Rhode Island, the Ocean State, is home to an extensive coastline, dangerous shoals and many lighthouses built to guide vessels to safe harbors. Beavertail Light, which guards the rocky southern tip of Jamestown Island, where Narragansett Bay meets the open ocean, is the site of the third oldest lighthouse in America. It will be the symbol of the 2013 SOFT International Conference. Throughout the conference will be opportunities that Light the Way for families meeting the daily challenges of doing what is best for their child or moving forward after their child’s passing. With clinics at nearby Hasbro Children’s Hospital, the banquet, educational and supportive workshops, a keynote speaker, book signings, Kris’ video, structured and unstructured times to visit and share experiences, and “field trips”, the conference will provide information, support, entertainment and respite in a remarkable geographic area.

The younger children will spend Friday at Roger Williams Park Zoo, a few minutes from the hotel and noted as the best zoo in New England. The older children and teens will travel to Mystic Seaport, the Museum of America and the Sea. There they will tour the restored village of houses, shops and interactive mid-nineteenth century industries, and see as many as sixteen sailing vessels. They will come aboard the Charles W. Morgan, the only surviving wooden whaling ship and the world’s oldest surviving merchant vessel. She made 37 voyages, some as long as five years, in her 80 years of service. Family Night Out is planned for Downtown Providence for shopping, dining and touring with the possibility of experiencing Water Fire, an art installation of over eighty bonfires on three downtown rivers, if it is scheduled. The annual Stroll for Hope, picnic, balloon release and auction will engage us, as always.

Join us from July 16 to 21, 2013, in Providence, Rhode Island. We will be staying at the luxurious and spacious Crowne Plaza Hotel at the Crossings just outside the city with easy access to the historic, educational and cultural Providence attractions and the coastal areas of the state. There are 266 large rooms, many meeting areas, two restaurants, lounges, a pool, whirlpool and sauna, fitness center and complimentary parking. Shopping, golf, local seafood restaurants and quaint gift shops are within a few miles.

Greene Airport is minutes from the hotel; Logan Airport in Boston about an hour away. The hotel is only minutes from I-95. Cape Cod, the ferry to Martha’s Vineyard, historic Newport and its elegant mansions, Rhode Island’s South Coast beaches, Boston and the Connecticut shore are an hour or less away for those extending their visit. The many local colleges provide an opportunity for teens to do a college tour. We hope a large group will join us in the smallest state. We hope to see east coast families we have not seen in a while and welcome those from the Midwest, west and south. We know an international contingent is planning to attend. Come to cool ocean breezes, vast vistas from broad sandy beaches and a steep rock bound coast and sheltered coves teeming with sea life. Plan to join us in July.

-Pam

Happy and Healthy Thanksgiving from your friends at SOFT
Can You Guess Who I Am?

See if you can guess who we are—some photos are recent, some not! The answers will be published in the next issue of The SOFT Times. If you just can’t wait, email your answers to me and we’ll see who guessed the most correctly!

jmgthompson@att.net

Page 2, The SOFT Times, November/December 2012/January 2013
President’s Corner
with the VanHerreweghe Family

Dear Families:

The 2012 conference is history and it is time to move on to 2013. Next year we will be in Rhode Island from Thursday 7/18/2013 to Sunday 7/21/2013. Our conference will be held at the Crowne Plaza Hotels and Resorts at the Crossings. This is located at 801 Greenwich Avenue in Warwick, Rhode Island. The room rate is $119 per night. You may register at reservations@providenceri.crowneplaza.com. Don’t forget to use the three letter group code of SOF. You can also call the reservation department at 401-732-6000 or 800-227-6963. Don’t forget to let them know you are with SOFT as that is the only way to get the SOFT room rate. The cut off date is June 25, 2013 so register now, the room rate is only good till that date and there are a limited number of rooms at that rate.

Our family is really looking forward to this conference. We have never been to Rhode Island and it gives us the opportunity to visit a beautiful eastern seaboard state.

We are weathering our storm Sandy here in New York as we speak. Lots of rain and heavy winds, we will see how the over night goes. Soon the beautiful colored leaves will be all off the trees. The snow will start falling soon after that and the Holiday season will be here. I love the holidays especially when we start getting all the holiday greetings with all the kids pictures. It is so much fun to see them all in the newsletter. Don’t forget to send your greeting for everyone to the Thom- sons so we can meet all your children.

Well, the new van we got for Stacy got hit by a lady as we waited for chicken barbecue. I have a funny story that goes along with that. As the lady hit us (I was sitting still), Judie yells out, Oh my gosh, she is old and shouldn’t be driving! Later as the police officer was asking for everyone’s birth date I gave him Judie’s and the lady who hit us says “Wow, someone older than me, I am a year younger than her.” Andy just turned around and started laughing as did I because Judie was so sure she was younger. It all worked out okay. Everyone was safe, we got the van fixed, we know Judie is the oldest of anyone and we won’t stop for any more Chicken Barbecue!

