May 2017 – August 2018

Support Organization For Trisomy 18, 13 and Other Related Disorders

Memories of Her...

Day 14 of Trisomy Awareness month...

Back to the beginning. This is shortly after Stacy was born. At this point we didn't even have the diagnosis of full trisomy 18. 8 years to have a baby then we found out she wasn't going to live. And look at her now. She has blessed our lives and touched many other people over the last 32 years. May your lives be blessed as much as ours with the unconditional love you receive from your kids or with the memories you have of your angel. ~Barb Van Herreweghe 2014

SOFT Times

INSIDE THIS ISSUE:
President's Corner ..........front page
Stacy VanHerreweghe tribute 2-3
SOFT beginnings.............4-8
Lunah update.................
Erin Jorgenson Scholarship...10-11
Trisomy awareness month...12-13
TRIS May 2017..... 14-16
Soft Of Utah gathering...17
Jack Laird Tribute...........18-20
Karson Friedmeyer............21
TRIS Sept 2017.........22-23
Milestone Birthdays ....24-25
SOFT Donations..........26-43

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 L. VanHerreweghe

Rochester: May 21, 1981-April 29, 2018 shy of her 37th birthday was born with Trisomy 18 being the second oldest survivor in the U.S. She is survived by her loving parents, David and Barbara VanHerreweghe; devoted brother, Andrew (Melissa) VanHerreweghe; Aunts, Sheila (Robert) Reynolds, Valerie (Donald) Krieg; nieces, Andrea & Nicole; cousins, Mike, Pete, Christine, Keith, Cory, Cassie; special long time friends, Judie Laird & Carrie Wies; devoted nurses, Judie, Lakeaya, Shonda, Octavia, Shana, Theresa & Shade; loving family and many dear friends.

Stacy was an inspiration to all and taught so many people on how to be a fighter and never give up. Her beautiful smile will never be forgotten. She will be deeply missed by all who knew her.

Stacy's visitation and celebration of life was held Saturday, May 5th 12-3 PM at Vay-Schleich & Meeson. Contributions can still be made in her memory to Support Organization for Trisomy 18, 13 and Other Related Disorders at www.trisomy.org. Many who attended the service wore pink to honor Stacy's love for Victoria's Secret Pink.

I can't get Stacy off my mind!!! Yesterday we lost a trailblazer in the Trisomy community!!! Stacy lived an amazing 36 years (less than one month from 37!!) with full Trisomy 18!!! She was so loved by her family and by all of our Trisomy community!!! Stacy was one of the oldest known living people with Trisomy 18!!! VanHerreweghe Family are hearts are broken right along side yours!!! Sending love, hugs, and prayers during this awful time!!!

-Casey Friedmeyer via FB April 30, 2018

"On Mother's Day I can think of no mother more deserving than a mother that had to give one back"
Enma Barnecek
Yesterday we received the heartbreaking news that Stacy, our path maker and matriarch in the trisomy world, went home to Jesus. She was 37 years old. Without her and her strength, so many of us wouldn't have had the opportunities we do. We love you, Stacy!
-Megan Rose Pare via FB April 30, 2018

We lost a shining light in the world yesterday, especially our Trisomy world. We are all heartbroken. Please keep Barb Blossom VanHerreweghe and her family in your prayers, her daughter, Stacy, went Home yesterday. She lived to be almost 37 years old. She and her family showed us HOPE in this sometimes scary journey. We will miss you, Stacy, but your life will continue to light our path. May God wrap His loving arms around your family during this hard time.
-Sheila Hall via FB April 30, 2018

Yesterday we learned that one of the brightest beacons of hope in our Trisomy community went home to Jesus. Stacy VanHerreweghe not only survived but THRIVED for almost 37 years with Full Trisomy 18!! When I first learned of Zoe's diagnosis, I had many doctors tell me that there were zero survivors...or that the only Trisomy 18 survivors were mosaic. Not until I found stories like Stacy's did I realize how much misinformation was out there and how many older kids and adults there actually were living with the same diagnosis as Zoe's. One of the main support groups that gives so much hope to Trisomy families like ours is Support Organization for Trisomy (SOFT) which is the Trisomy 18/13 charity that I support and endorse. Stacy's amazing mom, Barb Blossom VanHerreweghe is the President of the SOFT organization (www.trisomy.org) and is another reason so many families like ours are able to connect, share experiences, and advocate for resources and doctors who will treat our kids equitably. Please keep Barb and the rest of Stacy's family in your prayers. Thank you, Stacy for inspiring so many of us with your life. It is because of trailblazers like you that so many of us have HOPE for what you have proven is possible!
-Nga Ngyen Petersen via FB April 30, 2018

I am so sorry to hear about the passing of one of our pillars in the Trisomy 18 community, Stacy. What an amazing example and encouragement she has been to so many families. So thankful that her mom, Barb, shared her with so many of us looking for hope in our journey, and thankful for all she has done to advocate and pave the way for my family and so many more. Please help me pray for peace for this family and for so many that love her so much!! Stacy was 36 and would have been 37 next month. So amazing!!
-Renae Bradley via FB April 30, 2018
Thank you for the opportunity to take a stroll down memory lane and reflect on the beginning of SOFT. I remember...Brandy Woodcox. Her name will never be forgotten to our family. It was November 1977 and Kari was just two months old. We asked everyone, including strangers on the street if there were any other families who had children with Trisomy 18. The answer I received was always the same, “No”. Finally, as a passing thought, a nurse mentioned a family in Salt Lake City, but she would need to ask around for this family’s name. The excitement was overwhelming and when the nurse finally called back with the name of the family, we shouted with joy! She gave me the name of the Woodcox family and their phone number. Yes, another family, another child; we were not alone! I called Debi Woodcox and she shared her story about their daughter, Brandy. Brandy was 2 years old! Brandy smiled! Brandy played! Brandy was happy! Much to our disappointment, the Woodcox family moved to Iowa the very next day so letters and picture became our life-line. But, never ever would we feel alone again!

