2014 SOFT Conference:
July 9-13, Norfolk, Virginia
We all say in SOFT, “there are NO coincidences” and I have reason to believe this to still be true!

Kari lived beautifully for 10 ½ yrs. Much to our sadness, Kari died on June 3, 1988. Every year on the anniversary of this date, I buy a silk rose and place it in a large vase. Now, after 26 years, I have a big beautiful bouquet of roses, which warms my heart. On the anniversary date of Kari’s death, I don’t expect everyone to remember it as Hal and I do. But, when someone does, I am always delighted to know that Kari is remembered.

Tricia is two years older than Kari. They were truly the most adorable little girls and I loved having their portraits taken. Tricia was a sweet older sister and she adored Kari. She never seemed to notice anything was different with her little sister.

Tricia, lives with her husband, Ryan, and three delightful children in Springfield, Virginia. On the morning of June 3, 2010, I received a call from Tricia. I smiled at the thought that she remembered that this was the 22nd anniversary of Kari’s death.

Tricia was and still is a committed runner and bike rider. Near their home there was a beautiful bike and running trail along a small river. The scenery was beautiful and inspiring. Tricia told me about her morning bike ride and she was very excited to share a special story for this special day.

Tricia said she was just returning from a bike ride with her daughter, Ella, who was riding in the back seat. Ahead of her was a young woman running on the same trail. She glanced at the back of the runner’s t-shirt, but was only able to see a large numbers 1 and 8 and above the numbers were the letters, “Tri_omy”! Okay, she thought, “That is way too close to be anything except ‘Trisomy 18’!” She said she peddled harder and finally caught up to the young woman. She tried not to look like a stalker or scary biker-lady, so she carefully came along side and made an attempt to talk to her. The young woman saw Tricia and finally stopped. Tricia asked her what was printed on her t-shirt, and the young woman answered, “Trisomy 18”. Ahh-haa...she thought so! The young woman
then explained that her older sister has Trisomy 18. With delight, Tricia asked her how old her sister was. And the young woman’s reply, “She is still alive and she is 34 yrs. old.” Tricia then explained how absolutely wonderful and that she, too, had a sister born with Trisomy 18 who lived to be 10 years old.

The biker and the runner visited a while longer. When they finally said goodbye, Tricia turned and with tears in her eyes said, “Please give your sister a hug for me.......because you can!” They looked at each other with eyes and hearts of understanding and nodded their goodbyes.

As Tricia related this story, I was SOFTly reminded again ....

there are NO coincidences when it comes to SOFT!
President’s Corner by Barb VanHerreweghe

Dear SOFT families:

I was hoping to wish you a happy Spring but here in New York as in many other parts of the US it has been a challenging winter and Spring. The snow has come over and over this winter till all we can say is enough already. Today was no different, yesterday was over 70 today there were snowflakes fluttering to the ground and certainly not over 70 degrees. This year seems to be very much like many of our lives as we face the challenges of the journey with a child who has a Trisomy condition. It can feel like the snow is piling up and will never be over. Hopefully, in sharing this journey with others you will feel like the winter is ending and we may finally feel the warmth of the summer breezes.

The month of March proved to be a month of adventure, excitement and memories of the children we cherish who are alive and those that have received their angel wings too early. SOFT facebook challenged many to help with the awareness in the community and to post and complete activities. The players were committed and accomplished challenges put before them each day. The final day was the day they were waiting for. The Grand Prize for that day went to Kari Brockman Adamson who won one free registration for the 2014 conference in Virginia. Thanks to Therese and Terre for planning the activities for the month. Thanks goes to Terre for making all the wonderful ribbon pictures for all the families that requested them. What a perfect way to keep the awareness going with many of the people still using them on facebook for their profile pictures. So many people shared pictures daily of their kids and it was great to see the kids being kids in many activities they participate as well as seeing the pictures of the many angels who we know are watching over all of us. It was a great month and it is already time to start planning for next year. We will need many more volunteers to help pull it all together. If you are interested and have special talents in creating pics or just willing to help and be willing to learn, contact us so we can put you on our list. Barbsoft@rochester.rr.com

We also want to thank the Barnes’ for keeping all the activities on the website and for daily keeping our website fresh and new. They also keep us informed with the email blasts of what is happening.

It is that time of year, conference is quickly approaching. Time to get your hotel room, there are only a limited number of rooms left so get yours signed up now. A few years ago we had to have a waiting list and we were not able to get everyone into the hotel we were at. Don’t be left out sign up now. Registrations for the conference are due in June, make sure you sign up and get yours in before the deadline. You can also sign up for a balloon release. You do not have to be at the conference for us to release a balloon for your angel. Go to the SOFT website now and sign up or link to the hotel and registration information. www.trisomy.org and go to 2014 conference. Hope to see you all there.

Mark, Faye and Morghan Kubena-Kaufman attended the American College of Medical Genetics meeting representing SOFT this year in Tennessee. They were able to offer info about SOFT and share the SOFT website with Doctors and Genetic Counselors. They passed out the Care book to many in attendance and we will be sending many more to the participants requesting them in the mail. We are excited that these books are in the hands of those who may be diagnosing kids in the future and we hope they will learn from the book the needs of our kids and their families. There is a rainbow after the storm.

We hope you are enjoying the newsletter on the website and (Continued on page 5)
President’s Corner

(Continued from page 4)

we are looking to continue this feature. We are looking for you and your family to share things happening with your kids in the community. Send in those baseball games, prom pictures and special birthday celebrations. We want to share your story of your child who passed away. How did they change your life? Did your other children write something about their sibling we can share? Get the stories in. we want to share them with everyone. Do you have other ideas for the newsletter? Let us know. From our house to yours may you experience good health for all. See you in Virginia.

Love, the VanHerreweghes Barb, Dave, Stacy (Full T-18 33 yrs. Old) and Andy

New book Recommendation by Ann Barnes

Available on Amazon but expensive at $25.20 hardcover and 14.99 kindle. I suggest readers put it on reserve at their library! This is not a book specific to trisomy 18 or 13 but does briefly mention trisomy 21. Rather, it is about our basic biology and the possibilities brought about by genetic science.

**Inheritance** by Sharon Moalem, MD, PhD, 2014

This fascinating book is a must read for anyone interested in genetics. Dr Moalem, physician and researcher, teaches by introducing a number of his patients with rare genetic conditions, and by descriptive tidbits about art, history and more. Defining how the future of personalized medicine is in our genes, he explains that the new fields of pharmacogenetics, nutrigenomics and epigenomics are a means to treat and transform the genes we inherit and endow. Rightfully, he credits persons with rare genetic conditions, the families that advocate, and the answers sometimes discovered through research, as benefitting the common good of all mankind.

SOFT 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.

The Trisomy 13 Handbook (and other documents) has been available in Spanish for some time and we have just completed translating the Trisomy 18 Handbook, which will be posted to the website within a week.

The Thompson’s are retiring as editors. New editors for The SOFT Times will be preparing the next issue after the conference. Watch for the announcement after the board meeting.

The SOFT Times is published by SOFT, Inc. Editors for the 2013-2014 fiscal year: Margaret & Jim Thompson 1232 Seminole Drive Richardson, TX 75080 jmgthompson@att.net 972-234-8788 Please submit all stories, pictures, info, etc. to the above address. If you wish to have items returned, please include a self addressed, stamped envelope.