Stacy has been healthy except for a time period of possible seizure activity. We increased her Keppra a little and we are hoping that will stop the issues she was having. Just when you think you have everything under control she tends to send us a curve ball. I guess she doesn’t want to make life too easy. We are, however, going to go on a cruise again after 7 years of not going. I am sure she will be happier once she starts seeing the palm trees and feels the nice warm breezes in the Caribbean when we get there.

- The Van Herreweghes

We wish you all happy and healthy holidays. Enjoy your family time together and we will remember all those angels that had such a short time on this earth but who are forever in our hearts.
This is an impressive collection of 54 stories or reflections by mothers of children with Down syndrome. The children tend to be higher functioning with fewer medical issues than children of SOFT parents, but the shock at diagnosis, the initial concerns and disappointment, the questions they ask, the changes in themselves and the new friends they make will sound familiar.

The stories, each three to five pages long, are divided into five sections: The Gift of Respect, The Gift of Strength, The gift of Delight, The Gift of Life, the Gift of Perspective and The Gift of Love. Each mother reflects on the wonderful aspects of having a child with what once seemed an overwhelming diagnosis. The early tears and worry are replaced by smiles and abundant love. There is humor, poignancy, and delight in children for who they are, what they do and how they touch and teach family members. There are invaluable lessons that bring a new perspective.

One older mother upon hearing her son’s diagnosis feels as if she has been thrown into the deep end of the pool and cannot swim. She feels as if she were drowning but instinct kicks in, literally, and she begins to move her arms and legs, then starts treading water, then begins to float. Eventually, she sees her son at her side and realizes being in the deep end allows better experiences than the shallow end. Another mother who thought her perfect life was over when her son was born soon realizes she left a boring life for one that is bumpy but exciting and unique. She finds her true self in the process. Another mother who survives by making lists and by being ten steps ahead, learns to take slow walks with her son while he pats trees. She stops thinking about what must be done the next day and lets her cell phone ring. She discovers what is important. Another mother writes that her daughter has taught her to live in slow motion, which means she notices so much more.

Many stories are of simple events that in a larger context become life lessons. I loved the four year old who in a dance recital is well rehearsed but becomes captured by the new backdrop of Candyland when the curtain is raised. Focusing on lollipops, she forgets to dance until the last seconds of the number. She twirls a bit, then exuberantly takes her bow, delighting the audience. Her six year old brother praises her and when reminded by his mother that she missed most of the number, he replies, “She did the best she could and that’s what counts.” He remembers the blue ribbon he recently earned when he was the only one to do a science fair project in kindergarten and said, “sometimes you are a winner just for showing up.” A mother is delighted when her son says, “Bye Poopyhead,” because he spoke so clearly. Another mother is delighted when her toddler first scales the couch and deftly commandeers the remote control.

Mothers address the pain of prenatal diagnosis and the advice that is given. Some write of delivery; others write of the anguish of waiting during their child’s heart surgery. A number of children have medical complications: Tetralogy of Fallot, esophageal atresia, and holes in hearts, all requiring surgery. Some experience the attitude that not bringing a child with disabilities into the world is the more responsible and noble act, contrasting that with the teachers their children have been to so many. Young mothers fight for their children when others make unfair assumptions about their parent abilities or treat their children cruelly. A few stories will bring tears; many will bring smiles or even a chuckle. Some mothers talk of earlier experiences with children with Down syndrome, of having premonitions of their children or dreams, including one in which during her pregnancy a precious child reassures his mother he will be fine.

One mother writes of how mean she had been as a child and indifferent as an adult to those with disabilities and how she has changed and seeks to sensitize others. Another mother worked for the judge on the Baby Doe case in Indiana, much later had a child with Down syndrome and began to think differently. Mothers write of how they fall in love with their sons and daughters instantly and from the beginning see them through the diagnosis. They write of new routines, fears, broken marriages and their own education. I loved the mother of mischievous Brendan, who like his namesake saint, became the Navigator. She reflects, “Lucky for Me! Since his arrival in my life was also a departure into unfamiliar lands, I need someone with his skills to guide my way” (p.68). Brendan teaches her perseverance, strength, calm, openness to new adventures, attention to what is around him, and delight in both simply play and sloppy kisses. She realizes her son has helped her pick, not the easiest path in life’s journey, but the best one. Another mother believes she has been through the School of Life and earned a graduate degree. She comments, “What a small person I was before this little child came into my life” (90).

There is a wonderful story of paired golfers in a Special Olympic event. The young man with Down syndrome praises, encourages and teaches the older woman assigned to him who is far less competent a golfer. Her perspective changes as stereotypes drop. Many of the other children also lead the way and enlighten those around them.

This is a book that celebrates children and families. It speaks of courage, understanding and expectations and the realization that an extra chromosome is not a tragedy. This is a book by women of different ages and ethnicities raising children alone, in traditional families or with the support of extended families, delighting in toddlers, rushing through life with youngsters and amazed at teenagers. Many grieve what they imagine their child will never do; all celebrate what they accomplish. This is a good book for a busy parent because the essays can be read one or a few at a time, but chances are the reader will make time to read it all.