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

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

Pam & I made an appointment with Legal Services for the Handicapped. The meeting was encouraging and productive. The lawyer explained our responsibilities and recommended we first decide on a name for our new organization. Now, that sounded like fun! Hal and I decided that an acronym would work best and would leave a good impression without having to repeat the longer name of the organization. What we didn’t know then, but came to understand in time, the name of the organization grew longer and longer as the days and months went by as more families came into SOFT with numerous genetic conditions. We tried all sorts of combinations of words only to end up with a senseless word we couldn’t pronounce. Then Hal said he had figured it out! He said to write down the first letter of each word as he said the “new” name. It went like this --Families And Relatives of Trisomy. Oh no! I just couldn’t visualize letterhead with the acronym F.A.R.T.! He laughed and I crossed it out and we started over again! Somewhere in the combination of words we finally found the perfect acronym and S.O.F.T. was created. On September 10, 1980 we officially became SUPPORT ORGANIZATION FOR TRISOMY 18/13 (S.O.F.T.), INC. Our first governing board was President: Kris Holladay; Vice -President: Dr. John Carey; Treasurer: Pam Watson. The sound of SOFT warmed our hearts and we knew it would stay with us. John, Pam and I signed all the necessary legal papers and we were incorporated through the State of Utah. (Note: The original name was changed for accuracy at the Philadelphia Conference in 1988. The “/” was replaced with a comma. Later, “and Related Disorders” was added to the organization’s name.)

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

During this time of reaching out, we decided to print a SOFT newsletter and the first one was created by my sister, Karen. The newsletter still brings understanding, information, and connections. The original format is carried on today with the family’s letters linking us through the miles. For the first edition, we printed 25 copies even though we only had 14 names on our address list (which included grandparents, aunts, uncles, and friends)!
At last, we had a few members and we held our first “Gathering” on May 31, 1980 in Salt Lake City, UT. The meeting of new friends was memorable! We took pictures and shared stories. The second “Gathering” was held on February 21, 1981 and the family that traveled the longest was Pat Farmer and her family! She drove 3 hours and their family received a standing ovation for their sacrifice. Again, we shared pictures, stories, memories and more! We had more “Gatherings” and our address list grew longer and longer and we started to hear from families all around Utah and in California, Arizona, Montana, Idaho. Our growing bigger meant growing pains. I appreciated the referrals from medical professionals, but couldn’t believe the mail and phone calls it generated! SOFT continued to grow and we applied for a bulk rate mailing permit. I spent so much time at the Post Office that I think the local Post Master thought I had a crush on him!

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

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

SOFT always enjoyed hearing from a new family and appreciated the medical and educational professionals contacting us. However, I found responding to the vast amount of mail was becoming overwhelming and each time I would “catch up”, it generated more mail and more phone calls. Through this period of time, our daughter, Kari began a struggle with seizures, especially status seizures which often lasted for hours. She would be hospitalized and when released, we would begin rebuilding her lost skills. When Kari was six years old she suffered a stroke which left her the diminished use of her right side. Kari continued to smile and play with her same enthusiasm and these setbacks didn’t diminish her spunky personality! The Holladay’s were a busy young family with Tricia, Kari, and Bryce. Then in 1983, our family welcomed a newborn son, Nicholas. Kari was fascinated by this new “doll” that made sounds and she would roll, or scoot towards the new baby and watch with fascination.
Changes were on the horizon. During this period of SOFT’s history, Dr. John Carey and the University of Utah were my lifeline and sanity. John could see I needed help in sharing the responsibilities of this growing organization. In 1985, Debbi Stutz was hired to assist with SOFT’s growing needs. We slowly transitioned the paperwork and communication for SOFT to her home. Each week, I would drive an hour into Salt Lake City and meet with Debbi to bring her stacks of mail and talk about SOFT “stuff”. She had a fancy new computer and was able to bring SOFT into the digital age. Although Debbi didn’t have a child with a chromosome disorder, she was compassionate and felt an immediate love for our children and families. She worked long and hard for SOFT. Through this time, Debbi began to form an amazing dream for SOFT.

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

Opening day of conference was a terrifying day for everyone! Families from the east coast to the west coast, boarded planes, trains, and cars with only a hope that other families were coming too! In Utah, we all waited at the front doors at the Little America Hotel & Conference Center. We actually wondered if these families would show up!
History was unfolding before our eyes! Parents brought their precious children either in their arms or in their hearts. Photo albums were carefully carried and shared openly. Tears came first, then smiles and laughter. When it was all over, we shed tears again. Everyone’s dreams were realized in just a few short days. No matter what your situation, someone understood, cared and shared. We were no longer alone! We found a safe place with each other!

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

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

And finally, a profound thank you to SOFT’s President, Barb VanHerreweghe, for her unfailing commitment to SOFT and her unwavering devotion to all children born with genetic disorders and to their families. She has made it possible for SOFT to proudly say, “Families serving families for over 37 years”!

A final note: Our precious Kari celebrated the first conference with us in 1987 in Salt Lake City. But much to our sadness, she died just 8 weeks before the 1988 conference in Philadelphia. She was 10 years and 9 months old when she died. If we could “see” with our hearts, I believe that Kari and Rachael and all their angel SOFT friends are with us in spirit. We are truly watched over by angels!

The Hal & Kris Holladay Family is eternally grateful for this extraordinary journey we share with each of you! Holladay Family: Hal & Kris, Tricia & Ryan (Rayna, Ella, Joshua), Kari (our angel), Bryce & Tiffany (Hannah, Callie, Isaac, August), Nick & Tara (Reese, Nash, Irie), Devin & Miya (Lacey, Graham), and Savannah.
ORANJESTAD – The Aruba courts this week ordered the Aruba General Health Insurance (AZV) to pay heart catheterization and follow-up surgery for Aruba’s most popular toddler or as she is better known, baby Lunah. Hours later AZV reacted in a brief statement that they would comply, and already contacted the Children’s Hospital in Utah, USA.