Though you lose all hope, there is still hope, and it loves to surprise. ~Robert Brault

May/June/July 2014, The SOFT Times, Page 5
Hope is the only bee that makes honey without flowers. ~Robert Ingersoll
If you have love, you will do all things well.-Thomas Merton

Happy Birthday

34 Years Old!
Ms. Megan Elizabeth Hayes

34 Years Old!
Ms. Greta Rose Thompson
PROFESSIONAL VIEWPOINT: Journal Club

By: John C. Carey, MD, MPH, Medical Advisor, SOFT


This important paper by two intensive care specialists (one in neonatology and the other in pediatric care) working at the College of Physicians and Surgeons, Columbia University, supports the recent contention that there is an emerging dialogue in the medical literature regarding the care and treatment of infants with trisomy 18 and 13. While this review article focuses on trisomy 18, I would suggest that all the principles and recommendations that they present in the paper apply to the management of infants with trisomy 13 as well.

The piece is a comprehensive and relevant review of the literature on what is currently known about management and outcome in infants with trisomy 18. In particular Table 3 in the paper summarizes the existing information on the published case series of infants and children with trisomy 18 who have undergone surgery for congenital heart defects. The other tables provide an overview of population-based survival rates and of developmental achievements of children with the syndrome (from the 1994 paper by Bonnie Baty and coauthors, who obtained their data in collaboration with SOFT families).

There are a number of important points in his paper. One section highlights various findings that have been included in the Surgery Registry of SOFT (created and maintained by Ann Barnes). The authors state that some "sense of the interventions employed in the care of children with trisomy 18 in the United States and Canada can be gleaned" from the Registry.

Another feature of the paper are the Key Points composed by the authors. Their third point is particularly noteworthy: "Survivors are severely developmentally delayed, but routinely achieve cognitive and motor milestones; they are described as happy by parents and commonly enrich the lives of their families." Drs. Lorenz and Hardart extrapolate this point primarily from the social network survey paper by Annie Janvier, Barbara Farlow and Benjamin Wilfond that was published in *Pediatrics* in 2012. The authors include a detailed commentary of the Janvier paper within their References list (a nice feature of the journal which requests these comments on selected "Papers of particular interest").

The other notable highlight in this paper is that the authors present an approach to "formulating management plans" in the care of children with trisomy 18. The authors indicate that terms such as "lethal…terminal state…hopeless"… "are value-laden and inaccurate". Lorenz and Hardart outline a process for care that recommends defining the goals of management: "Goals should be developed jointly by informed parents and the physician." The authors proceed through a series of steps that I agree represent a workable approach in the care scenario. In their final paragraph they assert, "Effective strategies will begin with a shared decision-making model featuring bidirectional communication of medical facts and family values."

I think this paper is a timely and important work that adds balance to the ongoing discourse on management of infants with trisomy 18.
2014 Conference Planning Committee Report

The SOFT Conference Committee Norfolk 2014 is exciting about seeing everyone in Norfolk, Virginia July 9th-13th. We are hoping for beautiful weather as we will be “Rollin on the River” that is the Elizabeth River which is at the back of the Sheraton Norfolk Waterside, our hotel for the conference. Based on room reservations (6 weeks from the deadline for our group room rate) we have about 50 families who have booked their rooms so far.

Our SOFT Board of Directors will meet all day Wednesday and be ready for the Welcome Reception that starts Wednesday night to kick-off our conference. This is a meet and greet social event with heavy hors d’oeuvres and a cash bar. It is so nice to get together and see our other SOFT family members that we usually only see once yearly and also to meet new family that share in our journey.

The Stroll for Hope in memory of Jonathan Cook is Thursday morning. This is a fundraiser for SOFT and the conference. The Stroll for Hope will be held on the boardwalk behind the hotel. Please set up your fundraising page for your child at First Giving. There are prices for those raising the most donations for this event. So far we have 5 fundraisers signed up. Here is the link to set up your fundraising page [http://www.firstgiving.com/softstrollforhope/VA2014](http://www.firstgiving.com/softstrollforhope/VA2014)

The family night outing ballgame on Friday night will include a catered dinner at the backfield. Spend a baseball evening with the Norfolk Tides, as they play Atlanta’s Gwinnette Braves, at Harbor Park Stadium, within walking distance of the hotel. The outing cost includes dinner (5:30-7:00 pm) and admission (game starts at 7:05), and is $17 for age 12+ and $15 for children; SOFT kids are free. The stadium is about a half-mile walk East from the hotel, or take the TIDE Light Rail to the stadium.

Other opportunities on your own are the local upscale mall—MacArthur Mall which is walking distance from the hotel. This mall contains Nordstrom’s, Macy’s, Eddie Bauer store, movie theaters, food court to just mention a few. Also Nauticus, which is where the Battleship Wisconsin is parked, is walking distance from the hotel just down the boardwalk. This is an interactive museum with displays that teach about US Navy history and includes a tour of the battleship.

Don’t forget to bring items for the SOFT Auction on Saturday night. If you need to mail something ahead of your arrival for the auction you can mail it to Lynne Stockman, 5753 Bennett’s Pasture Rd., Suffolk, VA 23435. Popular items for the auction are personally hand crafted/painted, have a hometown/state or country flare, wine, jewelry to just mention a few. This is a lively event with both a silent and live auction.

The deadline to register for the conference is June 1st. The conference committee will have a lot to do after registration closes to get ready for your arrival. Shirts and bags will need to be ordered, head counts for food and event venues, and medical clinic coordination will all be done after the registration deadline. See you soon!

Submitted by Lynne Stockman

Hope is the word which God has written on the brow of every man. ~Victor Hugo
On April 18th 2014, Ashton Troi Wagner participated in the first annual Miss Hartvigsen Spirit Pageant. She was one of six contestants in her contained Special Education School in Salt Lake City, Utah. Each contestant was accompanied by a volunteer mentor to help the students on their very special day. The mentors were local pageant ladies who held various titles within the state, county, an city. The ladies were very professional, friendly, and kind. The pageant followed basic tradition with an introduction and meeting of the contestants, a modified physical fitness routine (Ashton rode around in a therapy tricycle), talent show (Ashton played the piano), evening gown, Q & A (Ashton was allowed to use a button communication device), and a final reintroduction of contestants where the mentors told the audience what they admired most about their student. In between each event a video was shown of the girls at home, at school, and/or on vacation doing their favorite things set to music (Ashton's theme was Katy Perry's Roar.) The judges included: Miss Utah United States 2013, Miss Hispanidad Utah 2013, Ms. Wheelchair Utah 2014, and one of Hartvigsen’s veteran physical therapist. Three honorary awards were given: Miss Diva, Miss, and Miss Congeniality (which our Ashton won.) The honor of 2nd runner up, 1st runner up, and Miss Hartvigsen Spirit were given to three older classmates. Each girl received a single rose, a tiara, and a printed award. It was a great day for all of the girls. The applause was loud, there may have been a few tears, and everyone was truly a winner that day! The pageant was spearheaded by a young teacher in the Physical Education Dept. who competes in local pageants associated with Miss America for scholarships. She called in several favors from her friends, fellow contestants, teachers, neighbors, etc to make this occasion happen. For everyone involved it was an awesome learning experience, and the proud show of school spirit. We can’t wait to participate next year! I am sending a few pictures of Ashton enjoying her day.

Raquel Wagner
SOFT Chapter Chair
Salt Lake City, Utah

The birds of hope are everywhere, listen to them sing. ~Terri Guillemets
Friendship is born at that moment when one person says to another: “What! You, too? Thought I was the only one” - C.S. Lewis

Miss Congeniality: Ashton Troi Wagner

I was Caught Being CUTE!

