President’s Corner

Dear SOFT Families:

So there has been some excitement in the VanHerreweghe family. On September 13th Miss Andrea Lynn VanHerreweghe was born weighing in at 7 lbs 4 ozs. Today she turned 1 month old and is now 9 lbs. Obviously, she is doing well and such a joy to have in the family. Stacy is not a fan of babies but somehow she seems to know that this baby is someone very special and another princess has joined our family. She says just call me Aunt Stacy!

The conference planning for next year in Tacoma Washington is going Strong! Meetings with the Doctors, hotel reserved and picnic site almost verified. It is all coming together. The dates for next year are July 20-24th. Start saving now, get your tickets and sign up for your hotel room at Hotel Murano. Remember we have a small room block. When it is gone, it is gone! Don’t forget to get your Bravelet to help support the 2016 conference.

In October, I was at the New York State Right to Life Conference to speak about the treatment of our kids after birth or at diagnosis, and the negativity we receive from the medical professionals. My goal was to help make everyone understand that our children are compatible with life! Families need to make their own decisions, not the professionals. Remember to keep watch in Missouri to follow the success of Simon’s Law as it continues to be reintroduced.

The air is changing and the leaves are full of color here in Rochester. Unfortunately, it is the sign that summer is over. Fall and winter are coming for sure. I guess we can see it as a way to get us closer to conference next summer! I hope this winter is easier on our kids and they can all stay healthy this year. I will pray for peace!

For those of you who haven’t visited our SOFT website recently, at www.trisomy.org make sure that you do! All of our books can now be downloaded from the website. Share copies of the books with your doctors. Educate them on the care of our kids with the wonderful Care Book. Give them a copy of the growth, height and weight charts, so they can compare your child with others like them. The more we can educate our Doctors, the better treatment our kids can receive. There are still some hard copies of the T18 book, the older Care Book and the Poetry book that we can send out if anyone wants them. The T-13 is only available online. Share the stories and links on the websites with your Doctors. Add your trisomy story to our Family Stories section; then we can recognize your child on their birthday! Give us suggestions as to what is helpful for you. If we can help, we will. We want to include everyone. All are welcome! If you want to add an article, pictures, event announcements, etc. to the newsletter, please send your items to Raquel Wagner. When something special happens, give her a shout!

Hope to see all the kids on the SOFT FB group sharing your holiday pictures! For those who have angels looking down on all of us, we want to hear about them too! - Never Forgotten!

Hugs to all, keep your letters and stories coming!

The VanHerreweghes
Barb, Dave, Stacy (34 yrs old with full T-18)
Andy, Melissa, Nicole and Miss Andrea Lynn

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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)
Shannon is eleven and this summer decided to open an iced tea stand with her two friends Diana and Faith. For two days they sat outside in the extremely hot sun while they convinced people passing to not only buy their delicious fresh brewed iced tea, but that by doing so they were making a contribution to SOFT. After covering their cost (tea bags, cups and napkins) they made $52.75 for SOFT. People generously paid for the tea and happily told them to “keep the change”. The girls were so happy to share what SOFT was all about. Shannon explained to people that her sister, Mary would have been outside with them, but the hot weather would not be good for her to breathe. She told them about all the other kids living with trisomy and how many of them live for only a short time. Shannon proudly told people about Mary (most knew already, but listened to her anyway.) The girls were so excited to do something good for SOFT and all our beautiful children. They are already planning how to make it an even bigger business next summer! I’m so proud of Shannon and her friends!

Left to right in the photo are Diana, Shannon and Faith
Simon Dominic Crosier

Memorial Golf Tournament Update

Story and Picture by Sheryl Crosier

After we lost our precious son, Simon Dominic Crosier, we really wanted to plan an event in his memory and at the same time help raise money for SOFT. We decided to plan a golf tournament at Spring Creek Golf Course in Seneca Kansas. Seneca is 90 miles from the Kansas City International Airport and Simon’s Grandparents live on the course. Their house is on the 11th hole with Simon’s tree and a photo of our little boy on a marker for all golfers to see.