LAW

AZV in its defense argued the law-stipulating clients right to specialized medical attention that is both ‘common and current’. In baby Lunah’s case, AZV acquired medical advice from places as far as the Netherlands, Colombia and the USA. Based on the recommendations received, the medical experts concluded that the toddler’s case is neither common nor current, and thus AZV rejected the parent’s request for medical coverage. The parents, not ready to give up, appealed and lost. The parents again determined to fight all the way, appealed the next latest verdict and this time came out winners -at least for now-, as this is an intermediate verdict, pending the official case to be handled in January of 2018. AZV must now comply with the temporary verdict, as the Aruba court determined that the toddler’s interests weigh far above that of AZV.

Aruba’s favorite baby Lunah wins another court battle

ORANJESTAD – A judge in Aruba order the Aruba National Healthy Insurance (AZV) to pay for already performed medical health services in the USA and those upcoming for now famed Aruba toddler ‘Baby Lunah’. It’s the latest in a series of court battles between Lunah (a baby suffering from trisomy 18 disease) and AZV. AZV however, is not responsible for Baby Lunah’s ambulance flight for a medical expo visit where Lunah was to be examined, nor should the Aruba Health Minister be held responsible for any of the abovementioned actions.

FIRST TIME?

This is not the first time AZV is presented with the medical bill (by a judge), as it was also ordered to pay for Baby Lunah’s catheterization operation in December of 2017, according to a November court ruling. Luna’s parents have been in an uphill legal battle since the toddler was diagnosed with the Trisomy 18 back in the early stages of her life. Against all odds, they embarked on a journey, with the only purpose being Lunah’s health. Refusing to give up, they’ve moved to Salt Lake City last year, and have since embarked on a mission to get the best medical health service for their baby. Lunah’s fight to live has given her native Aruba residents reason enough to support this mission, and even international medical experts are astonished at her will power to live, and how she seems to be beating all odds. At this point, her survival changes remain critical, but have long surpassed the initial survival rate. Medical experts in the US consider her a ‘survivor’.

You can follow Lunah’s story on Facebook @TheLightofLunah
This 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. The deadline for applying is June 1st each year.

Please go to: [http://trisomy.org/?page_id=5491](http://trisomy.org/?page_id=5491) to access the application form which you can print and mail along with your essay and two letters of recommendation.

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Erin Jorgenson Memorial Scholarship Essay

From elementary school to college applications the question of what inspires me in life, always seems to appear. Unlike many of my peers, my answer always seems to be my sister, Lyndsay. Lyndsay was born with full Trisomy 18, also called Edwards Syndrome. Statistically speaking, only 10% of children born with Trisomy 18 survive past their first birthday and a decreasing percentage every year following. This summer Lyndsay will be 17 years old and a junior in high school. There are not enough words for me to be able to describe to you how unbelievably proud I am of my sister and all of the obstacles she has overcome. Lyndsay has never let her genetic order define who she is or what she is capable of doing in life; rather she has defined what Trisomy 18 means.

**Please congratulate the 2017 recipient of the Erin Jorgenson Memorial Scholarship: Jordan Stockman**
I am a third year at Christopher Newport University and am majoring in biology with a political science minor. After undergrad, I plan to attend nursing school to achieve my dreams of becoming a Neonatal Intensive Care Unit nurse. Unlike many, my first year at college was pretty rough. I began my first year of college at James Madison University, which is about 4 hours from home. Like many, I was ready to move away from home and experience the independence that come along with college, but quickly realized my heart was missing something, my sister. At the end of my first year of college I decided to transfer to Christopher Newport University. CNU is only 30 minutes from home and enables me to visit my sister as much as I want to. Lyndsay has had one of the largest impacts on my life and is one of the reasons I want to become a NICU nurse. Since Lyndsay was in critical condition due to having Trisomy 18, after birth she spent many months being nursed to health in the NICU and after many countless surgeries. Lyndsay, on record, is the youngest person with Trisomy 18 to have open heart surgery at two weeks old. Lyndsay is the strongest person I have ever known and has taught me the life lesson on never giving up. No matter the challenges she has faced in life from countless surgical recoveries to overcoming boundaries some may set on her life, Lyndsay has always persevered with a smile on her face.

Lyndsay has also taught and shown me what unconditional love truly is. My sister is ultimately my best friend and never fails to make me smile on the worst of days. At the end of the day Lyndsay loves me despite all of flaws and mistakes I may make in life. Lyndsay’s unconditional love has taught me to give and care for others in many ways. I will forever thank the Lord for blessing my family and me with the miracle that is Lyndsay.
March is Trisomy Awareness Month. What is trisomy? I’m glad you asked. A trisomy occurs when a person has three copies of a certain chromosome in each cell instead of the usual two. Most of us have 23 pairs of chromosomes, but Samuel has an extra #13. Trisomy Awareness isn’t about finding a cure, it is about letting others know that people like Sam can have a happy life when given the chance. No one has the promise of tomorrow, not even those of us with the correct number of chromosomes. We were all fearfully and wonderfully made and God knows the plans He has for us, not to harm us but to give us a hope and a future. So if you know someone who finds out their baby will have Trisomy 13 (Patau Syndrome), Trisomy 18 (Edward Syndrome), Trisomy 21 (Down Syndrome) or another trisomy, give them hope by telling them you know a 19 year old living with Trisomy....his name is Sam and he...is...Awesome!!!