MOMS ROCK

Emerson Garst is having fun swimming with mom.

Greta, Margaret & Ashley at the ballet
Once you choose hope, anything’s possible. –Christopher Reeve

Greta Thompson Earns Gold and Silver at the Texas Special Olympics State Equestrian Games, takes 2nd and 3rd at Spring Horse Show
If we are to live together in peace, we must come to know each other better. - Lyndon Johnson

Happy Trails, Yellow Rose of Texas and Deep in the Heart of Texas was the theme for Greta Rose Thompson’s Pas de Deux at the State Games

Each May, Team Greta and Nick perform a pas de deux, in costume and to music. The theme was a hit and they each earned another gold medal for their collection!
Thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you

**SOFT Sincerely Appreciates Your Generosity, And We Recognize The Love That These Donations Represent**

<table>
<thead>
<tr>
<th>Donations to SOFT's General Funds</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Joseph Hetzel and</td>
<td>In Memory of Regan Adeline Lawson</td>
</tr>
<tr>
<td>BP Matching Fund Program</td>
<td>Joseph and Laurie Hetzel</td>
</tr>
<tr>
<td>Stephanie Barclay</td>
<td>In Memory of Nicholas Wright</td>
</tr>
<tr>
<td>Martin Laird</td>
<td>Karen Breckley</td>
</tr>
<tr>
<td>Musaab Bingaradi</td>
<td>Shannon MacMaster</td>
</tr>
<tr>
<td>Chris and Shari Laster</td>
<td></td>
</tr>
<tr>
<td>Scott Lindenbaum</td>
<td>In Memory of Addison Quinn Russell</td>
</tr>
<tr>
<td>Derek Brown</td>
<td>Jessica Green</td>
</tr>
<tr>
<td>Lisabeth Olver, Community Fund</td>
<td>Mary Ellen Wardell</td>
</tr>
<tr>
<td>of Boeing Company</td>
<td>“Bebowed by Jenna”</td>
</tr>
<tr>
<td>Joseph Cannizzo, United Health Group</td>
<td>In Memory of Zoe Karmis</td>
</tr>
<tr>
<td>Campaign</td>
<td>Christos and Anna Karmis</td>
</tr>
<tr>
<td>ThereseAnn Siegle</td>
<td>In Memory of Rowan M. Sibthorp</td>
</tr>
<tr>
<td>Kari Anderson</td>
<td>Courtney Huber</td>
</tr>
<tr>
<td>Scott Crosier and Peabody Matching Gifts/Dollars for Doers Program</td>
<td>In Memory of Glennon Lamprecht, grandfather of Jason Seilnacht</td>
</tr>
<tr>
<td>Kris Holladay</td>
<td>Jim Lamprecht</td>
</tr>
<tr>
<td>Terre Krotzer</td>
<td>Albert Lamprecht</td>
</tr>
<tr>
<td></td>
<td>Charles Seilnacht</td>
</tr>
<tr>
<td></td>
<td>The Morton Family (Robert and LaVerne)</td>
</tr>
<tr>
<td></td>
<td>Fran and Wanda Ruzicka</td>
</tr>
<tr>
<td></td>
<td>Ed and Kathy Gapsch</td>
</tr>
<tr>
<td></td>
<td>Bowles Elementary Social Committee</td>
</tr>
<tr>
<td></td>
<td>Carolyn Meyer</td>
</tr>
<tr>
<td></td>
<td>John and Gloria Norquist</td>
</tr>
<tr>
<td></td>
<td>Lori and Tom Courtney</td>
</tr>
<tr>
<td></td>
<td>Rose Mary Scheman</td>
</tr>
<tr>
<td></td>
<td>Marc and Sandy Silvey</td>
</tr>
<tr>
<td></td>
<td>Nancy and Jay Yedlin</td>
</tr>
<tr>
<td></td>
<td>Wes, Sharon and Megan Palmer</td>
</tr>
<tr>
<td></td>
<td>Lu Beczkala</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In Memory of
Isabella Carolyn Powell
The Powell Family

In Memory of
Patrick Brady and
In Honor of
“Mamma Suzie and Her Valentine”
Eileen LaHaye

In Memory of
Nicolas Victor Moustirats
Stephanie Barclay

In Honor of
Devon Victor
Donna Stewart
Thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you

**SOFT Sincerely Appreciates Your Generosity, And We Recognize The Love That These Donations Represent**

Pat Miller  
Robin and Jeff Hilse  
Brian Miller  
Kevin Miller  
Michael and Diane Siebert  
Gerry and Mary D'Angelo  
Karen Handy  
Jane Pfuhl  
Fred and Judy Searcy  
Mary J. Fischer  
John and Terry Bowles  
Patricia Barner  
Joann and Bob Ebert  
Patricia Barnes  
Bonnie and Stanley Wagner  
Danny and Jane Morton  
Jason and Kathy Lenz  
Mr. and Mrs. Alfred Rathert  
Sharon Ahillen  
Kenneth M. Anverdee  
Liz Kehoe  
Kathryn Sonderman  
David and Nancy Barker  
Al and Charlotte Schepers  
Karin Cason  
Tina Lohmann  
Sara Grieshaber  
Ruth and Mel Eslinger

In Memory of

Nicole (Nikki) Jennifer Waege  
Elise Vik

In Memory of

Alexander “The Great”  
Wyatt Flores  
Samantha Harris and the EPMO team  
Mary Laureno  
Julie McBee  
Jason and Michelle Stele  
Kim Payne

In Honor of

Leilani Megget  
Teresa Babers

In Honor of

Stacy VanHerreweghe and  
In Recognition of

Trisomy Awareness Month  
Lakeaya Hartzog

In Memory of

Annabelle Lynn Bordelon  
Cassie and Cody Putnam

In Memory of

Marc Logan  
Jamie Emmert

In Memory of

Daniel Raymond Wickman  
Breana Ledsma
For the past year those hurt in the Boston Marathon bombings have been in the news. We have heard their stories, watched their recovery and admired their positive attitudes and determination. Over 200 were injured, some badly. We watched as one by one they were released from Spaulding Rehabilitation Hospital, months after losing legs. We read of bonds built, friendships forged in the aftermath and a community of survivors that moved forward, changed but not defeated. They were inspired to make the most of a life unimagined last spring, and they were inspiring to so many. They faced disability, but they redefined it. The dancer who lost a leg, the athletes who lost a leg, the ordinary people who had their lives stopped for months to recover then learn to move in a new way, all redefined disability. This helps change attitudes toward disability to all who have challenges.

A few days before the 118th running of Boston, there was a poignant ceremony to remember the four young people lost so senselessly and to hear from those injured, willing to share about their own journey. The idea was we would focus on the loss, then celebrate the runners on Monday. Fittingly, it rained, but spirit shone through.

There was a perfect day for the marathon, a cool start and comfortable finish. There was a sea of runners. Those who did not finish last year were given a bib, more charity runners were there, including teams running in memory of those who died a year ago, and there was a good field of elite runners, along with those who met qualifying times in other marathons. There was high security and a route lined with cheering spectators.

The winners made their mark in more ways than winning. For the first time in thirty-one years an American male won, Meb Keflezighi. The fastest woman was three time winner, Kenyan, Rita Jeptoo who set a course record. The male wheelchair winner South African Ernst Van Dyk was the first in any category to garner ten first place finishes in Boston. The female wheelchair winner was Tatyana McFadden, whose own story reflects the spirit that has encompassed this year’s event. Her story speaks to the possibilities when there once seemed to be none.