August 8th was our third biannual tournament in memory of our son. Grandpa Duane, contacted the club pro and scheduled the event. He then started contacting hole sponsors and sent out fliers and e-mails. Grandma Lois contacted businesses for silent auction items and hole prizes.

We were so pleased and grateful for all of the support of this small community, a town of 2,000 wonderful people in Northeast Kansas. We are grateful to all the hole sponsors, all the teams that participated, and the nice items contributed for the silent auction and hole prizes.

The day of the tournament started out a little cloudy, chilly and a chance of rain but it turned out to be a beautiful day. We thanked Simon for that, for his “Simon signs” of butterflies were abundant. Scott, my husband and Simon’s Dad, introduced the family before the tournament and announced what the proceeds would be used for. This year was extra special because we had our daughter, Simon’s sister, Sabella with us. Sabella was so excited to experience Simon’s golf tournament. Simon’s big brothers, Samuel and Sean, golfed very well and really enjoyed the day. It made them feel very good to play well. Everyone who played in the tournament was very upbeat and positive and really made the tournament a great success. We were very pleased with how well it went and were happy we could do something in memory of our precious son, Simon.

Simon touched so many lives and continues to change hearts. Our son taught us so much and we learned that the quality of life is measured by love. Simon loved life, always so alert and had a beautiful personality with a bright spirit. He will always be perfect in every way and we continue to celebrate him always.

We love you Simon and miss you so much!
Back To School Memories…

Megan Elizabeth Barnes (t18) began attending Ridgeview Elementary school in Orange Park, FL in 1989. This wonderful Special Education program benefitted from the generosity of a group of Marines stationed at Naval Air Station, Jacksonville, FL. Perhaps the support of these marines is why the class space and equipment were so well planned out for these children. The teachers, aids and school were, by far, the best in all of Megan’s school years.

Megan was the smallest student in the school that year. Max, able to walk and talk, was the smallest boy because of a disorder. Max would position himself near Megan to take care of her. He loved her because she was smaller than he was. It’s a pleasure to share sweet memories and a photo of Megan.

Story and Photo by Ann Barnes

Welcome to the SOFT Family!
Andrea Lynn Vanherreweghe
born September 13th at 7:54 pm
7 lbs 4 ozs. 21 inches long

Pictures provided by
The Van herreweghe Family
“A teacher affects eternity; they can never tell where their influence stops.”

“Back to school” brings a flood of memories! I remember as a child, my own new classroom and the smell of chalk and erasers, new colored pencils, and brand new clothes. I remember my own children’s excitement and apprehension of going back to school after a long and lazy summer.

I remember Kari’s first day of kindergarten in September 1983. Although she had been attending preschool and therapies, I was her constant companion. But, going to kindergarten was “big time” and I wasn’t sure I was ready to let her go all by herself! All the preparations were made and the classroom was waiting and ready. I recall on that first morning of school, Kari and I were waiting for the school bus on the porch of our home. Kari was dressed in her new school clothes and she looked adorable and happy. I was worried and looked miserable! It seemed so wrong to send my five year old daughter to school in an infant car seat being strapped into the bus bench! (This was before the wonderful seating options and personalized wheelchairs available today. Those were the days of “one-size-fits-all”.

When the bus pulled up to our curb, I looked down at Kari and asked her if she was ready? She looked up at me with a look as if to say, “I am ready, but you don’t look so good!” We placed her carefully in the bus and tightened all the safety straps. I leaned down to kiss her good-bye and started to cry. The bus driver put her arm around my shoulder and promised me she would drive slow and careful the entire one mile to school. When I walked off the bus, I started the countdown until she would be brought back home in three hours. It felt like forever! As the bus pulled away from the curve, I ran to the house, grabbed the car keys and followed the bus to school. Sure enough, the bus driver went slow and careful and Kari went off to school.