-Aanne Drake Jackson March 1, 2018 via FB

Pics below L to R- Nicholas Wright, Delainey Leshawn and Natalie Siegle

Trisomy 9 Awareness Month, Day 8. Tomorrow is World Trisomy 9 Awareness Day! Easy to remember as Trisomy = 3 of a chromosome instead of the usual 2, March is the third month of the year, and we celebrate Bethany’s extra piece of the 9th chromosome on the 9th day of the month. We have chosen purple with a silver border as our ribbon color. Purple for proud!. Because this syndrome is so VERY rare, with perhaps 200 families world-wide, it is not widely known to even the medical profession. Tomorrow, on Friday, March 9, I am asking all my friends and family to wear purple, and post a picture of yourself in purple on Facebook to show your support of Trisomy 9. Tag me so that Bethany can see all the people who are honoring her and her friends! Thank you! (When posting on social media, please use the hashtag #wt9d) -Freda Branch March 8, 2018 via FB
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

Leila Hope Adamson Family
Reynolds, Lindsey, Harper and Hartley Brabner
Yolanda, Milan and Tony Myrick

John Hart and Harley “Princess Warrior”
Hart Mar 15, 2018 via FB
When looking up the definition of “sabbatical”, I found the traditional “a period of paid leave granted to a university teacher or other worker for study or travel, traditionally one year for every seven years worked” as well as the origin of the term from the Greek and Hebrew meaning “to rest”. In my experience, this opportunity to focus on research is typically for a semester rather than an academic year. During this time, the faculty member does not teach courses or participate in university duties such as committee work.

Why explain what a sabbatical is? Because I just completed one this spring, though I am still finishing up some of the materials I had hoped to finish by the end of semester. My sabbatical project is preparing online modules for families and medical professionals consisting of Power Point presentations, rare trisomy specific resource lists and a glossary.

I receive requests for information about the care and treatment of children and adults with rare trisomy conditions all the time. I share TRIS project articles, links to online information and help connect parents. Yet, a recurring need has been development of concise and informative modules for parents and medical professionals in order to raise awareness of the abilities and needs of children diagnosed with a rare trisomy condition (e.g., having information in one “place” rather than reading multiple research articles). These modules will go beyond publications and presentations in including recommendations for daily and medical care from TRIS Survey results and anecdotal reports from parents and caregivers. There is also the potential to reach a greater variety of audiences with the ability to access modules online through the TRIS project website and other sites such as the International Trisomy Alliance.

Each online module includes an historical overview, key research findings, information related to prenatal testing, phenotypic characteristics, common medical needs and interventions and day-to-day management of basic and medical care and corresponding recommendations. Parent voices are included describing sources of support and unmet needs as well as key statements from newspaper articles and television/online stories highlighting families with a member with a rare trisomy condition. TRIS Survey data is summarized throughout the modules. Photos are included to illustrate phenotypic characteristics and, more importantly, to emphasize long-term survivors. To date, there are completed modules for trisomy 18 and trisomy 13, and close to completion for trisomy 9 mosaic. The online module for trisomy 8 mosaic will require additional data mining and analyses. The estimated timeline for completion is October 2017.

A number of individuals have been assisting with module development and provided valuable feedback on the template, content and overall presentation. Thanks are extended to Dr. John Carey, Ann Barnes, Barb VanHerreweghe, Kristen Cook, Angie McCauley, Kari Adamson, Kristina Haynes, Sara Chappell, Gabi Serb and Callie Mcmunicgal.
There are several intended outcomes. It is hoped that the modules will offer information beyond research articles and case studies in planning and decision-making on behalf of children with rare trisomy conditions. In addition, module dissemination is projected to reach new audiences through collaboration, for example, with state level University Centers for Excellence in Developmental Disabilities Education and international trisomy-related organizations such as SOFT UK and UNIQUE. Finally, the modules are also intended as an additional avenue of outreach to recruit participants to the TRIS project such as a medical professional sharing the module with an expectant parent.

TRIS project: Next steps
September 2017

The SOFT Conference in Madison, WI was truly wonderful! Reconnecting with families, meeting new ones, many activities and a true focus on providing the best care and advocating for children with rare trisomy conditions.

I always return from a SOFT Conference with renewed energy and motivation. How could I not? For me, it’s about watching parents interact with their children, discussing research with premier medical professionals and being part of the emotion of the balloon release. It’s also late night conversations about many topics, rare trisomy related and otherwise. Ultimately, it’s about community. I am thankful to be a part of this one.

Some of my colleagues give me grief about my involvement with my “research participants”. I always tell them “research participants” is the name for people you never meet, the people who agree to be part of your project but not part of your life. I knew the tracking component of the TRIS project would bring me into contact with parents but never imagined having relationships spanning ten years! I am truly thankful for the privilege of seeing children grow and progress as well as families face issues and decisions never thought possible such as “what type of high school experience should my daughter have?”. This long-term connection also gave rise to the TRIS project case studies, which have been shared around the world.

I was also fortunate to share the solar eclipse with a TRIS project family. I live at the point of longest duration. I saw the mom post about traveling from Wisconsin to see the event. She talked about stopping in Effingham, IL, which is two hours north of the Carbondale/Makanda area. A few Facebook messages later, her family was at my door and we spent August 21st together. It was truly wonderful!
So, what’s next for TRIS project? I recently submitted a manuscript with data on 31 children diagnosed with trisomy 9 mosaicism. Should hear back any day now. I am also working on a new case study on behalf of a mom in the Netherlands. This mom has singlehandedly been paving the way for her daughter for close to three years. Just recently, she has found a few medical professionals to work with. In addition, I’m planning to analyze survey data focusing on trisomy 8 mosaicism. It will be the largest of its kind with close to 30 completed surveys. There are also several parent-initiated research questions I hope to answer in the near future.

Just as my kids count down the days to sleepaway camp in June, I am already checking the calendar to see how long before I see my trisomy family again in Omaha, Nebraska next July.