Born with spina bifida, with necessary surgery delayed, Tatayana spent six years in a Russian orphanage with few medical or educational resources. When she was six, in 1994, the commissioner of disabilities for the US Health Department on a mission for the White House visited the St. Petersburg orphanage and saw a spirited young girl getting about by walking on her hands. Tatyana had been waiting for her mother to enter her life; her mother was going about her business with no intentions of adopting. However, unable to get Tatyana out of her mind, Deborah McFadden began adoption procedures and brought Tatyana home in May, 1995. She was amazed by a little girl whose favorite phrase in Russian was that she could do it herself.

Efforts to build Tatyana’s strength led to an interest then a passion for sports. Despite her disability, she was a gifted athlete. The determination that helped her survive served her well in training. Last year, in her first attempt in Boston she won. She also distinguished herself as the first competitor in any category to win four marathons in a single year, adding London, Chicago and New York to her debut Boston run. She not only defended her title and won but set a course record in London a week before Boston this year. More amazing is that a month ago she won a silver in at the Sochi Paralympics in cross country skiing. She celebrated her 25th birthday by winning Boston again.

For the Boston Marathon McFadden wore a singlet memorializing Martin Richard, the eight year old who died in the bombing. His six year old sister, 

(Continued on page 17)
Strength of Spirit

(Continued from page 16)

Jane, had her left leg amputated, now wears a prosthesis and is playing basketball. A few days earlier about a mile from the finish line, she joined two brothers, each an amputee from bombing injuries, as they completed their rainy all day walk of the marathon route.

So many have demonstrated the spirit of determination and confidence, despite what could be discouraging and limiting. It is this spirit that must be celebrated, just as we in SOFT celebrate all that our children and their families do. Each of us at some point felt overwhelmed or disappointed or shocked, but we shook that off. Each of us started an unexpected journey and found the spirit that keeps us going and somehow makes sense of what at first seemed so impossible. We found each other along the way and learned, laughed and celebrated. Watching the coverage, I felt both the strength of spirit and the strength of community. We have both in SOFT. Does that make us SOFT STRONG?

Get ready for “Rollin’ on the River”… the Elizabeth River, that is.

International Committee Report

We have been continuing to get international members, most recently from Australia, New Zealand, Northern Ireland, Seychelles, Turkey, England, English family in Poland, Scotland and Canada, as well as renewals from families in England and Canada. Diagnoses of the children have included full trisomy 13 and full trisomy 18, as well as mosaic T-18, partial T-13 and tetrasomy 13q. Some of the children have the same birthdate and death date or lived days or weeks. One child lived a few weeks nearly three decades ago; another lived a day twenty years ago; another who has just one date is remembered seven years later. We share the need to keep our children in our hearts and lives, even when they were with us briefly. They remain important in our families across cultures and time. One child was born this winter; another in the fall. We hope for the best for them and their families. One with partial trisomy 13 just turned 31, joining the growing ranks of those in the fourth decade of life.

We welcome new members, remember their children and celebrate new births and birthdays. We are digitally connected, shrinking our world and joining those who have had found blessings despite disappointment. We all said good-bye to an imagined child and upon diagnosis welcomed and loved an unexpected child who made an important difference in our lives. I would like emails and pictures from international members, for the next article. Contact me at healeylex@aol.com.

Hope is patience with the lamp lit. ~Tertullian
The Sound and The Fury

by William Faulkner

I recently reread Faulkner’s masterpiece, *The Sound and the Fury*, written 85 years ago, and often assigned in American literature classes. I focused on how Faulkner uses stream of consciousness to tell the story of a deteriorating Southern family. Each of the three sons contributes a story that patches together three decades of a once prosperous family, whose members repeatedly fail to do what must be done to save land and name. There are four Compson children, but there is only one child in the next generation, and she, like the mother that abandoned her, takes off to find something better. There is nothing left but a story to be pieced together around the sister who left. It is a story of loss, but it is also a story of acknowledgment and love.

The book opens with Benjy’s chapter, and Benjy gives snippets about a dozen episodes in his life jumping from one to another, then back, the time only deduced by who cares for Benjy during the events he reports. Benjy builds a story from pieces of memories, stacked haphazardly and clumsily like blocks that become a structure that lacks recognizable form but reveals truth. Benjy tells what he remembers, unfiltered, untarnished by self interest and unencumbered by agenda or cultural constraints. He interprets nothing; he just recounts what he has seen, heard, tasted and felt.

Benjy, the youngest of four Compson children, was born just before the turn of the twentieth century. At the story’s three day recounting during Easter weekend, 1929, Benjy is a thirty-three year old man who has been a three year old most of his life. He bellows and makes undistinguishable sounds, but he does not speak. He walks ploddingly around the rural property, watched by servants, accompanies his siblings on their adventures, but well into childhood he prefers to be carried, usually by his sister, Caddy, five years his senior. Benjy’s tale is of his sister who sees beyond his limitations, who sees ability when everyone else is annoyed, inconvenienced and embarrassed by his disabilities. She is the only family member willing to accommodate his simple wish and carry him physically and metaphorically. She explains for him, sleeps with him, comforts him and defends him. She is more a mother to him than their mother, taken to bed with a hot water bottle and a Bible is to any of her children. When his mother, aware of his limitations, changes his name from Maury, a family name, to Benjy, Caddy sometimes calls him Maury to retain that identity. Ironically, Uncle Maury, who without conscience uses others to make his life easier or more pleasurable, is never the person Benjy is. Benjy is admirable both by comparison with more capable characters and simply by being the person he is.

Faulkner gives Caddy no chapter in his book, and she is brought to life best by her sibling who no one else understands. Benjy understands and appreciates her, loves her and makes her the force she is in the novel. Faulkner adored her, called her “his heart’s darling.” She is the sister he never had; she is the daughter he lost in infancy. Caddy is best presented by the brother who loves her unconditionally, warns but does not judge her, misses but does not blame her. Faulkner writes a timeless story of a special sibling relationship that transcends the declining southern aristocracy, the early twentieth century.
century and the missteps and tragedies of one family.

Benjy's disjointed memories recounted in the opening chapter of the book center on his beloved Caddy. She loves him unconditionally, when their parents see only shame and some divine punishment or test in his existence. She looks beyond his primitive sounds to what he is trying to say. She bends to his level, looks into his eyes, and asks, "What are you trying to tell Caddy?" She puts words to his sounds, tells him what she knows he is saying and acts on that information. She not only listens, she acknowledges his disapproval and changes her ways, when she can. She gives Benjy agency, hope, love and protection.

Caddy becomes his fierce defender, fighting another brother after he cut up the paper dolls Caddy had just made for Benjy. With the dolls destroyed, she assures Benjy they will make more soon, and they will be better. That said, she attacks the brother who willfully hurt Benjy. The day comes when Caddy is gone and that older and more angry brother agrees to Benjy's cutting to protect others.

Caddy becomes pregnant, thereby disgracing the family, just as Benjy had by his existence. She moves away but leaves her child to be brought up in the Compson home. Her name is forbidden to be spoken in the house, but Benjy does not forget her. He cries when he hears "Caddie" called by the golfers playing on what was once Benjy's pasture. He returns each day to the gate and awaits his sister. Without Caddy's protection he is left vulnerable to misinterpretation and punishment and is finally, years later, brought to the state institution that had been considered and threatened most of his life. This placement is made none too soon for his petty and self absorbed remaining sibling. Without Caddy Benjy is not seen by family members as capable of thought, opinion, love, needs or importance.