I had a wonderful 10 years and 9 months of caring for Kari and trying to provide opportunities for her to become her best. But, in truth, I realize that I was the “student” and that Kari was my “teacher”. Although Kari could not walk, she gave me legs to run. Although Kari could not speak with words, she taught me to voice my thoughts. Although Kari was hearing impaired, she taught me to listen with my heart. Although Kari was mentally disabled, she taught me to think more clearly. Although Kari’s vision was limited, she gave me the ability to see beyond now and look into eternity. Although Kari was considered hopeless, she taught me about HOPE!

I think back on this and all the many amazing experiences we have had and all the incredible people we have met and all the cherished memories we hold dear, all thanks to this little girl!

Kari was and still is, my finest teacher!

“We gain strength, and courage, and confidence by each experience in which we really stop to look fear in the face ... we must do that which we think we cannot.”

~Eleanor Roosevelt~
Donations to SOFT’s General Fund
Suzanne Revere
Local Independent Charities of America,
Larkspur, CA
Give With Liberty Employee Donations
First Giving: represents funds raised on SOFT’s behalf through firstgiving.com
United Way of Chester County, PA
Nicole Cagna

Donations to Joey Watson Fund:
Cindy Sauve, In Memory of Elizabeth Grace Stiles

In Memory of Raymond Hippenstiel
Ann L. Pagel, Jim and Joyce Eckerd, Shirley Kiefer, Joe and Sandy Gribben,
and Barbara Cressman, Fellowship Community, Holy Family Manor

In Memory of Boone Shepherd Ladd
Jason and Kerry Ladd, Boone’s parents, and many family members and friends

In Memory of Dawson Faye Seydler
Happy 1st Heavenly Birthday, Dawson Faye! From Grandma and Papaw

In Memory of Ella Marohn
Shelly Murphy, Dean William Goldbeck and Mary Ruth Goldbeck

In Memory of Eliana, daughter of Kimberly Collins
Therese Ann Siegle

In Memory of Whit Emmet Livovich
John and Christine Larr, Denise Samocki
Frank Haughee and Jennifer Grayalny, and The Seydel Family
In Memory of George DiMitri
Susan and John Pucci and
The Pucci Family

In Memory of Sienna Prestella
The Canzoneri, Griffith and
Murphy Families

In Memory of Lily Annaliese Wheeler
Joann Carrigan at Empower Retirement

In Memory of Baby Isabel
Janna Poth

In Memory of Kelsey Page
The Magnus Family

In Honor of Angela Ricker
Wayne and Joyce Couch

In Memory of Lily Grace Morhard
Derwin Hodder

In Memory of Regan Lawson and
In Honor of Lilian Monaghan
Elliott and Patricia Lawson

In Memory of Caleb Joseph Munoz
The Grossman Family

In Memory of Nicholas Wright
Shannon K. MacMaster

“We make a living by what we get, but we make a life by what we give.”
Winston Churchill

“What we have done for ourselves alone dies with us; what we have done for others and the world remains and is immortal.”
Albert Pike
Build your SOFT Chapter– have a party!
If you are a Chapter Chair wanting to know what members are in your area, please contact our Chapter Chair Committee at www.trisomy.org

Top Left- Jaime Jesperson, Juli & Arianna Snell, Jacqui Jesperson, Leslie & John Carey And G-ma Hutchings

Top Right- Kira Knobel
Center- Madelyn Morianne Woolley

Bottom Left– Tim Watson and Ken Knobel

Bottom Right– SOFT of Utah Sibs
**SOFT of Utah Annual BBQ**

Top Left - Julie Knobel and Kindra & Pam Watson

Top Right - Arianna Snell (T13)

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Gavin, Chevelle and Ashton (T18) Wagner with The Utah Batman at the 2015 Salt Lake Comic Con

Ashton Troi Wagner with her namesake Counselor Deanna Troi (Marina Sirtis) from Star Trek TNG
TRIS Project: Spotlight on Case Studies

Article and Picture by Debbie Bruns

A key component of the Tracking Rare Incidence Syndromes (TRIS) project is raising awareness and providing information about children and adults with rare trisomy conditions. In addition to published articles and presentations to parent and professional groups, a series of 12 case studies were developed in 2014.