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

FIRST SOFT CLINIC IN ITALY: JUNE 2017

On June 16, 2017 I had the privilege and distinct pleasure of participating in a clinic with 3 families who have children with trisomy 18. I was invited by my friend and colleague, Dr Agatino Battaglia, to work with him at the Institute called Stella Maris where he practices near Pisa, Italy. Dr Battaglia and Roberta Gullone, mother of Francesco and Vice President of the Associazone Soft Italia, orchestrated a “clinic” there at Stella Maris on that Friday in June. I had the opportunity to meet with 3 families, including Francesco, Virginia, Francesca and their parents. With the help of Dr Battaglia interpreting for me, we tried to answer the families' important questions.

The photo shows the children, (Virginia in front, Francesco standing by his Dad, and Francesca trying to get her friend’s attention), their parents, and Dr Battaglia and myself (in the back row).

I am hoping to be able to return next April for the annual gathering of the SOFT families of Italy.

John Carey
Founding Professional SOFT
SOFT of Utah held its annual barbecue and pool party last month on August 19th and as usual, fun was had by all. We had a special guest from Aruba, Lunah and her family. Lunah and her family have been waiting for heart surgery in Utah at Primary Children’s and have been staying at the Ronald McDonald house since last year. Aruba is not being too quick in approving her surgery and it’s been quite a long haul for the family. Many of you might remember meeting Lunah and her family at the 2016 conference in Tacoma. Thanks to John Carey for picking them up and bringing them to our gathering so we could all meet this little doll. We all fell in love with this little sweetie and her family. We had a couple of new families attend as well as our regulars and the company and food and swimming was enjoyed by all.

Thanks so much to our awesome active chapter and all they do for SOFT. We love you all - and appreciate your participation which is why we have this annual “thank you” barbecue and swim party. We can’t wait until next year to do it again. UPDATE: The 2018 barbecue was held on Sat. Aug 18 and we had over 50 in attendance including an appearance by our founders Kris and Hal. Again we had a great time. SOFT OF UTAH ROCKS!!
Rochester: Wednesday, August 30, 2017 at age 75. Predeceased by his sister, Mary Alice (Laird) Russell. Survived by his loving wife of 53 years, Judith K. Laird; his children, Jennifer J. Laird-Moreland, Martin J. (Agnes) Laird; grandchildren, Jessica R. Woodruff, Alexa L. Lewis, Elsie A. Laird and Onnolee E. Laird; cousins and dear friends. Jack dedicated his time volunteering for SOFT (Support Organization for Trisomy 18, 13 & Related Disorders), he was a dedicated member of the Charlotte High School Reunion Committee, loved golf, music, drum corps and traveling with dear friends. Contributions can still be made to SOFT in his memory at www.trisomy.org click on the “DONATE TO SOFT” heart.

In Loving memory of Jack Laird –a true “SOFT HERO”
1941-2017

The theme for the 2015 SOFT conference was “SOFT HEROES” and besides our SOFT children, the first person that comes to mind when we say SOFT HERO is our dear friend Jack Laird. He truly loved SOFT and its membership.

I first met Jack at the 2002 conference in Chicago. He was very involved in registration and we spoke by email several times. When I finally arrived at the conference and I was able to meet Jack, we seemed to become instant friends. He’s been like a father to me ever since.

Barb VanHerreweghe spoke at Jack’s memorial service and recounted that she first met Jack when Stacy was just 7 years old. A dear friend of hers had lost her T-18 daughter and had a wonderful nurse that could possibly take care of Stacy. This was 29 years ago and Judie Laird has been Stacy VanHerreweghe’s nurse since then. Of course Jack and Judie both became part of the VanHerreweghe family from that moment on.

Judie Laird recounts that at the 1994 Toronto SOFT conference she had invited Jack to drive to Toronto from Rochester for the family night out Blue Jays game. She recalled he agreed to come and has attended every SOFT conference since then until he got sick in 2013. He was hooked.
Barb also recounted that Jack was asked to help with some work with the SOFT membership for the 1999 conference in Rochester New York. He was a busy man as a mechanical engineer for Eastman Kodak. He was reluctant, but agreed to help and took over from there building a database for SOFT membership, which changed the organization and brought SOFT into the 21st century. Jack retired from Eastman Kodak in 2003 and devoted much of his spare time to SOFT in his retirement.

Having co-hosted 3 conferences myself since then, I was so blessed to have been able to work with Jack, who pretty much took over registration during conferences. He would sit in registration for 2 days and did it willingly as he truly enjoyed meeting all the families face to face and getting to know them. Jack did so much work behind the scenes for every conference and I didn’t realize how much until co-hosting a conference myself. His son Marty recounted that Jack would say “if you’re going to do something, do it right” and that’s exactly what he did.

Jack became very ill before the 2013 conference in Rhode Island. Many people had to jump in to help and do what Jack did. Not one person could fill in for Jack it took many as he did so much to make a conference happen.

Jack ended up with kidney failure and had to go on dialysis at that time. It was so hard for me not to see my dear friend at conferences after that, but I was so excited to see him with Judie and his daughter Jennifer at the 2014 conference in Norfolk. What a treat!!! Jim and I had missed him so much. He was there even though he was on dialysis which shows you how much he loved SOFT.

Jack passed away on August 30 a few weeks ago early in the morning. We were notified of this a few hours later. I immediately felt that I needed to be there for Judie and to let his children Jennifer and Martin know how special we thought Jack was. I was blessed to attend the beautiful memorial service for this wonderful man that spent his retirement years in the service of others.

I was very touched at the comments made by both Barb VanHerreweghe and his son Martin. Barb spoke about how much Jack did for SOFT and never turned her down on a request for help with SOFT needs and how much he and Judie were part of their family even going on a cruise together – what great memories.
With permission from his son Martin – I’d like to recount a story that he told in the eulogy he wrote for his Dad.

Martin said that after Jack had passed, his parent’s house was bustling with friends and family in and out of the house and he was finding it difficult to get some quiet time to write his Dad’s eulogy.