-Pam
Family Story: Emerson Garst

Emerson was diagnosed with partial trisomy 18 at his 17 week ultrasound and amniocentesis. We knew about this condition from a genetic translocation that resulted in partial trisomy 18 in both our first child and my oldest sister. Emerson was born at 40 weeks and 2 days, (June 23rd, 2011) and weighed 5 pounds 15 ounces. Our first son only lived 9 hours, and it was based on that experience that we opted to come home as soon as we could after Emerson’s birth to spend as much time with him and his 2 big brothers, Evan and Elijah, as a family on Hospice.

Emerson struggled with apneic episodes the first couple weeks of life resulting in a need for oxygen, and he had feeding difficulties that resulted in a need for an NG tube. His coloring was pale and he struggled more with his breathing if he was not skin to skin with Mommy, so he spent most of the first 2 months of his life living in her shirt or in a moby wrap. Emerson kept getting stronger, and it was clear that despite his issues, he wanted to live. We began seeing specialists, and Emerson was diagnosed with a diaphragmatic hernia – not a severe one though, a coarctation of the aorta – also not a severe one, and he began castings for his club foot. He had no issues putting on weight, and he proved to be our little warrior. At 4 months of age, he started in with sinus infections. The next 5 months we went off and on antibiotics (mostly on) because he just could not handle having the infection and breathing at the same time. Antibiotics and his nose freda nose sucker were his life savers at that point in his life. He did continue to put on weight however, and in February at 7 months of age he underwent his first surgery – a mandibular distraction to bring his lower jaw out to make swallowing and breathing easier, a g-button placement to get rid of the NG tube, ear tubes to help out with hearing and all of those infections, and a diaphragmatic hernia repair. The attempt was made to take out his adenoids, but they were unsuccessful because his jaw was set so far back that they could not be visualized. Emerson was able to get rid of his oxygen and BIPAP, and he passed a swallow study to enable him to start making attempts at oral feeding. His infections continued however, so in May he got the metal hardware removed from his jaw and his adenoids removed. Emerson is now learning how to sit, make attempts at crawling, and he is learning to take steps with support. He is constantly smothered in kisses from his brothers (Mom and Dad too!), and he has proven to be an amazing little gift from God. For Emerson’s first birthday we decided to collect donations for charity. These are the donations that were directed towards SOFT.

From The Garst Family – Tyson, Terra, Evan, Elijah, and Emerson

Emerson’s Update

Emerson was found to have bilateral kidney nephroblastosomosis on his routine ultrasound and subsequent MRI done at the end of August. Up until this point in his life, we have been blessed with wonderful physicians that have fought for Emerson as much as we have. Despite the desire for all of Emerson’s direct physicians wanting to treat his potential kidney cancer, other physicians outside of our care team did not feel that he should get treatment due to his trisomy 18. This sparked a need to go to the ethics committee at our hospital so that Emerson’s treatment plan could be protected. Our physicians were confident going into the meeting that the board would agree with our plan, yet it was still nerve racking for our family. We took a poster full of pictures demonstrating not only all of the things that Emerson can do, but also how valuable he is to our family. We also made a resume for Emerson - we titled it "Emerson’s Resume for Life". It described his achievements (Defying hospice, beating statistical odds, and exceeding medical expectations), his experiences (all of his surgeries and "rough" times), and also had a life objective - to live my life to its fullest potential while fulfilling the purpose that God gave me. Emerson of course came with us to the meeting dressed in his tie and "I'm Rocking This Extra Chromosome" jacket. We described his life, his fight and strength, and how much he is loved and valued. We were asked what our opinion was of the physicians that did not feel Emerson should be treated. We responded that it angered us because they made their decision without ever meeting Emerson. We also respectfully commented that it was unprofessional behavior to act in such a way. The board was so moved by our amazing little boy that they cried, asked to please keep and share the resumes that we made, and unanimously voted in favor of treating him. He was scheduled to start chemo on October 1st, but due to a severe upper respiratory infection (para influenza 3), treatment has been postponed until the beginning of November. We continue to be reminded that everything happens for a reason - God truly has a perfect plan - we don't always like it, but it is a perfect plan!
Recommended Reading

**Top Screwups Doctors Make and How To Avoid Them (2011)**

*By Joe Graedon, MS and Teresa Graedon, PHD*


“How can you protect yourself or your loved ones from health care harm? Health care screwups are one of the leading causes of death in America, killing as many people as heart attacks or cancer do. Whether the diagnosis is arthritis, diabetes, reflux or osteoporosis, learn how to avoid the mistakes doctors make before they cause damage or death. Get a copy autographed by authors Joe & Terry Graedon and take advantage of the early bird special!” (Advertisement at www.peoplespharmacy.com) You can also find this book at www.amazon.com Check with your library for availability.

Written in easy to understand words, the Graedons have done a public service by putting together this eye-opening book for anyone dealing with medications, hospitals, doctors and any other health care situation where mistakes can occur. Parents, caretakers, and every person, including doctors, will find useful information and up-to-date resources listed throughout this book which was fueled by personal loss.