Faulkner masterly gives Benjy voice decades before other authors explore the complexity of those with severe cognitive limitations. He presents a character who lives in the moment, cannot understand much of what occurs, confuses language and action, but sees truth and knows what matters most. Faulkner understands that Benjy brings out the best in those who meet him at his level and look for what is there. Faulkner writes of the dispossessed and the marginal. He celebrates those who are misunderstood and reveals their importance.

The title *The Sound and the Fury* comes from a passage in the fifth act of *Macbeth*: Life is "a tale told by an idiot, full of sound and fury and signifying nothing." Although Benjy is the one who remains a perpetual child, unable to speak words or live independently, his tale is full of love, of a primitive wisdom, of gratitude and of a deep sense of what matters. He is observant, kind, protective and hopeful. He seeks order and

---

*Book Review by Pam Healey*

There is no hope unmingled with fear, and no fear unmingled with hope. ~Baruch Spinoza
Book Review by Pam Healey

(Continued from page 19)

comfort. He reaches out to others, and loves. The idiots are the alcoholic, lazy, cynical, self serving, complaining, irresponsible members of his family, who add little to the family’s success and make few positive connections with others. The family wastes away, money gone, land gone, prospects gone, dying out. In Benjy Faulkner creates a character who at one level mirrors their decline, but in reality carries the core of the admirable qualities the rest have lost.

I thought of all the sibling relationships in SOFT. The siblings are the protectors who defend their sister or brother with trisomy. They speak for them, send those who malign them away, when explanation does not change their understanding or their hearts. They educate the uninformed. They bend down to wheelchair level and communicate in the ways that matter. They dance with them, sing with them, guide those who walk, rough house, make them laugh and just hold them. I look through the pictures I have taken through the years and see so much pride, happiness and love. Caddy would understand. These are pictures of connections some siblings never achieve. Many have found professions that honor their siblings by carrying forward what they have learned: nurses, special education teachers, therapists. Like Caddy, they take the time to be present and make life better for those who need their attention and love. Like Caddy, they are sincere, blessed and changed by a sibling whose communication is challenged and whose understanding is limited but valuable. Like Caddy they have the right values. Like Caddy they grow up and try to keep a balance between their own needs to leave home and become adults and their sibling’s need for their presence. Like Caddy, they may find themselves in their best light when in the presence of a sibling with both challenges and gifts.

One of my favorite SOFT moments happened at my first conference, Soft Lights Harbor Place, Baltimore, 1992. I was sitting behind Mary and Alan D’Aprile who had two children in wheelchairs, Leslie, who had trisomy 18 and was then a teenager, and Brian, who was about four and I believe had cerebral palsy. Leslie functioned at a higher level than did Brian. There were many presentations that morning, and we had been sitting a while. Leslie reached around the armrest and wheel of her seat and found Brian’s hand, his limp arm dropped at his side outside his wheelchair. She held his hand for a long time. Leslie was both Benjy and Caddy. Faulkner had it right: look past the limitations and find truth and what matters most; look past the assumptions and be amazed.

Did You Know?

SOFT’s 1181 members include 391 Trisomy 18 families, 235 Trisomy 13 families and 19 Trisomy 9 families. 166 families with other chromosome diagnoses are registered along with 310 professionals and 61 supporters. Data are from 3/31/2014

God puts rainbows in the clouds so that each of us — in the dreariest and most dreaded moments — can see a possibility of hope. ~Maya Angelou
Running with Krissy & Larry

With the boom of the cannon Krissy (Krotzer) and Larry (Wheat) were off and rolling in the Alamo 13.1 – their second half marathon but this time they weren’t alone. Today Larry and Krissy were joined by Grace’s Mom, Cami Lundt. Cami joined the Running for Trisomy team to run in memory of her daughter Grace who lived 5 beautiful years with Trisomy 13.

The crowd supporting Running with Krissy for Trisomy Awareness was bigger than their first race in the Portland (Oregon) Half Marathon in October of 2013. This time Larry and Krissy’s families were joined by other families and other Trisomy children as they cheered the runners on.

The race route began at the historic Alamo and wound through downtown San Antonio. The day was sunny and cool and the wind had a bite, but that didn’t dampen spirits. Krissy was all smiles and squeals as she, Larry & Cami made their way through the course!

We waited anxiously for them to round the final corner and make their way to the finish line. As they rounded the corner the announcer gave them a shout out acknowledging Trisomy Awareness month and wishing Krissy a Happy 14th Birthday!

All eyes were on Team Krissy when just a few feet short of the finish line they stopped and Larry (after running 13+ miles) leaned down and helped Krissy out of her running stroller and walked Krissy the remaining feet to cross the finish line in 2 hours and 14 minutes. It was an amazing sight to behold and while the sight of Krissy and Larry crossing the finish line was something – so was the sight of all the photographers crawling on their bellies and edging each other out in their attempt to get the photo! Now THAT brought even bigger tears to this Mommy’s eyes.

It was just happenstance that Krissy and Larry ended up in the Alamo 13.1. Larry was simply looking for a race and it seemed like a good choice not realizing that March was Trisomy Awareness month. Perfect fit, right? It gets better. It turns out the Alamo 13.1 is produced by Mike and Janelle Hennessey of Ironman for Kids fame, who are longtime supporters of Trisomy Awareness. Coincidence? I think not!

(Continued on page 22)
Running with Krissy & Larry

Our mission began for Trisomy Awareness, with Krissy and Larry running to raise funds for a Butterfly’s Touch and SOFT. After the first race we realized that in order to continue running they would need a more suitable stroller, one that fits Krissy (and Larry!) and also one that could take the distance. For that reason the funds raised from the Alamo 13.1 will also help to fund Krissy and Larry’s new running chair and we are almost half way there!

Our goal is to have the chair by the SOFT Conference in July. To help us make that happen go to: http://www.gofundme.com/6hm2go

Watch the video that tells how it all began: http://runningfortrisomy.org

(Continued from page 21)
Over the years there have been many requests to SOFT for an official Trisomy Awareness Ribbon so in preparation for Trisomy Awareness month we hired a designer to create one. The idea is that the ribbon is the same for every Trisomy with the exception of the number. While it great that we celebrate our differences, if we want the world to come to recognize the Trisomy ribbon, and thus bring awareness and recognition to Trisomy, then a ribbon for Trisomy was needed. The ribbon was created in the rainbow colors which have represented SOFT for over 30 years.

March was Trisomy Awareness month & SOFT Celebrated in style!

Hope is faith holding out its hand in the dark. ~George Iles

Everything is a confirmation of **Awareness**. Even a denial of it is yet another confirmation of it. And so it's inescapable... Awareness is that which knows you are here right now.

- Bentinho Massaro

Personalized Facebook profile photos and cover photos were created and displayed proudly on almost 200 Facebook profiles during the month of March.

Hope is some extraordinary spiritual grace that God gives us to control our fears, not to oust them. - Vincent McNabb
The Twelfth Angel: A Heartwarming Story of Belief and Courage, by Og Mandino, 1993, Random House

The Twelfth Angel, a short novel by inspirational author and speaker Og Mandino, is a touching story of lost love and lost hope. It is a story of those who leave our lives, but, more importantly, it is a gentle tale of those who enter our lives just when we need their wisdom and presence. It is a New England story, set in New Hampshire; it is a summer story told from the baseball diamond in a small town. Most of all, it is the story of how the loss of loved ones is not overcome by time, despair, immobilization, reverence or drastic actions. Such a loss is attenuated by small miracles and big realizations. It is a story of courage and perseverance by some and the possibility of defeat by others. It is a story of what happens when the people who suddenly enter our lives are just the people needed to create change. For an executive at a major computer company, the first person to arrive was a childhood friend with a proposition that seemed ridiculous. This friend unwittingly brings a small boy who arrives on a rusty bike, carrying a frayed mitt and armed with an arsenal of positive sayings.