Apparently Jack lived his advice, “if you’re going to do something, do it right”. He was very involved in drum corps when he was younger and passed that love on to his son, having the best teachers teaching him what he needed to know to “do it right”. He also spoke of his Dad becoming very involved with his baseball team, not happy with the team having a losing season the first year of play, he got involved and ended up becoming commissioner of the league and they had many winning seasons under Jack’s direction. When Marty was trying to find a place to have some quiet time to reflect on writing his Dad’s eulogy, he decided to go to the ball park where his Dad had spent so many hours with him during his childhood. He parked the car and got out to go sit and start writing. When he exited the car, a woman came up to him and asked if she could help him, as her group was obviously in the middle of something out on the field. As he looked over he said to her “that’s a drum corps” “I can’t believe that there’s a drum corps here”. He promptly told the woman that he had come here to write his Dad’s eulogy because his Dad had spent so much time here teaching him to play baseball. He also told her how his dad had been involved in drum corps as a teenager and how he loved it, and how he had passed that love on to him. He then asked the woman where their drum corps was from. She replied they were from Cincinnati. He again couldn’t believe it. His dad had attended the University of Cincinnati for his engineering degree and met the love of his life Judie there. She was a nurse at a local hospital and he had met her through his best friend. The Cincinnati area always had a special place in his heart and in the hearts of his children because their parents met there. Martin said the words just started to flow after that and he knew without a doubt that Jack was there, showing him he was still with him, helping him and guiding him. What a touching tribute. It brought tears to my eyes and Jack’s presence was definitely felt that day.

We are so saddened at Jack’s loss and will feel that loss for a long time. We pray for comfort for our sweet Judie his wife of 53 years and his two children Jennifer and Martin and his grandchildren Jessie, Lexie, Elsie and Onnolee and Martin’s wife Agnes.

Jack my dear friend, we will always miss you and your giving spirit. We celebrate a life well lived in the service of your family and others especially SOFT.

Submitted by Debbie Dye – SOFT Secretary
Keeping Up With Karson Friedmeyer isn’t easy! She has been a busy lil’ lady! Last December, Hunger Games star Jennifer Lawrence visited Norton Children’s Hospital. Although J Law was not able to visit Karson’s unit, she did give her an autographed poster and mom got a hug! In January, Karson with friends and family made and donated red hats to the Cincinnati Children’s Hospital for congenital heart disease awareness. Later in February, Karson was featured on the Jumbotron at KFC Yum! Center while attending a Louisville Athletics men’s basketball game. Tickets to sit in a suite were donated to the Kourageous Kids Palliative Care Program. You can follow Karson’s adventures on Facebook @keepingupwithkarson or by #keepingupwithkarson on Instagram.

Update from Karson’s mom, Casey: “I can’t describe the feeling I feel knowing how much Karson is loved!! It’s time for an update…that, frankly, I never thought I’d have to give…

ECMO was not successful last night…

Karson went to her eternal home with our Heavenly Father….2 Timothy 4:7 I have fought the good fight, I have finished the race, I have kept the faith.”

Please keep the Friedmeyer family in your prayers.

For the latest updates and all things SOFT go to: www.trisomy.org

You can also follow us on
Facebook (SOFT—Support Organization for Trisomy 18, 13, and Related Disorders),
Instagram (@trisomy_soft),
Twitter (Trisomy_SOFT)
And Pinterest (SOFT Trisomy 18 & 13)
TRIS project: Next Steps
September 2017
Debbie Bruns, PhD

The SOFT Conference in Madison, WI was truly wonderful! Reconnecting with families, meeting new ones, many activities and a true focus on providing the best care and advocating for children with rare trisomy conditions.

I always return from a SOFT Conference with renewed energy and motivation. How could I not? For me, it’s about watching parents interact with their children, discussing research with premier medical professionals and being part of the emotion of the balloon release. It’s also late night conversations about many topics, rare trisomy related and otherwise. Ultimately, it’s about community. I am thankful to be a part of this one.

Some of my colleagues give me grief about my involvement with my “research participants”. I always tell them “research participants” is the name for people you never meet, the people who agree to be part of your project but not part of your life. I knew the tracking component of the TRIS project would bring me into contact with parents but never imagined having relationships spanning ten years! I am truly thankful for the privilege of seeing children grow and progress as well as families face issues and decisions never thought possible such as “what type of high school experience should my daughter have?”. This long-term connection also gave rise to the TRIS project case studies, which have been shared around the world.

I was also fortunate to share the solar eclipse with a TRIS project family. I live at the point of longest duration. I saw the mom post about traveling from Wisconsin to see the event. She talked about stopping in Effingham, IL, which is two hours north of the Carbondale/ Makanda area. A few Facebook messages later, her family was at my door and we spent August 21st together. It was truly wonderful!
So, what’s next for TRIS project? I recently submitted a manuscript with data on 31 children diagnosed with trisomy 9 mosaicism. Should hear back any day now. I am also working on a new case study on behalf of a mom in the Netherlands. This mom has singlehandedly been paving the way for her daughter for close to three years. Just recently, she has found a few medical professionals to work with. In addition, I’m planning to analyze survey data focusing on trisomy 8 mosaicism. It will be the largest of its kind with close to 30 completed surveys. There are also several parent-initiated research questions I hope to answer in the near future.

Just as my kids count down the days to sleepaway camp in June, I am already checking the calendar to see how long before I see my trisomy family again in next July.

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
The article below was submitted for the SOFT times 5 years ago when Morghan Kubena had just turned 16 and Ashton Wagner had just turned 13. Now here we are 5 years later with another milestone birthday for both girls as Morghan just turned 21 on September 14 and Ashton just turned 18 on October 11. I am resubmitting the same article and have changed the birthdays to reflect 5 years later.