Joe Graedon, MS, consumer pharmacology expert, and Terry Graedon, PhD, medical anthropologist, are nationally known patient advocates and experts on pharmaceuticals, nutrition and home remedies. It was in 1997 that Joe’s mother died in Duke Hospital due to a series of “medical errors that did not need to happen.” How difficult this realization must have been for these experts. “Although we have spent thirty-five years trying to prevent drug interactions and complications for others, we could not save a woman we loved.” Not wanting this to happen to anyone else, the Graedon’s wrote this book, to help the public be safer healthcare consumers. It is dedicated to the memory of Helen Graedon; and “to health care providers who strive to give safe, effective and compassionate care.”

Detailed in this book is a wide range of actual mishaps patients have encountered in the health-care system. Listing 10 points on all topics, the Graedons cover doctor errors, pharmacist errors, diagnostic disasters and how to prevent hospital screwups. They also list screwups patients themselves make. They lay out 10 steps to ensure patient safety and 10 tips to promote good communication with your doctor, and much more.

The Preface allows the reader insight into Helen Graedon’s death and the decision Joe and Terry made to try to work with Duke to find ways to reduce medical errors and improve patient safety. When they began doing research for this book, they soon realized they were “seeing only the tip of the error iceberg.” The introduction begins with the message that medical mistakes are the 3rd leading cause of death in the USA. When a patient is harmed as a result of health care, doctors call it an adverse event and such events, called screwups by Joe and Terry, can lead to “pain and suffering as well as death or disability”. The Graedon’s generalize that “truth-telling about adverse events in medicine doesn’t always happen as many physicians do not openly admit their mistakes.”

The Graedon’s write that whether they are informed or not, patients often know when something bad has happened, and that patients and families want acknowledgement of mistakes and an apology. Those harmed also want changes instituted to protect others from the same mishap. The unique expertise of this couple enabled them to write this book to empower the consumer in their dealings with healthcare.

Using lists of 10 points as shown below, to help “focus the readers mind,” the Graedon’s explained each point listed for a topic. Below is the first of 14 topic titles. The next four discuss doctor and diagnostic screwups, why doctors make errors and questions to ask to reduce diagnostic mistakes. The next five deal with prescriptions, drug interactions, pharmacists, and generic drugs, and the last four cover the geriatric patient, screwups patients make, questions to ask before agreeing to surgery, and how to promote good communication with your doctor.

**Top 10 Tips to Stopping Screwups in Hospitals**
- Expect mistakes
- Drug check
- Be assertive
- Say no!
- Track transactions
- Call (condition H) Help
- Deal with discharge
- Cultivate communication
- Double-check everything
- Take a family member or friend

Anticipate there will be errors, some minor but others harmful is the message in the #1 tip. SOFT parents can relate to the *Mother as Advocate* quote within this chapter. “My daughter had complex medical problems and was hospitalized many times at a prominent children’s hospital. There was at least one medication error during every stay. My daughter was disabled, so I stayed with her while she was in the hospital and always

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Top Screwups Doctors Make and How To Avoid Them (2011)
By Joe Graedon, MS and Teresa Graedon, PHD

(Continued from page 6)

checked her medications carefully. This avoided many potential errors. “She also had a latex allergy. I examined every item that entered her room…..Eventually her chart was flagged, and the nursing supervisor visited her room frequently to make sure everything was going smoothly.”

The message is to always have someone stay with your child in the hospital and don’t be afraid to be difficult. The Graedons’ give this same advice for all patients, not just children. They look at every aspect of the health care system where errors can happen. Above in #10 they recommend taking along a family member to the post hospitalization checkup to make sure all the information is heard and further advise that everyone take along a friend or relative for medical appointments for the same reason.

Very insightful is the chapter on Top 10 Screwups Patients Make and the message that “we all need to take responsibility for our own health and its care.”

Under point # 9- Not reading the fine print is the warning to never sign a mediation agreement if you or your child must be hospitalized. You will find words about mediation agreement in a hospital admission form. When signed, they can be used to take away your right to sue if something goes terribly wrong during the hospitalization.

Jo and Terry relate the almost impossible tasks and pressures that physicians encounter in providing care. The details of the Top 10 Screwups Doctors Make begin with Not listening to patients. “Studies show that many doctors have a habit of interrupting patients within twelve to twenty seconds of the beginning of an office visit and the patient might not ever get to finish telling the doctor about her concerns.” Good communication is vital and the Graedons provide tips to make sure your story is heard and understood. Similar tactics are advised for a doctor to use to be certain a patient heard all instructions given. A collaborative effort to communicate and work together between doctor, patient and family, diminishes screwups.

With their knowledge of medications and years of hearing patient’s stories they cut right to the core about how unsafe healthcare is or can be for the consumer and why. The Graedon’s provide the readers an outline of topics in the appendix so the reader can easily reference themes personal to their situation. “In each chapter we have tried to provide tools that will empower you to prevent problems and improve outcomes.”

HOLIDAY GREETINGS
So quickly the times goes by as we come to the close of another year — we look back and realize how blessed we are and have always been, thanks to our family and friends and of course our Father in Heaven.