Each case study provides a comprehensive overview of birth history, medical needs and interventions including medications and surgeries as well as developmental status and therapy services. Each case study includes a minimum of three years of TRIS project data (TRIS Full Survey and Follow-up Survey). Most published case studies do not provide this depth and breadth as the focus is generally on a medical condition and its resolution such as a cardiac defect or oral health needs.

All TRIS project case studies include photos with one from the newborn period and one at the time of case study completion. These images are intended to raise awareness and celebrate each child and also be a counterpoint to the many representations of conditions such as trisomy 18, trisomy 13 and trisomy 9 that are not as positive (e.g., close-up photos of defects, autopsy photos).

Developing the case studies was a collaborative experience with each child’s parents. Initial data analyses and compiling the resulting information was completed by TRIS project staff and then sent to the child’s parent for review. Questions were incorporated into the case study draft to ensure accuracy. There were several drafts for each case study. No case study was uploaded to the TRIS project website without final parent approval.

The link to the case studies is http://tris.siu.edu/case-studies/index.html - feel free to download and share them with family members, friends, co-workers and medical professionals. All are in PDF format. Any questions can be sent to Debbie Bruns, TRIS project Principal Investigator, at dabruns@siu.edu.

Begun in 2007, the Tracking Rare Incidence Syndromes (TRIS) project seeks to increase the knowledge base on rare incidence trisomy conditions including trisomy 18, trisomy 13 and trisomy 9 mosaic through data collection, analysis and sharing the results with various audiences. The three forms of the TRIS Survey collect data focusing on common medical conditions, developmental milestones, therapeutic needs, family-related concerns and demographic data of families with a child (living as well as deceased) with rare trisomy conditions. The resulting information is shared through publications and presentations to raise awareness, increase treatment choices and enhance child and family outcomes.
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/timeline

If you have any questions please send an email to the TRIS project at tris@siu.edu or dabruns@siu.edu

The 30th Annual SOFT Conference will be held in Tacoma, WA
July 20 – 24, 2016 in the shadow of grand and majestic Mt. Rainier.

Plans are underway for this historic event which will be held at the Hotel Murano in downtown Tacoma. The hotel is conveniently located in the heart of the city providing lots of tourist and sightseeing experiences walking distance from the hotel. Mary Bridge Children’s Hospital, just 10 minutes away, will be the host hospital for the conference and will host clinics featuring a good variety of specialists with an emphasis on therapies including Physical Therapy, Occupational Therapy and Speech Therapy. We will have outings for the sibs and a special Remembrance outing for our families to honor and remember their SOFT child. The conference will all culminate with our Annual Ryan Cantrell Picnic and Balloon release and of course the fun filled SOFT Auction!

Be watching the SOFT website (www.trisomy.org) as well as the SOFT Facebook group for updates and opportunities to contribute. Registration will begin in March.

Decide today that you and your family will be there. Get an idea of what it is going to take to get there. Start making travel plans, find out what it will cost and start saving for it now. If you wait until May it may feel out of reach so don’t let that happen.

Plan to spend extra time on one end or the other of the conference. There is a lot to do and see in beautiful Washington State. From sightseeing in and around the hotel to a trip just a few miles up I-5 to visit Seattle, a beautiful ferry trip, a Gondola ride up the slopes of Crystal Mountain for one of the best views of Mt. Rainier, or even day hikes in and around Mt Rainier; Washington State has you covered for a phenomenal and Memorable family vacation.

There will be lots of opportunities to help out and even contribute to the conference. Donations of any size are encouraged and welcome. A sponsorship opportunity list will be posted soon but you needed wait until then. Go to www.trisomy.org to make a donation to support the conference in honor of or in memory of your SOFT child. You can contribute items to the auction and even give of your time before or during the conference. Remember, SOFT is 100% a volunteer organization and 100% supported through the generosity of those with SOFT hearts.

