abnormal than normal so I didn’t act normal. I finally realized Kari had the same needs as every other child, so I let go of my fears and embraced every opportunity to love and care for her – however long. As the hours turned into days, and the days into weeks, and the weeks into months, it was with surprise and delight that we were able to celebrate Kari’s first birthday!

My sister, Karen, wrote the following poem for the invitation to Kari’s first birthday party. We sent 35 invitations and had over 120 people attend her celebration. Our wonderful family and friends shared our unexpected joy in honoring Kari’s life.

We were blessed to have Kari for ten years and nine months and we delighted in her charming smile, her spunky determination and her perfect love. The years have come and gone, but every day for 39 years I have loved her dearly. From the first time I held her to the last time she was in my arms, I feel I was blessed beyond my dreams. I will hold Kari in my heart forever!

Hugs …. Kris

**My First Year Birthday Party**

Birthdays are so special  
For the young and for the old,  
But, mine’s especially special  
And a story to behold.

Mommy can’t believe it,  
Daddy thinks it’s grand,  
Tricia’s real excited,  
Still, it’s hard to understand.

See, I wasn’t supposed to stay long,  
Just a week or two,  
Guess I have a little more  
Here on earth to do.

I’m Grandpa’s “Little Visitor”  
With problems here and there,  
But Grandma says it’s all okay,  
A gift they love to share.

So I went to Heavenly Father  
And asked of Him one day,  
“Would you mind allowing me  
A little longer stay?”

They try with all their might  
To care for me and love me  
And make it seem all right.”

He looked at me a moment,  
I hope He might agree,  
A nod, a smile, a glance of grace,  
He said, “So let it be.”

I cried all night for joy,  
Mommy didn’t know,  
But ever since that happened,  
A smile I always show.