When John Harding returns home after taking a CEO position nearby, he is celebrated as the local boy who made good. Once a baseball wonder boy, he had become a computer superman. He, his wife, and his young son begin to make their new house a home and to settle into a community where many boyhood friends, neighbors and teachers remain. What seemed the perfect life is suddenly shattered, when his wife and son are killed in an accident, John sees no future without them. Although as a teenager he had bitterly questioned how his favorite author, Ernest Hemingway, could have shot himself, ending such promise, he suddenly understands, and sits at his desk holding a pistol. He understands the pain that can be relieved only by oblivion.

Although he had cut a wire in his doorbell and learned to ignore insistent knocking, John responds to an old friend, who is not to be ignored. Bill pounds on whatever would make the noise necessary to rouse John. John responds, greets him, and with Bill’s insistent yet empathetic prodding opens up enough to explain he has resigned from his new company. He explains that he is unable to get out of bed in the morning, so clearly he is unable to take the reins of a large computer company. Bill listens. He then takes him for a short ride to the baseball diamond they had play on as boys. He proposes that John help coach a Little League team. He says, “They will love you.” John, certain he had no love to give back, balks. He has the baseball expertise they need, but he is in no shape to deal with ram-bunctious young boys needing adult guidance and encouragement. John is sure they need more than he can offer at a time when he feels so broken, so he politely declines. Despite this, he finds himself one of four managers at the Little League draft a few days later. He wins the coin toss and his team, the Angels (of course!), gets the strongest player. The team also gets the weakest player, a new wisp of a child unable to bat, throw, run, or catch.

It was this weakest player, his twelfth angel, the last boy remaining in the draft, who gives to John what he needs to change his outlook. Soon John gives young Timothy Noble extra practice sessions at dusk, after the other players have returned home. He encourages him, listens to his philosophy of life and worries about him. When he examines the boys’ tattered glove, long past usefulness, he gives him his son’s baseball glove. He gives him his son’s bike, when he learns Timothy walks four miles to get to practice and games. Eventually, he gives him a hug. Timothy gives John and the boys on

(Continued on page 25)

Book Review by Pam Healey

When hope is hungry, everything feeds it. ~Mignon McLaughlin
Trisomy 18/13 Research Project

Pam Healey, who conducted an experiences at diagnosis survey in 2001-2, is conducting a similar study to compare experiences. This is open to parents who received a diagnosis of trisomy 18 or 13 in the past five years. This includes a prenatal or postnatal diagnosis and is for parents of all children with a diagnosis of trisomy 18 or 13 (full, partial, mosaic), including stillborn, elected termination, and liveborn. It is important that as many people as possible participate. There were 117 responses to the first study, and many parents wrote that it was therapeutic for them to share their story and have their child be part of a study that will help other parents. All responses will be coded and kept confidential.

If you are interested please email your interest and address to Healeylex@aol.com, call 781-862-8273 or write to Pam Healey 18 Richard Rd. Lexington, MA.
SOFT attends the ACMG Annual Clinical Genetics Conference sponsored by the American College of Medical Genetics and Genomics (ACMG) held in Nashville, Tennessee, March 26-28, 2014.

Submitted by Mark Kubena

Faye, Morghan and I had the pleasure of representing SOFT at the Annual ACMG conference in Nashville, Tennessee this year. It was a successful three days to introduce and promote SOFT to the numerous attendees. The conference was attended primarily by geneticists, genetic counselors, physicians, medical professionals, researchers and various company representatives in the field of genetics. The conference was well attended with people from throughout the United States, Canada, Europe, South America, Asia and the Middle East.

After the conference, I received an email from ACMG with a conference summary. It was interesting to know that the ACMG conference had a total attendance of 2,595 people (an 11% increase over the 2013 conference). The following is a breakdown of the attendees:

Professional Attendees: 2,008 (11% increase over 2013),
Exhibit Personnel: 553 (11% increase over 2013),
Accompany Persons / Guests: 30
Press: 4

A total of 147 companies had exhibit booths at the conference, which is a 14% increase over 2013.

The conference summary would suggest that this forum is a valuable opportunity for SOFT to meet face to face with geneticists and genetic counselors who counsel expecting couples, in the future healthcare and potential challenges they may confront in caring for a child diagnosed with Trisomy 13 / 18, or a related genetic disorder.

Additionally, the conference is the ideal forum to introduce SOFT to genetic counselors and medical professionals who are just starting their careers in the field of genetics and who are unaware of our organization. Many we met stated that they were aware and familiar with SOFT from our webpage. Other stated that they were also aware of SOFT and “keep up” with SOFT through the webpage. A few were familiar with our Facebook page. Nevertheless, the primary means of information dissemination is through the internet and the value of the SOFT webpage and Facebook page was never more obvious.

Many of the attendees we met stated that they recommend expecting parents or parents who have received a diagnosis of Trisomy 18 or 13 to visit the SOFT webpage. Is it gratifying to know that the SOFT webpage is a valuable resource for parents to seek out information regarding their child’s diagnosis, read stories of our SOFT children, view photographs, and an avenue to contact a SOFT member.

A lot of attendees thanked us for bringing Morghan. Several professionals indicated that the impact of meeting a full Trisomy 18 child of advanced age and putting a face with the diagnosis was important. Meeting Morghan was a contrast to what some professionals were taught and knew of Trisomy 18 chil-
Our fellow exhibitors involved in prenatal diagnosis and genetic testing said we had the best booth because of Morghan's attendance and her potential influence on those who observed and met her. (Morghan and I would occasionally take a stroll through the conference hall).

We encouraged all of the attendees we met to join SOFT to expand our membership and spread the word of SOFT and assist SOFT in our mission to inform the medical community, parents and expecting parents of what life is really like with and for a child with a chromosomal or genetic disorder.

We passed out the care books, the Trisomy 13 and 18 Handbooks for Families, SOFT trifolds brochures, SOFT pens and the 2014 SOFT Norfolk conference announcements. We did our best to promote the annual SOFT conference. Hopefully, some of the attendees in the Virginia, North Carolina area will attend this year’s SOFT conference.

Faye and I thought the ACMG Conference was a great venue to introduce and promote SOFT. We found the conference to be informative, enlightening and thought provoking. Having Morghan at the conference was an added bonus to attract attendees to the booth. Many people were happy to see her and meet her, or to engage her. Morghan even decided to try and convince one young attendee to hold her hand and take her to LUNCH. Needless to say, that was eventually my job while Faye held down the fort.

Faye, Morghan, and I look forward to seeing everyone this summer. Happy and safe travels to everyone on your exciting journey to Norfolk.

SOFTly written,
Mark and Morghan Kubena / Faye Kaufman.
Many trisomy 13 and 18 children do not live to be one year old, but there are those that do survive much longer. Doctors tell the parents that trisomy is incompatible with life, but this just is not true. Doctors are not always aware of the capabilities of trisomy children and may not expect children to survive years or even decades.