Folks, be there or be square… this one will go down in the history books!
During the month of October, *A Butterfly’s Touch* held their 2015 Inaugural Infant Loss Memorial Run/Walk fundraiser. The event gathered 89 participants who honored all the little ones lost too soon. Teams of friends, families, and neighbors were created and fundraising goals were set. Throughout the month, our participants took afternoon strolls through local parks, along river paths, and around special places holding memories. There were no specific distances or time requirement. Our participants were allowed to complete the run/walk any time during the month of October (infant-loss remembrance month.) Each of those who registered received a commemorative t-shirt and finishers’ medal. If you'd like to share, we would love for you to send us a picture of you and/or your team with your t-shirts and/or medals to: info@abutterflystouch.org

Approximately $2000 was raised last month through registration fees and donations! All proceeds go directly to funding *A Butterfly’s Touch*’s mission to provide memory boxes and funeral assistance for other parents enduring infant-loss. Thank You for your participation!

Article and pictures provided by The Wheat Family

You can still purchase small and XL “A Walk To Remember” t-shirts and “Honoring Little Lives Lost” medals for only $15 each by emailing: info@abutterflystouch.org

You can also continue to make donations at: http://abutterflystouch.org/how-to-help.html
Katie and Larry Wheat are the co-founders of *A Butterfly’s Touch* which was started in memory of their daughter who gained her wings on August 9, 2002 due to Trisomy 18. You can read Abigail’s story on her site at [www.trisomy18angel.com](http://www.trisomy18angel.com). Larry and Katie are currently stationed at Ft. Sam Houston, TX and have been married for 16 years. Larry is a Nurse Anesthetist with the US Army, and Katie stays at home and cares for and schools their children. They have a 22 year old daughter named Tara who is currently in nursing school, a 13 year old son named Jhia-Vhonnii and an 11 year old daughter, Mara Jade.

Larry Wheat -

13.1 miles run and done this morning for the A Butterfly’s Touch Infant Loss Memorial Virtual Run/Walk! Special thanks to Pastor Zak White for joining me and keeping me strong. We love and miss you Abby and will always remember you! #running #infantloss in Schertz, Texas.

Ihia-Vhonni Wheat took 2nd in the cross country category mountain bike at the Huntsville Classic this past October. This is his best finish to date! He is rated Top 10 in the state in his age group, and has only been racing for a year!

Congratulations, Vhonni!

Story and pictures by The Wheat Family

**SOFT Sib in the NEWS!**

If you would like to your SOFT Sib(s) featured in the SOFT Times, please send a picture and/or a short story to our Newsletter Committee at [www.trisomy.org](http://www.trisomy.org)
PROFESSIONAL VIEWPOINT


by John C. Carey, MD, MPH, Medical Advisor, SOFT.

In the course of 8 weeks from mid August to early October, I had the opportunity to attend two noteworthy scientific meetings: The first was the David W. Smith Malformation & Morphogenesis Workshop (named after Dr. Smith who was a coauthor on the original paper with his colleague, Dr. Patau, on trisomy 13 and the first author of the second paper and the first in the US on trisomy 18). The second meeting in October, the American Society of Human Genetics, is considered the most important annual scientific conference on human genetics in the world.