Jim – has been traveling for the last 4 years for Kroger and has been a long distance husband, Dad, and now “Papa”, only being home on the weekends. Jim was offered a job back at the Smith’s division in Utah, so after 4 years, he’s home to enjoy the family again and “sleep in his own bed” as he puts it. We are truly blessed to have him back in our lives again for more than the weekends. He is so happy to be able to enjoy baby James and watch him grow.

Debbie – happy to have Jim back “sleeping in his own bed” again. Life is better when Jim is home. Job is good – can’t complain. Love being “Nana” to baby James.

Chelsea and Spencer – BUSY raising baby James, who will celebrate his first birthday on Dec. 2. Wow, where has the time gone? What will toddler baby James be like?

Kimber and Kade – finished school – YEAH – finally have time for each other, but still busy as ever. For now their doggie Zoey is our only grandogger – and we love her too.

Morganne – our little guardian angel – forever in our hearts – making us better people.

So to make it short and sweet – We want to wish you all a wonderful Holiday. Take time to reflect on your blessings – enjoy your family and Happy New Year to you all. We love you and think about you often.

Love and Prayers,
The Dye Family

T is for trisomy which brings tears, then blessings imagined,
H is for Holladay: Kris and Hal, who knew someone else was out there,
A is for arriving at a hotel lobby filled with friends giving hugs,
N is for never giving up and finding others who believe in possibilities,
K is for bright kerchiefs, and our golden girls who wear them,
S is for siblings who are forever changed then change the world,
G is for geneticists who walk beside us and help us find our way,
I is for immeasurable love, unconditional and unending,
V is for summer vacations spent with friends from SOFT,
I is for images on ultrasound, photographs, websites, and finally, in our hearts,
N is for Noah’s Never Ending Rainbow, helping SOFT families in many ways,
G is for the glimpse of heaven we are given by our angels among us.

-Pam Healey
Here So Short a Time

By Pam Healey

Just after Conor’s death we joined an infant support group at our hospital. The leader was less than helpful. She had an agenda for us to follow. We had different issues to explore. For instance, the women still carrying pregnancy weight all felt fat. We had no baby to explain or justify the extra pounds. It was just symbolic, but also concrete. She was heavier than any of us, making the situation a bit awkward. None of our babies had lived more than a few weeks, most far less. We had few memories. We were all feeling the physical pain of empty arms and the emotional pain of a future lost. We redefined postpartum depression, both hormonal and emotional. We endured the sessions, then spent an hour or more in the lobby, doing our real grief work. For years we wrote round robin letters and stayed in touch, as we each welcomed children into our families.

I remain in touch with one of those couples. He was here for graduate school in 1986, and two years later they returned to the Midwest. I remember that a few months after their son Brad had died, they went to Old Deerfield for the weekend. Deerfield was a seventeenth century English settlement on the Connecticut River in western Massachusetts. It endured vicious attacks during the French and Indian war and citizens fought back. In a retaliatory attack the Abenaki and other tribes surprised the settlers and killed many adults and 25 children. Others were kidnapped and died en route to Quebec. It is a place of magnificent eighteenth century architecture and beautiful landscape that carries ancient sorrows. My friends wandered through the colonial graveyards, reading the epitaphs on slate and granite headstones. They focused on the many children who died in infancy and early childhood. So many graves listed babies; many listed mothers who had not survived childbirth. They came away with both greater sadness and a sense of being part of a shared experience that covers centuries. It helped them begin to heal.

Six months after Conor died, my grandmother died. Our car stopped a ways from her gravesite, and I looked out the window to see a gravestone listing an infant. We slowly moved on, and I saw a few more graves of young children from a mid nineteenth century industrial community. I realized many before me had felt as I did then.

Ten months after Conor’s death we chaperoned our church’s youth group on a trip to Italy. We celebrated a special mass in the catacombs beneath the home of St Priscilla, where first century Christians hid from those trying to stop the new religion by killing disciples and new converts. There were 47 adolescents and five adults in our group. We entered through an ancient house, now a monastery, and walked down into the catacombs, where early popes and martyrs were buried. In these catacombs are frescoes representing the first Christian symbols. The earliest known painting of Mary holding the infant Jesus is on a wall in the catacomb. A steep walkway was lined floor to ceiling with small recesses where infant bones once lay. I slowly and sadly walked down the steep slope and put my hands on the dusty surfaces of the rectangular niches and felt a connection with parents who lived nearly two thousand years earlier. We gathered for Mass, and I offered the communion cup to the young man who had been cup minister at Conor’s funeral mass. I was in a place where healing could occur.