**SOFT BIRTHDAYS – A Reason to Celebrate**

As we come to the end of another year, I have to reflect on the awesome experiences I have had with so many people in SOFT. I can’t imagine what my life would be like without my associations with so many wonderful people and their beautiful children. Two of Morganne’s Trisomy friends have recently had milestone birthdays. Morghan Kubena, who we met when our Morganne was 6 months old, and Ashton Wagner who we met after Morganne had passed away. Since they both have just celebrated birthdays, we will honor both of them in this article.

**Morghan Kubena just turned 21 years old.** What a beautiful young woman she has become. I remember like yesterday when that cute little toddler cradled in her Daddy’s arm’s posed for a picture with our Morganne at a local restaurant here in Salt Lake. I had met Faye on the internet, and being that she named her daughter the same special name I had named mine gave me reason to strike up an email conversation with her. Mark and Faye came to Utah for a ski vacation and we were able to meet up for dinner and became instant friends. I think Mark and Faye and Morghan are a couple of just a handful of our SOFT friends who were able to meet our Morganne in person. How lucky and how blessed we are for that meeting. Morghan has been a true joy in our lives, and we will forever be grateful for that little sweetheart. Happy 21st birthday sweet girl and thank you for being in our lives and for bringing your parents into our lives. We cannot put into words how blessed we feel. Thank you to all 3 of you for always being there for us. Even though we only get to see each other once a year at conference, we pick up where we left off. We are forever a SOFT family.
Ashton Wagner just turned 18. I first met Steve and Raquel, also on the internet, and through conversation realized that they lived less than 5 miles away. This was about 9 months after Morganne had passed away. I stopped by their home on my way home from work one day and met this tiny, fragile little baby. I was so scared because I had instantly fallen in love with her, and she was the first trisomy baby I had met since Morganne had left us. What a blessing she has been in our lives. She was so tiny and only 5 months old. I feared that I would get attached and lose her too. I was so wrong, thankfully, and have had this beautiful little girl in our lives for 18 years now. Her siblings and parents have also become very close to our family. Again, we have been blessed because of our own Tri-somy 18 angel. I know she is watching over us. These two trisomy blessings from heaven are part of our lives because of our little angel who we only had for 7 short months. She continues to bless our lives and always will.

We also just celebrated Morganne’s 19th birthday on October 8th. It was a great day to remember a beautiful little girl. We decorated her grave with all the fun things a 19 year old would love. We left a big “HAPPY BIRTHDAY” balloon for our baby’s 19th birthday. We spent some time together as a family at the cemetery. I’m sure she was joined by other SOFT friends to celebrate her day. That day will always be special in our lives, and we will forever celebrate that special day. Thank you Morganne for making our lives so special and for bringing such wonderful people into our hearts. There are so many friends that she has brought into our lives, not just Morghan and Ashton, and we will forever be grateful for all of our SOFT associations.

A couple of years ago I traveled from Salt Lake City to New York to celebrate Stacy VanHerreweghe’s 35th birthday. She was in the hospital at that time. That was one of the last times I saw Stacy. I was able to see her one more time when I attended Jack Laird’s service. I am grateful every day that SOFT has brought the VanHerreweghe family into my life. I miss Stacy with all my heart, but I am so grateful to call her one of my best friends. LOVE and MISS YOU STACY LYNN!! Until we meet again my sweet friend. Give Morganne a kiss for me. I’m sure there are birthday parties in heaven.

Here’s to many more birthdays for all of our SOFT KIDS. We are forever a SOFT family because of our angel Morganne.

Submitted by
Debbie Dye
SOFT SECRETARY
SOFT- Appreciates your generosity and recognizes the love and care that these donations represent

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In Memory of Hayden Brown  
Harry and Holly Bryant

In Memory of Robert Chabert  
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In Memory of Jackson Jerry Priest  
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In Memory of Mia Welji
Katherine Blair: “The Nurses from the Cardiac Care Unit of Piedmont Atlanta Hospi-
tal are donating in memory of Mia Welji who lost her battle with Trisomy 13 after two
weeks on this earth. Even though her time was short, her memories and influence will
outlive her. God Bless.”

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In Honor of her mother, Terri Evett
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Because Animals Matter: “Our thoughts are with Casey, Andrea and the entire family at this time of terrible loss. We hope this donation may help to support research efforts and in turn help another Trisomy family in the future.”
In Memory of Nora Rosalia Morrison  
Sean and Tracy Morrison

In Memory of Kelsey Guadalupe Crossland  
Chris Brown

In Memory of Logan Frisius Gordon  
Rebecca Prosen: “Logan was born with Trisomy 13 which was undiagnosed prenatally. He touched our hearts in his short time on earth.” Belly Bliss.org

In Memory of Mattea Fitzpatrick  
Tony, Barbara and Olivia Lawry: “We are making this donation to honor the memory of our friend’s daughter that was born prematurely with Trisomy 13.”

In Memory of Braeden Mark Riccini  
Mark and Heather Riccini  
Michael Valenches  
Linda Haddad  
Halina and Jerry Lenczewski  
Susan Terrill  
Mark and Lisa Proffitt  
John Wayne Conner  
Mary and Bob Salerno  
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In Memory of Baby Grace Kowalke  
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The Mattison Family: Margy, Rusty, Tyler and Josh
Elena, Trajanka and Dime Petkovska
JoAnne Antonacci

Thank You for your Kindness
In Memory of Megan Barnes and Matthew Butler
Ann and Frank Barnes

In Memory of Patrick Showalter
Anne Showalter

In Memory of Janessa Siebert
Andrew and Melissa Siebert, “SOFT was very helpful in giving hope after we received the prenatal probably diagnosis. SOFT was also helpful in finding information regarding surgery and expected outcomes, as well as advocacy for surgery. Janessa received open heart surgery at 8 months of age to repair an AVSD/DORV. She lived 3 years and almost 4 months! We also benefitted from the SOFT community of parents.”