At the first meeting, I heard a monumental talk by Dr. Diana Bianchi of Tufts Medical Center in Boston. Her talk, entitled "Prenatal Presentation of Genetic Conditions: Insights from the Amniotic Fluid Supernatant Transcriptome", is likely the most significant work regarding trisomy that I have heard in years. Dr Bianchi showed that each chromosomal condition (trisomy 21, trisomy 18, and trisomy 13) has its very own “unique but consistent pattern” of gene expression (the process whereby genes are turned on to make proteins or turned off to shut down protein-making); she calls this pattern, the transcriptome. Knowledge of these syndrome-specific patterns could ideally lead to the development of prenatal treatment for chromosomal conditions. Her laboratory had already created a mouse model and demonstrated some benefit to mice with the mouse equivalent of human trisomy 21/Down syndrome (trisomy 16). When the mice were treated in early prenatal development by turning down genes involved in “oxidative stress”, the adult mice treated prenatally did better than untreated mice with trisomy 16 on tests of learning. Dr Bianchi also showed that the fluid cells of fetuses with trisomy 13 and trisomy 18 had their own particular “transcriptome.”
These findings raise the point that someone in the scientific world of animal models needs to develop a model for trisomy 13 and for trisomy 18.

I will admit that in 40 years of thinking about the science of trisomy, I have never seen an opportunity for potential prenatal treatment like this. I could not have imagined designing such a study or thinking it was possible even 10 years ago. If you want to read more about the transcriptome, see Dr. Bianchi’s article in the September issue of the *American Journal of Medical Genetics*: Guedj F, Pennings JLA, et al. 2015. The Fetal Brain Transcriptome and Neonatal Behavioral Phenotype in the Ts1Cje Mouse Model of Down Syndrome. American Journal of Medical Genetics 167A:1993-2008.

The second presentation was a poster displayed at the American Society of Human Genetics in October of this year. Dr. Nishi and her mentor, Dr. Tomoki Kosho (a name well known to the readership of *SOFT TIMES*), performed a study quite similar to the one they published in 2006 with trisomy 18 newborns. Like in the previous investigation, the authors offered full intensive care treatment to 24 families of newborns with trisomy 13 who were admitted to Nagano Children's Hospital. With their approach, 24 infants with trisomy 13 were administered mechanical ventilation and other modalities, including tracheostomy, when needed. Thirty eight percent of the infants were discharged home and 1-year survival was 46%, remarkably increased over any other investigation of outcome in trisomy 13. Median survival was 335 days where in most other studies, it is about 10 days. While the sample size is small, this study demonstrates "longer survival in patients with trisomy 13 having pediatric intensive management than in the cohorts described in previous population-based studies." This analysis again addresses the question of outcome in infants with trisomy syndromes when a more interventionist approach than what is traditional is taken. We look forward to the submission and publication of this novel work.

For more medical related articles go to [www.trisomy.org](http://www.trisomy.org).
Look under the Professional and Publications headings for these featured items: *Cardiac Surgery, Ethics, and Management, Professional Viewpoint—Journal Club, Surgery Tables and Growth Charts, Care of the Infant or Child with Trisomy 18 or Trisomy 13 (e-book)*, and other helpful materials.
November is Adoption Awareness Month!

Waiting for Sabella: An Adoption Story by Grant Recipient Sheryl Crosier

I have been a Christian since childhood, but nothing would test my faith more than losing seven children to miscarriage and our son after his short visit on earth. I prayed that if I did get pregnant, the Lord would allow me to hold our baby in my arms. The Lord answered my prayer on September 7, 2010 when I was able to hold Simon in my arms for 88.5 days until he went to his eternal home at 10:45 a.m. on Friday, December 3, 2010. The Lord used Simon to teach me how to live in the moment, patience, compassion and most importantly, unconditional love.

Simon was diagnosed with Trisomy 18, otherwise known as Edward’s Syndrome on his 3rd day of life. Simon had three of the number 18 chromosome which causes heart defects, bilateral cleft lip and other medical complications. The doctors were quick to say that Trisomy 18 means “incompatible with life.” Even before the “label” during the pregnancy, because of Simon’s cleft lip, medical professionals encouraged termination. Even though we changed hospitals, things didn’t change. We tried to explain the value of our child, but our words fell on deaf ears. We believe that all children, regardless of their “label,” possess inherent dignity and value. Simon was not incompatible with life. He was alive and living. I realized that God did not bless us with a syndrome; He blessed us with a son.