Three years later, we travelled with Patrick to northern Maine for my paternal family reunion. Before the afternoon clam and lobster bake we wandered around the small fishing town my grandfather had left as a teenager more than a century earlier. We found the silvered, weather-worn clapboard Cape house my great-great-great grandfather had built while my grandmother lived in a tent with a cow for warmth. We wandered through an ancient family cemetery with blueberry bushes and roses brushing up against gravestones weathered by wind, rain, snow and salt spray. We found the grave of Elizabeth Merritt, who had died as did Conor in early April. She had died at two years, four months and eight days in 1902. Her small white marble headstone was beautiful: a square on end flanked by carved leaves and topped by a simple flower. Nearly a century later it was blackened in spots, cracked, its letters worn. I was struck by the effort made in this poor community and the careful chronicling of her days on earth. Her twin brother died nine years later, the end of that line. We found the double grave of my grandfather’s two siblings who died young, Herman at three and Olive at seven, a day after her birthday. I had been told my grandfather was the oldest of five, but there were seven with two siblings who had died 16 months apart. Eight years later my great grandmother had her last child, twenty years younger than my grandfather. It was a beautiful but harsh land and survival was not guaranteed. Children were lost and families were often large, perhaps in part in acknowledgement of that reality. One relative, an only surviving child, lost three husbands and one fiancé at sea over sixteen years. She had surviving children with all of them (yes, fiancé too) and lived another fifty years to see four lines continue.

A friend has spent much of his adult life tracking his family back to England and the continent. His ancestors settled in New England in the first quarter of the seventeenth century. He listed the generations, determined where his ancestors lived and what they did and from that wrote a history book. As he worked with the lists he

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Here So Short a Time, continued

(Continued from page 8)

developed, he was struck by how many infants and children had died, especially in early colonial generations and during the years of the young republic. His one year old grandson represents the 30th generation of the family name being carried through the male line. Seeing the hundreds of names of those who died as infants or in childhood and still others who died as youth reflected the precariousness of life in earlier times, and the challenge to a continuous line, a rare occurrence.

He organized these children by first name, later by immediate family. There were four named Abiah, seven Josephs, six Abigails who had died young. There were six Davids, three who died as infants in two years, six named Emily, three dying as infants. Six of nine Georges died as infants, seven of thirteen named Henry died as infants and at least half of fourteen children named Sarah died as infants. Eight of 23 named Mary died as infants, another eight before the age of five. The list is overwhelming. So many died soon after birth. Others were taken by disease or accident during childhood. The six pages of single spaced names included only those who were born, no miscarriages. There were more losses in this family line in earlier centuries, but two infants died in the last half of the twentieth century. Infant death remains part of the human condition.

Many families faced such tragedy multiple times. Elijah and Abigail had nine children with six surviving to adulthood. Children born over eleven years died over fourteen years. Samuel and Elizabeth in the decades before the American revolution had three children die as infants over thirteen years. A fourth was born the year after the last death, died as a youth. Joseph and Mary named their daughter Martha, but she died quickly. Four years later they named another child Martha, and she died after a few years. Isaac and Lucy named two daughters Lucy and both died as infants, as did their son Isaac. Jonathan and Rebecca during and after the American revolution had two infants and three children die. In the early twentieth century a couple named two infants Marion and both died in the year of their birth, a year apart. There were many families in which the wife survived childbirth many times, which was not always the case, and had children into her late 30s or 40s. Infant death in those later pregnancies might have been because of trisomy. In 1672 Thomas and Margaret named their daughter Hopestill, but she died within months. I thought with each birth, despite the statistical likelihood that there would not be survival, all these parents must have held hope still.

The death of an infant is an unexpected and devastating event. Such loss was once more common, as was the death of young children. I remember learning that in nineteenth century America 25% of children died. Mark Twain’s books which celebrated childhood were important, because he gave us Tom, Huck and Becky, who were not short adults but real children, mischievous, funny, clever, kind, and cruel, but qualitatively different from adults. He revered childhood. Conceptualizing children as less capable adults, not beings delightfully different, may have protected adults some from the pain of loss. I cannot imagine either frequency of loss or viewing children less sentimentally ever made the loss any easier. The pain must have remained. Just knowing a child has a limiting genetic condition such as trisomy 18 or trisomy 13 does not make his or her death any easier.

The progress we have made in this country increasing infant survival is not universal. Infant mortality is a yardstick for the health of a country or region. In other parts of the world infant and child loss is often high. Projections for 2012 indicate Afghanistan, Niger, Malia and Somalia have the highest rates of infant mortality, all more than 100 per 1000 live births or more than 10%. Infant mortality includes perinatal mortality of fetuses at least 22 weeks gestation to the seventh day after delivery, neonatal mortality in the first 28 days of life and post neonatal mortality from 28 days to a year. Deaths from one year to age five are considered child death.

We do not have good historical records for infant mortality, since birth and death records were not kept across the United States until 1933. Rates have been studied, and Michael Haines of Colgate University has given rates for both fertility and infant mortality. He notes the United States and France were the only countries in which there was a fertility decline as early as the beginning of the eighteenth century and preceded the decline in infant mortality. The number of children parents had was limited independent of likelihood of loss.