My daughter, Nicole (Nikki) was born with full trisomy 18. We were told that she would not live to be one, and she would not show emotion nor would she know us. That is totally untrue as many of you that knew her could attest to. She always had a smile for us, even when she was sick. She knew us and others because her face just lit up. Nikki loved her little sister, but I think she was jealous when she was born. So much for not showing any emotions!! She loved to give hugs and touch us and others, but it had to be her idea. She hated to have her hands touched. She loved to be around people, more than anything else. She loved to go swimming whether it was in the lake or the pool, and she even loved to ride the Tilt-A-Whirl.

In February I put a picture in the paper of Nikki hugging a fellow student and requested from anyone that remembered something about her to send me an email. I did get a few comments on my Facebook page, because I put a story of Nikki there, but I was disappointed that I only got one response to my email account. Thank you Ed!!

Each child with trisomy is considered to have full trisomy if there is a complete extra chromosome in all body cells. The remaining few (about 5%) will have a rearrangement of the chromosomes called a translocation, which is when a chromosome or part of a chromosome is attached to another chromosome, will have part of a third chromosome or will have mosaicism which means there are both normal cells and trisomy cells.

Our children have a number of medical problems including heart defects, scoliosis and feeding problems. There are also birth defects associated with each trisomy. Children with a specific trisomy resemble each other but also look like their parents. I was at a SOFT national conference in Chicago not long after Nikki passed away, so that I could release a balloon for her. There, I met a young girl that looked so much like Nikki. I really wanted to take her home with me. She had the same beautiful smile and hated to have her hands touched. I just found out a little while ago that she passed away. Because she reminded me so much of Nikki, it felt like I was losing Nikki all over again. I have recently seen pictures of others that looked like Nikki did during different times of her life.

The Support Organization for Trisomy 18/13 and Related Disorders (SOFT) has a National Organization which meets every summer in a different state. During this time there are clinics in which parents can have their child seen by a medical specialist. They also have seminars, social gatherings, a silent auction and the famous Ryan Cantrell Memorial Balloon Release. This is a day filled with a picnic, socializing and releasing a balloon after the name of a child that has passed away has been called.

When Nikki was a baby, we traveled in a pick-up truck to Phoenix to visit one of my brothers. While we were there we went to Mesa and met Kris Holladay and her daughter Kari. It was awesome to meet another child with Trisomy 18, as well as the founder of SOFT. The medical advisor of SOFT is Dr. John Carey. When I attended a SOFT conference in St. Louis in 1990, I was privileged to meet Dr. Edwards who was the first to discover Trisomy 18.

Editor’s Note: The above was sent to a local newspaper for Trisomy Awareness Month. Elise Vik, mother of Nikki Waege, also took Ann’s book with the link to the labeled page, the TRIS Project, Running with Krissy, Trisomy Talk, Noah’s Never Ending Rainbow, A Butterfly’s Touch, Simon’s video and the Trisomy.org website, along with a link to the fundraising page for Nikki. This is an excellent example of parent advocacy and education.
The dreams of the broken are mightier than the wishes of the dead. - Dodinsky

Self-Nurturing Activities

- Walk in the rain
- Exercise
- Keep a journal
- Sign up for a yoga class
- Take a warm bath
- Have breakfast in bed
- Get a massage
- Buy yourself a rose
- Take a bubble bath
- Have a manicure or pedicure . . Or both
- Stop and smell some flowers
- Watch the sunrise or sunset
- Relax with a good book and/or soothing music
- Rent a funny movie
- Play your favorite music and dance to it by yourself
- Go to bed early
- Take a ‘mental health’ day off from work
- Go for a walk
- Call a good friend or several
- Go to the beach
- Meditate
- Browse in a book store as long as you want
- Work on a favorite puzzle
- Work a crossword puzzle
- Write a letter to an old friend
- Bake or cook something special
- Buy a meditation CD
- Listen to a positive, motivational message
- Listen to a symphony
- Plant a garden
- Write a special diary about your accomplishments
- Find something good in EVERYone you meet
- Make a list of your good qualities
- Hug a child
- Have a good cry
- Go to a concert
- Daydream
- Waste time without feeling guilty
- Turn OFF the TV/media
- Read a magazine
- Doodle
- Look at clouds
- Listen to the rain
- Make herbal tea
- Express appreciation
- Tell someone you love him or her
- Say ‘no’
- Go to a museum
- Donate blood
- Apply fragrant lotion
- Take a nap
- Fly a kite
- Swing
- Rock
- Sit buy a fire and read
- Wear new socks and underwear
- Look out a window
- Have a picnic
- Take 10 deep breaths
- Close your eyes and relax your muscles one by one, starting from your head and work down to your toes
I thank God upon every remembrance of you.-Philippians 1:3

**Remembering SOFT Angel Wings**

<table>
<thead>
<tr>
<th>Name</th>
<th>Born</th>
<th>Angel Wings</th>
</tr>
</thead>
<tbody>
<tr>
<td>May Levinsky</td>
<td>May 1, 1988</td>
<td>May 1, 1988</td>
</tr>
<tr>
<td>Evie Parsons</td>
<td>April 1, 2014</td>
<td>May 1, 2014</td>
</tr>
<tr>
<td>Aine O’Corrghaile</td>
<td>October 17, 1986</td>
<td>May 3, 1994</td>
</tr>
<tr>
<td>Katie Slotkin</td>
<td>March 4, 2002</td>
<td>May 3, 2002</td>
</tr>
<tr>
<td>Tucker Wesley Reite</td>
<td>April 5, 2001</td>
<td>May 3, 2003</td>
</tr>
<tr>
<td>Erin Margaret Jorgenson</td>
<td>November 4, 1994</td>
<td>May 4, 1995</td>
</tr>
<tr>
<td>Jessica Riley Warpehoski</td>
<td>May 4, 2002</td>
<td>May 4, 2002</td>
</tr>
<tr>
<td>Audrey Regalado</td>
<td>January 10, 2013</td>
<td>May 4, 2013</td>
</tr>
<tr>
<td>Jenna Marie Keating</td>
<td>April 28, 1999</td>
<td>May 9, 1999</td>
</tr>
<tr>
<td>Matthijs De Kievit</td>
<td>February 23, 1999</td>
<td>May 9, 1999</td>
</tr>
<tr>
<td>Morganne Jayme Dye</td>
<td>October 8, 1998</td>
<td>May 13, 1999</td>
</tr>
<tr>
<td>Noah Thomas Campbell</td>
<td>October 10, 2000</td>
<td>May 14, 2001</td>
</tr>
<tr>
<td>Frederick Carranco Ciriano</td>
<td>May 15, 2001</td>
<td>May 15, 2001</td>
</tr>
<tr>
<td>Leah Nadine Danner</td>
<td>May 16, 2000</td>
<td>May 16, 2000</td>
</tr>
<tr>
<td>Chloe-Alexia Wrightson Gallagher</td>
<td>May 7, 2012</td>
<td>May 16, 2012</td>
</tr>
<tr>
<td>Natalyia Destiny Modest Codrington</td>
<td>May 16, 2013</td>
<td>May 17, 2013</td>
</tr>
<tr>
<td>Kayla Violet Garcia</td>
<td>January 27, 2010</td>
<td>May 18, 2010</td>
</tr>
<tr>
<td>Hailey Rayelle Saunders</td>
<td>January 27, 2013</td>
<td>May 18, 2013</td>
</tr>
<tr>
<td>Madison Gabrielle (Gabby) Aultman</td>
<td>April 17, 2008</td>
<td>May 21, 2009</td>
</tr>
<tr>
<td>Clodagh Treise McGill</td>
<td>May 21, 2007</td>
<td>May 22, 2007</td>
</tr>
<tr>
<td>Ricky Tucker</td>
<td>October 9, 1990</td>
<td>May 23, 1997</td>
</tr>
<tr>
<td>Isabella Josephine Wolfe</td>
<td>May 23, 2011</td>
<td>May 24, 2011</td>
</tr>
<tr>
<td>Rebecca Csontos</td>
<td>May 26, 2001</td>
<td>May 26, 2001</td>
</tr>
<tr>
<td>Karina Renee Calvert</td>
<td>May 27, 2005</td>
<td>May 27, 2005</td>
</tr>
<tr>
<td>Laurin Delany Roarty</td>
<td>March 8, 1994</td>
<td>May 31, 1994</td>
</tr>
<tr>
<td>Aimee Marie Sahota</td>
<td>February 25, 1999</td>
<td>May 31, 1999</td>
</tr>
<tr>
<td>Daniel Michael Berst</td>
<td>January 21, 1999</td>
<td>June 2, 2000</td>
</tr>
<tr>
<td>Kari Deann Holladay</td>
<td>September 8, 1977</td>
<td>June 3, 1988</td>
</tr>
<tr>
<td>Felicia Shumbo</td>
<td>June 4, 1993</td>
<td>June 4, 1993</td>
</tr>
<tr>
<td>Kinsey Marie Wise</td>
<td>June 4, 2009</td>
<td>June 4, 2009</td>
</tr>
<tr>
<td>Jordan Lynn Moore</td>
<td>June 5, 2009</td>
<td>June 5, 2009</td>
</tr>
<tr>
<td>Christopher Anderson Ramsey</td>
<td>June 6, 2013</td>
<td>June 6, 2013</td>
</tr>
<tr>
<td>Jordan Elizabeth Chamberlin</td>
<td>June 4, 2009</td>
<td>June 7, 2009</td>
</tr>
<tr>
<td>Paxton Nelson</td>
<td>June 7, 2008</td>
<td>June 8, 2008</td>
</tr>
<tr>
<td>Isaiah John Joslin</td>
<td>May 10, 1999</td>
<td>June 11, 1999</td>
</tr>
</tbody>
</table>
His loved ones are very precious to Him and He does not lightly let them die—Psalm 116:15