I started to feel a strong indescribable love for special needs children, because of Simon. I know the Lord gave me this love. I knew that children were not defects or disposable; they are created by our Maker. Sharing Simon’s story is the ministry that the Lord granted me and Simon continues to impact people all over the world. Hearts are being changed and many have come to Christ and have been awakened spiritually because of our son. I learned very quickly that God does not want us to keep our testimony to ourselves!

As a Christian, I am called to spread the good news of the gospel. “Whoever does not bear his own cross and come after me, cannot be my disciple,” Luke 14:27. It is because of my faith and hope in Christ Jesus, that I can rest in Him. It is clear to me that all things work together for those that love Him. Our story is part of His plan.

It was a few years after we lost our son Simon, that the Holy Spirit kept nudging us to adopt. In late 2012, we began the paperwork for international adoption of a waiting child. We wanted to help a child with special needs. God led us to China. We believe our Simon also found his sister who had been waiting for years in an orphanage, and the Lord used our friend, Maggie Weik, as a vessel to introduce us to our daughter. This moment was so special. When we saw the picture of her in April 2013, we knew that she was our daughter. We also were humbled to discover that while I was pregnant with Simon in January 2010, our daughter was born, abandoned in a village and then moved to an orphanage.

In July 2013, at a Trisomy conference in Rhode Island, we named our daughter Sabella. Her name, which means “consecrated by God,” kept popping up everywhere and we were sure it was a sign from Simon in heaven. Throughout our adoption journey, both my husband and I learned patience and allowed the Lord to comfort us when we were anxious. God gave us a peace and wisdom, and we realized that this was our “pregnancy on paper.” We knew that we wouldn’t get our daughter over-
night, so we prayed for Sabella and asked Jesus to keep her safe until we got there. While we were waiting for Sabella, the was our “pregnancy on paper.” We knew that we wouldn’t get our daughter overnight, so we prayed for Sabella and asked Jesus to keep her safe until we got there. While we were waiting for Sabella, the Lord placed many compassionate people in our path: those who had lost a child and those that had adopted a child. Maggie Weik and her husband had already adopted nine girls from China. We were learning that love truly crosses oceans.

The journey was long and arduous, but after record snowfalls, school closings, travel delays and language barriers, we were finally able to hold Sabella in our arms at the Taiyuan Civil Affairs Office on February 10, 2014. Our daughter wobbled into the room after a seven hour train ride from her orphanage, turned towards us and walked into our arms. Our guide introduced us as Mama and Papa. We could hardly believe our eyes. She was absolutely beautiful and so small. Our daughter who we had been waiting for was finally with us, four years old, 34 inches tall and only 23 pounds. We couldn’t wait to love and nurture her.

While in China, we witnessed something that will forever be disturbing. Sabella was absolutely starving. I am sure she never knew what the feeling of “full” was in her life. For several days, Sabella ate more than my husband and I combined. We could not believe our eyes! We were reaffirmed over and over why the Lord sent us our daughter. We were helping our daughter, previously an orphan, feeding the hungry and clothing the naked. We would have taken ten children with us. No child should go hungry. I couldn’t stop thinking of little Sabella so hungry and in need of a family...our family. Scripture is clear that we are called to care for the orphans and we know that God has his hand in our adoption journey. We are teaching Sabella about Jesus and this is an absolutely beautiful experience. My daily prayer is that our daughter will feel God’s love through our family. We were learning that God granted Sabella to us to look after and for that alone we are forever blessed.

Sabella has brought so much joy to our family. We know that if it wasn’t for Simon, we wouldn’t have Sabella. We most likely would have never considered adoption. Sabella has taught us to stop and take in the moment that God gives us. Everything is a first to her. We are so appreciative that we have food, shelter and freedom and can share this with her. We are not the same people we were before Sabella. Our hearts continue to be molded by Christ. Yes, our story is part of God’s plan and all children possess inherent dignity and value regardless of their diagnosis or label. Our daughter deserves medical care and an opportunity to thrive. Sabella was from the poorest region in China and became another vulnerable child that was abandoned at birth. Yet, I am forever grateful that she was given life. She has so much value. I love how the Lord led us to her country and gifted us with a beautiful daughter.