In 1850 the infant mortality rate was 216.8 for 1000 births for white babies and 340 for black babies, the numbers being 2-3 times higher than the current most affected countries. By 1900 the white mortality rate was 110.8 children per 1000 and the black rate was 170.3 infants per 1000. Both groups improved, and by 1940 the rate for white babies was 43.2 and 73.8 for black babies. In 1960 the United States had an infant mortality of 22.9 per 1000 for white infants and 43.2 per 1000 for black infants. Both groups had declining mortality rates but the ratio of nearly 2:1 stayed the same. By 2000 a rate of 5.7 per 1000 for white babies and 14.1 per 1000 for black babies. Today it is 5.9 infant deaths for each 1000 births with rates varying by region and ethnicity. Some native reservations and some areas of inner cities see more deaths, believed to be a function of poverty, less available health care, life style and nutrition. We have work to do. The United States is more than 100 countries below the best, although termination of diagnosed fetuses and different record keeping skews the ratings.

Fertility has also declined. In 1800 women averaged 7.04 children, a function of an agrarian society and child loss. In the next 50 years fertility declined by almost two children per woman. By 1900 the rate was 3.56 for white women and 5.61 for black women. The decline for both groups continued, and by 2000 both groups had about two births per family. Lower infant and child mortality contributed to the fertility decline, along with fewer agrarian families, more education, and growing independence and ambition of women.

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Through the centuries and across geography many families have held their infants too short a time. They have seen their dreams of watching their children become adults dashed. When a couple faces the impending death of a child they have just welcomed and later begins the difficult journey of going on without their child, they feel alone. Historically and geographically they are not. They join others who have also felt such loss. Those of us in SOFT whose children died, many in infancy, share an experience with other members. We also share a no longer universally common, but once widespread but never ordinary experience across time.
PROFESSIONAL VIEWPOINT:
Reflections on the Recent Bioethics Conference in Denver

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

On October 5 and 6 of this year, I had the opportunity to attend and participate in an exciting conference at the Center for Bioethics and Humanities on the Medical Campus of the University of Colorado. The Conference was creatively entitled, "Perinatal and Neonatal Decisions: A Pathways Approach Using Trisomy 18 and 13 as a Paradigm," by its Director, Dr. Peter Hulac. The meeting involved over 25 participants from various disciplines, including developmental pediatrics, neonatology, medical ethics, nursing, palliative care, pastoral care, and parents of family members with trisomy 18. SOFT was well represented at the Conference: Besides myself, Ann and Frank Barnes, Pam Healey, Jude Wolpert, and Scott and Vivian Showalter joined this multidisciplinary group. Scott and Vivian had a major role in helping Dr. Hulac plan and host the meeting. In addition to SOFT, the Conference was sponsored by the Bioethics Center, the Neonatology Division of the University of Colorado’s Department of Pediatrics, and the Trisomy 18 Foundation.

The purpose of the meeting was to discuss decision-making in the care of babies and children with trisomy 18 and 13 in the context of a care model called, “Pathways.” Dr. Hulac and colleagues had adapted this approach to decision-making from a spinal injury clinic at the University of Colorado. Pathways emerged as one of several main themes discussed at the Conference. Pam Healey has nicely summarized the structure and content of the meeting in her accompanying piece in this issue of SOFT Times, and I recommend reading Pam’s article as well. I would like to focus my reflections on another theme that was suggested early in the opening minutes of the Conference: “Shared decision-making as a working, guiding principle.”

The singular idea that shared decision-making would occur in the initial diagnosis of a fetus or infant with trisomy 18 & 13 reshapes the current paradigm whether we are discussing the prenatal or neonatal setting. From my experience in talking to families and doctors around North America over the last 2 decades, the approach at the time of diagnosis tends to be more directive—rather than a model that would include families and health professionals making care decisions together. If we as health professionals and families embrace this guiding principle at the time of diagnosis, the problems (and tension) with the “status quo”, as articulated by Dr. Hulac in his opening comments, would change—I believe—to a more balanced approach.

In the afternoon our working group broke into smaller units that were charged with applying the pathway model to various decision points in care (e.g. the time of first obstetric concern, the anticipation of delivery room care of the baby, etc.). As we split up into our individual group meetings, Dr. Hulac provided us with four questions (previously offered by one of his colleagues, Dr. Glover) useful in framing the initial approach to the counseling of families in difficult medical situations. His thought was that these queries might be helpful in pondering the Pathways model in the various scenarios:

What is the understanding of your child’s (fetus) condition (“fetus” added by me)?
How has the illness affected your family?
What is most important in the care of your child?
What do you fear most? What would you like to avoid?
What are your sources of strength and support?

Incorporating an approach using these questions and shared decision-making early in the process of diagnosis whether the setting is prenatal or perinatal—I would propose—“reshapes the current paradigm”. Along with these potential guiding questions listed above, I would suggest—as I did in the recent paper in Current Opinion in Pediatrics—that this process should include “presentation of accurate (and current) figures for survival that take into consideration the individual clinical findings…, the avoidance of language that assumes outcome…, a realistic but balanced communication of developmental outcome that does not predispose that one knows the family’s perception of quality of life, and the recognition of families choice whether it be (pure) comfort care or (medical) interventions”.

The ultimate plan of the group is to summarize the ideas and principles discussed at the Conference in a publication in a medical scientific journal. I certainly look forward to that goal.
We can only be said to be alive in those moments when our hearts are conscious of our treasures—Thornton Wilder

Thanksgiving Comes But Once a Year

Thanksgiving comes but once a year,
But when it comes it brings good cheer.