Come share in our excitement,  
It’ll be a lot of fun,  
September 8th will mark the date  
That I will then be one!

~~~~~~~~~~

“If tears could build a stairway and memories a lane,  
I’d walk right up to Heaven and bring you home again.”
SOFT APPRECIATES YOUR GENEROSITY AND RECOGNIZES THE LOVE AND CARE THAT THESE DONATIONS REPRESENT

SOFT’s General Funds
Bravelets
The Benevity Community Impact Fund
United Way of Buffalo and Erie County
Give With Liberty Employee Donations
United Way of Salt Lake City

Joey Watson Fund, to assist financially challenged families coming to the annual SOFT conference
Catherine and Michael Maetke and family, in Memory of Mary Donohue

SOFT’s Medical Research Fund
Ann and Frank Barnes, in Memory of Megan Elizabeth Barnes
Ann and Frank Barnes, in Memory of Mary Donohue

In Honor of Rachel M. George
The Vasilatos Family
Peg Wysong
Jean Kelley
Salli and Bill Ward

In Honor of Angel Kern and
In Honor of Sydney Carpenter
Charitable Contributions Committee at NCMIC Group, Central Iowa

In Memory of Grace Ann Cooper
Baptist Foundation of South Carolina
In Memory of Sarah M. Banks
Bill and Cindy Brady, Sarah’s Grandparents

In Memory of Roger Morel
Susan Pucci

In Memory of Dahlia Phillips
William Morgan

In Memory of Gabriel Isaac Mason
Micah and Bryson Fletcher
Amanda West

In Memory of Caroline Grace Boggs
William and Pat Aldridge
The Browne Family

In Memory of Gavin Mark Reimer
Harriet Dygert
Tracey Oberschmidt Salmons “In Loving Memory of Baby Gavin”
Children’s for Children
Melissa Kingma
Julie McLaughlin
The Kellner Family
Mary Martin
Amanda Barber
Alice D. Campanella
Pam Marlowe and Lantheus BT 21000
David Singer
Wendy and Tim Bankes
Shannon and Robert Carraway
In Memory of Vida Elyse Mora

Vida’s Aunt/Godmother, Yvonne Acosta Figueredo, is running a marathon in the memory of Vida Elyse Mora. Many of her running friends have supported her cause to raise money for SOFT in Vida’s memory.

“My Sister, Yvonne Figueredo, Vida’s Aunt and Godmother, is running to help bring awareness and support to the entire Trisomy family. These 31 dollars represent the 31 beautiful days Vida Elyse was with us earthside.”

Isabel Almazan-Hernandez
Karean Sigler
Joely Rodriguez
Delvys Alvarez
Nancy Lim
Richard Acosta

Caroline Wagner, “My niece Natalie has Trisomy 21, and she is the most courageous person I know. I am so happy Yvonne has brought awareness to this cause in our running group. She is so highly respected by so many!”

Tony Spears
Vivienne Carrasco, “Run, Yvonne, Run! “
Eileen Ramos
Isabel Viso
Robyn Hamilton

Beatriz I Jimenez, “Vida Elyse Mora was a #warriorprincess who taught so many what it means to be strong, have faith, to live each moment to the fullest, and to appreciate what God gives us, no matter for how short a time. Her family is my heroes for their courage, faith and values.”

Roxanna Stein
Norma Toledo
Ileana Rionda
Lauren Mullis
Brian Vallinas
Maria Vallinas

Nilda and Amado Acosta “In honor of my granddaughter, this donation is given to assist a family caring for their child’s needs.”

Alberto Lorie
Ana Miret
Raquel Diaz, “Yvonne is my running mentor. I am proud to donate to such a cause and to support such a great family.”
The Collins Family
Madeline Luaces
Shirlei Kozak
Kathy Azcue
Jeanette Acosta
Christine Acosta
Maria Margarita Vallinas
Carolina Blanco
Luisa Pineda
Isabel Ortiz-Rodriguez
Elizabeth Rosquete
Giselle Fuentes Zayas
Jesus M. Torres “Yvonne Figueredo will be running 26.2 miles in memory of her niece, Vida, and we will all be right there with her.”
The Fired Up Athletic Force
Floribeth Arrautt
Juan-Pablo Ospina and Tatiana Mora
Jackie Brown
Arlyn Palacios “To keep the #GiftofVida legacy alive!”
Happy Tails Cindy
Adriana Brown
Asya Cabral
The Fernandez de Castro Family “Vida left our hearts imprinted with love and peace!”
Andres, Nico and Alex Marquez “It is an honor to be donating to such a great cause!”
Raul Milian
Julie Kreeger “Run, coach, run!”
Albert Lorie
Pamela Moreno “To be dear friend Yvonne for raising awareness through her running!”
Gigi (Graciela Garcia)
Lisette Herran
Monica Granados
Susan Owens “this donation is for a very special little girl who has touched the lives of many. Wishing Yvonne the very best in her marathon. We are all thinking of you #vidahasyourback”
Mark Minichiello
Tere Pujol Burns “Helping Yvonne Acosta Figueredo achieve her goal as she runs in memory and honor of Vida and the Eirie Marathon”
Giselle Fuentes Zayas

In Honor of Ella Grace Revere’s First Birthday
Suzanne and Mike Revere Sr, Ella’s Grandparents
Robert and Emily Pechier
The Reynaud Family
Lauren Bercier
Lori and Creighton Crain

In Memory of James David Chudada, our Nephew
Brian and Allison Propp and family and friends

SOFT Rainbow: July 23, 2016
By Pam Healey

It was the Saturday of the conference, and I was driving to Maine for a nephew’s wedding the next afternoon. Logistics were involved with work schedules, and Saturday afternoon Tara headed to work after moving two-and-a-half-year-old Cyrus from her car seat to mine. We then headed north to the house in Wells my sister was renting for the week. Patrick would meet us there later, after golf with his cousins. Just before we left, I received a text from Clarice saying they were heading for the picnic.

Cyrus was less than happy to be still sitting in a car, and traffic was slowing our progress. Black clouds lay ahead of us, but so far, no rain to slow us further. We made it across the Mass. border into the sliver of New Hampshire that ends at the coast, a part of New Hampshire that seems to exist only for toll booths. The 140-mile trip from Rhode Island into Maine is toll free except for the sixteen miles across the tax free state of New Hampshire. At least with a transponder, we no long lost time lined up at the tolls.
We left the granite state, and rain had still not fallen, but the afternoon still darkened. We were heading straight for a mass of thick, black clouds, but they were moving eastward at a good clip, and there was light at their western fringe. Cyrus was getting restless, so I assigned him the important job of telling me when it started to rain. He looked out his window. A few miles later the rains came, but we seemed to be skirting the edge of the storm, so not as bad as I expected. My wipers were still going when I looked east, and where the clouds were blackest emerged a double blob of a rainbow, two chunks of color one above the other, the start of a double rainbow. The colors brightened in contrast to the clouds that swallowed the arc. I checked my clock; the balloons were probably being launched in Washington. I looked east again, the colors almost looked like two balloons hanging above the horizon. I continued driving, and the rainbow remained, bright and comforting, connecting me to what I was missing. I would not see the full arc until we reached the Maine coast, and I stopped and looked behind a row of stores to the open Atlantic.