We are honored and humbled by the generosity of the Archbishop Robert J. Carlson Adoption Fund and their donors. The adoption assistance grant was an absolute blessing to our family. We are so thankful and continue to pray that this adoption fund may be of assistance to other families like ours, who at times struggle on a single income. May the Holy Spirit stir in more hearts every day that more families can be blessed by the miracle of adoption.

In Christ, Sheryl Crosier

Picture provided by Sheryl Crosier

Adoption Fund Awards Grants Annually To Couples Seeking Adoption

Since its inception in 2010, the Archbishop Robert J. Carlson Adoption Fund has awarded grants to 14 families over six years, for a total of more than $55,000 directly supporting the gift of adoption. Applications are due in the fall of each year for the following year’s grants. If you know someone who would benefit from a grant, or you would like to donate to this fund, you can find more information throughout this site or call the Office of Natural Family Planning at 314-997-7675 to speak with a representative.
Who Inspires You?

I have been Kammie Wolpert’s live-in caregiver and “Community Connector” for seven years. I already had a passion for and experience working with people with special needs, as well as having a father who was severely disabled by a stroke, before moving to Colorado and seeing the Craigslist ad for being Kam's caregiver. I hang with her outside of school. We’re often doing different activities in the community like going to the Farmers' Market, our downtown walking mall, concerts, festivals, summer camps, movies, sports games, etc. In the community, I facilitate Kammie’s communication with other people as well as working on her communication goals with her. She’s shown a marked improvement in how often she nods her head for yes or shakes her head for no in response to questions. We work on making choices between two things with this also. She’s also gotten much better at "saying" hello to people she doesn’t know, by making eye contact & smiling, & sometimes reaching her hand out. Her improvement in reaching her communication goals is just one of the many ways Kammie inspires me.

Kammie inspires me also by how present in every moment she is - she’s not caught up in anxiety about what might happen in the future or bogged down by what happened in the past. She takes each moment as it comes and reacts genuinely to it -- she doesn’t care about social pressure to be a certain way. If she likes something, she shows it - smiles, laughs, dances - and if she doesn’t, she shows she’s bored or mad, but then let’s it go as soon as it’s passed. She doesn’t get stuck in complaining about something didn’t go the way she wanted it to, she just rolls on with the next moment. There are some peers at school that are going through rough things in their home life, & they gravitate toward Kammie because she’s so present, genuine, and non-judgmental. Kam has also inspired many people through her Trisomy story of beating the odds. It gives you hope and puts things in perspective.

It’s been a joy to work with Kammie and share her life with others, hopefully spreading some of the inspiration too!

-Kristi Plucker
Inclusion Through Social Media

"That picture of Kammie with the Chippendale's guy was so awesome! We were all talking about it at school the next day!" one of Kammie's friends told me at the soccer game last night, five months after posting that picture of her in Las Vegas. Kammie has her own Instagram (kambamt18) and Facebook (Kammie Wolpert) accounts, and moments like these illustrate why she does. Kammie is 18 years old and is doing a super senior year in high school. We promote social inclusion and try to do many things that are age-appropriate. Being able to interact with Kammie's peers on Facebook has been super helpful for increasing her social life with peers outside of school. She was in StuCo (Student Council) the past three years, and FB was the only way I knew what was going on! Especially because Kammie is nonverbal, her IG and FB accounts give her a way to share her out-of-school adventures with her peers. It provides something for them to talk with her about. It is my hope that it also is a way for people to see a person with special needs enjoying an awesome life and realize that she doesn’t need to be pitied, and perhaps isn’t so different from typical people after all. Also, I want to show people what someone with full Trisomy 18 is capable of!

-Kristi Plucker