In Memory of Faye Marie
Scott Sigler

In Memory of Jace Peterson
Melissa Saulsbury

In Memory of Jack Laird
Mark and Jayne Wright
Lynn and Buster Stockman
Doug and Tricia Oppelt
Horizon Productions, Durham, NC, and
In Honor of Jack’s daughter, Jennifer Moreland

In Memory of Hayden Elizabeth Brown
Laura and Mike Grace

In Memory of Malakai Miller
Courtney, Stacy and Mallory Martin

In Memory of Regan Adeline Lawson’s birthday
Uncle Joe and Auntie Laurie
In Memory of Jack Laird
Mark and Jayne Wright
Lynn and Buster Stockman
Doug and Tricia Oppelt
Horizon Productions, Durham, NC, and
In Honor of Jack’s daughter, Jennifer Moreland

In Memory of Hayden Elizabeth Brown
Laura and Mike Grace

In Memory of Malakai Miller
Courtney, Stacy and Mallory Martin

In Memory of Regan Adeline Lawson’s birthday
Uncle Joe and Auntie Laurie
In Memory of Braedon Riccini
Ursula Hartman

In Memory of Sarah Valentine and
In Honor of her Grandmother Pauline’s retirement
The Sunshine Club and Pediatric Associates of Fall River, MA

In Memory of John Gibson, Ryan Steele’s Grandfather
John and Barbara Cangemi

In Memory of Regan Lawson
Christine Mikuly

In Honor of Akaiya Davis
Suzanne Albright
In Honor of Payton Thompson
The Hill Family
Kristin Kay
Dalane Lamm, “Happy Birthday, Payton. You’re an inspiration.”

In Honor of Thristan Williams
Mary Botello

In Memory of Rachel Maurer
Hoagland, Evett and Price Families

In Memory of Addalyn Grace Froehner
Nathan Merriman

In Memory of Lilly Hollowell
Lisa Hollowell

In Memory of John and Kalli Martin
Mercy Martin

In Honor of Amara Tegan Micah Behr and
In Memory of Tegan Anne Mary Enss
Bo and Karen Enss
In Memory of Vida Elyse Mora and
In Honor of her sister, Liv Marie Mora

Yvonne Figueredo, “Christine and John Mora lost dear Vida Elyse Mora after 31 days of pure love on January 5, 2016. God blessed them with Liv Marie Mora who entered this world on October 20, 2017. Although Liv Marie will never get to meet her sister, Vida Elyse, we know Vida lives on with the Mora Family of 5 forever! In lieu of flowers for Liv Marie’s birth, this donation is being made to honor and remember Vida Elyse and celebrate Liv Marie’s birth. This donation is also being made in lieu of Team FDC registration fee, for the 2018 Miami Half Marathon.”

In Memory of Micayla Carlson
William Wade

In Memory of Sabastiaan Xavier Keg
Antonia and Frank Keg

In Honor of Jolynn Ryan
Vanessa Barney

Thank You for your Kindness
In Memory of “Bud” Benites 25th Heavenly Birthday
Joanne and Cameron Lee (T18)

In Memory of Don Seilnacht and
In Memory of his son, Jason Seilnacht
Rick and Nita Langford
Tom and Sue Kuse
Rose Ann Austin
Cliff and Sue Collins, “Donnell “Rabbit” Seilnacht was a dear friend to many and will be greatly missed.”
Jill Buatte
Marc and Sandy Silvey
Don and Sallie Berlemann
Teresa and John Marino
Mary Robbins
Charlie and Sue Nordstrom
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In Memory of Carter James Levrault
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In Memory of Caroline Rosie Frost
East Carolina University, English PhD Students

In Memory of Kaden Bradley
Sneak A Peek Ultrasound
Diane and John Paul

In Memory of Giovanni Goecke
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In Honor of Pete Hoagland for Father’s Day and
In Memory of his granddaughter,
Rachael Maurer
Vicki Price

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Anne Showalter
In Memory of Witt Harris Lupher
Karen Daenzer
Laura Crawford
Michael Womble
Peggy Witt
Craig and Sarah Stanfield
Deela Roe, Sherley and Floyd, and John and Shailey, “This donation is in memory of Witt Lupher, who touched countless lives, too many to know with his infectious smile and his precious personality. So grateful to have been a part of his world and his life. He will be missed by all who knew him.”

In Honor of Haven Bower
Denise Anzlovar

In Memory of Cassius Alexander McGill
Natasha McGill

In Memory of Herbert Marohn, loving and dedicated grandfather to Ella Marohn
David Schooley
Jennifer, Pearl and Mabel Azure
Lauren Ratner
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Susan and Gabriel Palombit
Patricia and John Prohl
In Honor of Amanda Leal’s 26th Birthday

Regina Nobida, “My daughter Amanda was born with Partial Trisomy 13. She will be 26 on February 18. She is MY GREATEST BLESSING.”

In Memory of Isabel Jane Brady

Ann and Jim Ewel, “My granddaughter was born with Trisomy 13 and lived three short days. Her parents, my kids, found the help and support they got from SOFT to be invaluable on this journey. I so appreciate that you all were there for them and want you to be able to be there for other families, too.”

In Honor of Venna Miller

Connie Merkle

In Memory of Collins Reese Baudin

Macy Baudin

Thank You for your Kindness
In Memory Caitlin “Caiti Bug” Johnson
Ashley Johnson

In Memory of Everett Lail
Loren’s Tennis Team – Tough Love

In Honor of Zoe’s Fund of Nga Nguyen Peterson
Hanh Nguyen

In Memory of Gabriella Hina Obtuhan
Andrew Gemon

In Memory of Chloe Messer
Janeen Moser

Donations to Joey Watson Fund
In Honor of Hayley King
Janis King, “Hayley is my 27 year old daughter with Trisomy 18”.

In Memory of Ian Ryan Asay
Bridget A Crowley