Still on I-95, still with only chunks of color, I relaxed and headed for route 1. Suddenly, from the back seat, I heard, “Nana, I just love rainbows.” That’s my boy! His mother and uncle roll their eyes when I chase down a rainbow when weather conditions are right, but I need to get to a clearing. They laugh when I stop the car and take pictures, or run barefoot down our street for a better view. This is my rainbow child who has the sense of wonder at nature’s delightful shows. We walk the neighborhood in Rhode Island and check the snails and brine in a tidal pool, play Pooh sticks on a tidal creek, peek at the swans hiding behind the cat o’ nine tails, look up at the ospreys in their platform nest, turn our heads to the dragonflies darting ahead of us when we cross fields to reach the tidal river, gently move the baby snapping turtle to a safe place and examine the rabbit scat beneath the shade of the grape arbor. He is the great observer, and he joined me in watching the rainbow. As balloons were being launched 3,000 miles away, as we were approaching one coast and the friends I was missing were not far from the other coast, he celebrated the double orb rainbow that joined us on our journey.

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

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He never ate a Happy Meal or ran the bases or spoke a word. His mom says he spent half of his 22 years in the hospital. The most he ever weighed was 55 pounds. But Donald Robert Heaton's family and friends believe that everyone is born for a reason, and Donnie was a gift. They believe his reason was to teach lessons of love and strength. "We used to pray for Donnie to be healed," said his aunt, Miriam Wood. "But we realized God created him just the way he is because his life touched so many people."

Donnie was born on Sept. 10, 1992, to Karen and Don Heaton who, for their first 18 years together, had never really entertained the thought of having children. It just never happened, until one year, it did. But from the day of Donnie's birth, he had severe health problems. "We had this doctor saying that he wasn't going to live, and if he did it wouldn't be more than a year," said Donnie's mother, Karen Heaton. Donnie was diagnosed with Trisomy 18, a chromosomal disorder that disrupts the development of the fetus in such a devastating way that many Trisomy babies don't survive pregnancy, and half of the full-term babies are stillborn. Of those babies who survive to birth, less than 10 percent reach their first birthday. But Donnie lived for 22 years, nine months and three weeks.

On June 1, Donnie graduated from the Nina Harris Exceptional Student Center. He was awarded the "Papi's Perseverance Award," an annual recognition of students who set an example through accomplishment, positive attitude and individuality. In her nomination of Donnie, his teacher, Christie Vaughan, wrote of his contagious laughter, smile and spirit. "Though he didn't speak, he let people
know his feelings, which were usually upbeat. "We all questioned how much Donnie could under-
stand," Wood said. "But we knew when he was happy. He was always happy. He would smile and 
clap his hands with great feeling. If you could see him smile, you'd be ashamed of yourself for com-
plaining about your life." Here is a boy who cannot walk, talk, eat or drink; who has persevered 
through so many surgeries and hospitalizations," Vaughan wrote. "He has a purpose on this earth, and 
that is to bring joy to all those who care for and love him."

Donnie's father died when Donnie was 11, leaving Karen to parent him alone, creating a strong bond 
between the two. A Tampa Bay Times story in 2013 detailed their relationship. According to family 
friend Sarah Knight, Donnie became the man of the house, in his own way, giving love and comfort 
back to his mother, who battled cancer and a stroke over the last few years. "After Karen's stroke, she 
was lying on the floor with him on his pallet, and he rolled over and put his arms around her," Knight 
said.

Karen Heaton believes that, though his mind was that of a 6-year-old, Donnie's faith in God was real, 
and together they attended Journey Church in St. Petersburg. Pastor Craig Brown said Donnie would 
respond vocally in church and raise his hands in the air. "When I would raise my voice in church and 
he liked what was happening, Donnie would get excited and clap his hands and speak like he could," 
Brown said. "Sometimes that was the only amen I got."

Knight recalled the many people who loved Donnie and wanted to make him happy. On Donnie's 
18th birthday, a family friend rode his motorcycle over to the house to take him for a ride. "He said, 
'You're 18 now, and you don't have to listen to your mama. I'm going to take you for a ride on my 
motorcycle,'" Knight said. "He set him up there and got behind him and Donnie was just squealing 
with glee. He was crazy happy."

Two weeks after clapping for his friends at graduation, after receiving his award, 22-year-old Donnie, 
who loved school, happy songs, crinkly things, hugs, the movie Cars and most of all, his mother, fell 
ill and was hospitalized again. His mother tried not to worry too much. They'd been there before. 
"I just knew he was going to come back from the hospital," she said. "He had resiliency; he bounced 
back every time. But he didn't come back this time."

He died on Father's Day. There were more than 200 people at his memorial, so many that the venue 
was changed from their small church to the Gateway Christian Center. "He touched every life there," 
Knight said. "The special ones have a hidden holiness. Donnie was closer to Jesus than most of us." 
Karen Heaton believes her son is with his dad now. Wiping her tears, she said: "He was my life. He 
made me so happy. I loved being his mom. I thank God for my friends and relatives, but there's no 
one to take Donnie's place."

Donald Robert Heaton
Born: Sept. 10, 1992
Died: June 21, 2015

Preceded in death by his father, Don Heaton. Survived by his 
mother, Karen Heaton, and several aunts, uncles, cousins 
and friends.

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