# Remembering SOFT

## Angel Wings

<table>
<thead>
<tr>
<th>Name</th>
<th>Born</th>
<th>Angel Wings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sophee Olivia Widner</td>
<td>November 23, 2010</td>
<td>June 12, 2011</td>
</tr>
<tr>
<td>Gabriella Ann Romano</td>
<td>February 2, 1992</td>
<td>June 13, 2000</td>
</tr>
<tr>
<td>Lisa Lynn Gershkoff</td>
<td>June 5, 1983</td>
<td>June 15, 1983</td>
</tr>
<tr>
<td>Ryan Cantrell</td>
<td>October 4, 1985</td>
<td>June 15, 1986</td>
</tr>
<tr>
<td>Faith Meghan Lewin-Reeder</td>
<td>May 9, 2013</td>
<td>June 15, 2013</td>
</tr>
<tr>
<td>Tabitha Sarah Lambrecht</td>
<td>April 10, 2010</td>
<td>June 18, 2010</td>
</tr>
<tr>
<td>Michael Edwin Weber</td>
<td>June 18, 2011</td>
<td>June 18, 2011</td>
</tr>
<tr>
<td>Carey Ann Neufeld</td>
<td>September 12, 1983</td>
<td>June 18, 2012</td>
</tr>
<tr>
<td>Jaime Fran La Rosa</td>
<td>August 21, 1985</td>
<td>June 19, 1988</td>
</tr>
<tr>
<td>Grace Anne Cooper</td>
<td>June 19, 2007</td>
<td>June 20, 2007</td>
</tr>
<tr>
<td>Henry Mack Prinz</td>
<td>June 20, 2013</td>
<td>June 20, 2013</td>
</tr>
<tr>
<td>Alexis Morris</td>
<td>November 23, 2005</td>
<td>June 21, 2006</td>
</tr>
<tr>
<td>Sir Jaxon Tyrone Tasby</td>
<td>June 17, 2010</td>
<td>June 21, 2013</td>
</tr>
<tr>
<td>Daniel Luis Dionysio Guzman-Puente</td>
<td>January 9, 2001</td>
<td>June 23, 2001</td>
</tr>
<tr>
<td>Christian Mansfield</td>
<td>June 24, 2000</td>
<td>June 24, 2000</td>
</tr>
<tr>
<td>Fegan Kathryn Parks Cuzzoloni</td>
<td>January 20, 1994</td>
<td>June 25, 1994</td>
</tr>
<tr>
<td>Amazing Grace Browning</td>
<td>April 27, 2013</td>
<td>June 27, 2013</td>
</tr>
<tr>
<td>Jack Matthew Astrup</td>
<td>May 4, 2000</td>
<td>June 28, 2009</td>
</tr>
<tr>
<td>Brandy Kaye Woodcox</td>
<td>September 25, 1975</td>
<td>June 29, 1994</td>
</tr>
<tr>
<td>Shorey Anna Marie Elizabeth</td>
<td>September 20, 1989</td>
<td>July 2, 1990</td>
</tr>
<tr>
<td>Katherine Marie Getto</td>
<td>September 29, 1983</td>
<td>July 5, 1986</td>
</tr>
<tr>
<td>Kayla Kay Copeland</td>
<td>June 21, 2000</td>
<td>July 5, 2000</td>
</tr>
<tr>
<td>Dominic Hugh REPPE</td>
<td>May 25, 2009</td>
<td>July 5, 2009</td>
</tr>
<tr>
<td>Tyler Denim Westona-Lily</td>
<td>July 8, 2002</td>
<td>July 9, 2002</td>
</tr>
<tr>
<td>Mieko Jessica Johnson</td>
<td>March 9, 2004</td>
<td>July 11, 2008</td>
</tr>
<tr>
<td>Adrienne Leigh Irvin</td>
<td>June 26, 1996</td>
<td>July 12, 1998</td>
</tr>
<tr>
<td>Mia Nicole Stokley</td>
<td>May 20, 2001</td>
<td>July 15, 2006</td>
</tr>
<tr>
<td>Jonathan Terry Watson</td>
<td>May 9, 1992</td>
<td>July 21, 1992</td>
</tr>
<tr>
<td>Jillian Ryan Patch</td>
<td>April 2, 1990</td>
<td>July 21, 1995</td>
</tr>
<tr>
<td>Duenas Eika-Rayne Mariana</td>
<td>July 11, 2009</td>
<td>July 22, 2009</td>
</tr>
<tr>
<td>Isabella Carolyn Powell</td>
<td>December 12, 2011</td>
<td>July 26, 2012</td>
</tr>
<tr>
<td>Matthew Paul Hergenrather</td>
<td>July 18, 1996</td>
<td>July 29, 1996</td>
</tr>
<tr>
<td>Emmanuel Dixon</td>
<td>July 30, 2013</td>
<td>July 30, 2013</td>
</tr>
<tr>
<td>Catheryn Hope Pittman</td>
<td>July 31, 2013</td>
<td>July 31, 2013</td>
</tr>
</tbody>
</table>
We’re linked to the internet at http://www.trisomy.org

Deadline for the August/September/October 2014 Issue of The SOFT Times Is 15 July 2014

Join SOFT July 9-13, 2014