For in my storehouse on this day
Are piles of good things hid away.

Each day I’ve worked from early morn
To gather acorns, nuts, and corn,
Till now I’ve plenty and to spare
Without a worry or a care.

So light of heart the whole day long,
I’ll sing a glad Thanksgiving song.”

By Thornton W. Burgess,
a beloved New England storyteller

Guess whose poem this is:
Peter Rabbit        Billy Mink
Spotty the Turtle
Happy Jack Squirrel
Jimmy Skunk        Sammy Jay

Thanksgiving

By Ralph Waldo Emerson

For each new morning with its light,
For rest and shelter of the night,
For health and food,
For love and friends,
For everything Thy goodness sends.

We Thank Thee
For flowers that bloom about our feet;
For tender grass, so fresh, so sweet;
For song of bird, and hum of bee;
For all things fair we hear or see,
Father in heaven, we thank Thee.

Ralph Waldo Emerson
(1803-1882)

A poem for the children, and a question at the end!
SOFT BIRTHDAYS – A Reason to Celebrate

Submitted by Debbie Dye

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

Morghan Kubena just turned 16 years old. What a beautiful young woman she has become. I remember like yesterday when that cute little toddler cradled in her Daddy’s arms posed for a picture with our Morganne at a local restaurant here in Salt Lake. I had met Faye on the internet, and being that she named her daughter the same special name I had named mine gave me reason to strike up an email conversation with her. Mark and Faye came to Utah for a ski vacation and we were able to meet up for dinner and became instant friends. I think Mark and Faye are a couple of just a handful of our SOFT friends who were actually able to meet our sweet Morganne in person. How lucky and how blessed we are for that meeting. Morghan has been a true joy in our lives, and we will forever be grateful for that little sweetheart. Happy sixteenth birthday sweet girl and thank you for being in our lives and for bringing your parents into our lives. We cannot put into words how blessed we feel. Thank you to all 3 of you for always being there for us. We will be forever friends. LOVE YOU GUYS!!!

Ashton Wagner just turned 13 years old. I first met Steve and Raquel, also on the internet, and through conversation realized that they lived less than 5 miles away. This was about 9 months after Morganne had passed away. I stopped by their home on my way from work one day and met this tiny, fragile little baby. I was so scared—I had fallen instantly in love with her, and she was the first trisomy baby I had seen since Morganne had left us. What a blessing she has been in our lives. She was so tiny and only 5 months old. I feared that I would get attached and lose her too. I was so wrong, thankfully, and have had this beautiful child in our lives for 13 years now. Her siblings and parents have also become very close to our family. Again, we have been blessed because of our angel. I know she is watching over us. These two trisomy blessings from heaven because of our little angel we only had for 7 short months. She continues to bless our lives and always will. Love the Wagners!!!

We also just celebrated Morganne’s 14th birthday on Oct 8. It was a great day to remember a beautiful little girl. We decorated her grave with all the fun things a 14 year old would love. We went to get a bouquet of balloons, but apparently there is a helium shortage, so the local party store didn’t have any. But, yes, I do work for a large grocery store chain. Certainly one of them has some helium, and I was successful in my search to leave a big HAPPY BIRTHDAY Balloon bouquet for our baby’s 14th birthday. It just happened to be Columbus Day, so everyone was off. We spent some time together as a family at the cemetery and released balloons to heaven for our angel. I’m sure she was joined with other SOFT friends to celebrate her day. That day will always be special in our lives, and we will forever celebrate. Thank you Morganne for making our lives so special and for bringing such wonderful people into our hearts. There are so many friends that she has brought into our lives, not just Morghan and Ashton, and we will be forever grateful for all of your associations.

Last year we traveled from Salt Lake to New York to celebrate Stacy Van-Herreweghe’s 30th birthday. I don’t know of any better reason to travel across the country than to celebrate a special birthday. YEAH for milestone birthdays!!! Here’s to many more for all of our SOFT KIDS. We are forever a SOFT family because of Morganne. Jim and Debbie Dye
Holladay, UT
softofutah@aol.com

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Trisomy 18 and 13: What’s new in 2012

Stephen Braddock MD  Cardinal Glennon Children’s Medical Center addressed the board during the lunch break at the St. Louis conference

By Pam Healey

Dr. Stephen Braddock began by explaining that in looking for something new on trisomy 18 he googled and found 46,000 articles, but only a few were on clinical topics. He chose the three newest, all since summer, 2011 to review. These were on the changing technologies of genetics and decisions to treat aggressively.

Maeda et. al. 2011 reported on the impact of cardiac surgery on patients with trisomy 18 in Japan. There were 134 patients from neonatal units in Japan. There were 126 or 94% who had congenital heart disease. Of these 59% had ventral septal defect (VSD). Another 11% had double outlet right ventricle (DORV). Pulmonary hypertension was diagnosed in 52% of the patients, and 46% had valvular disease, typically polyvalvular disease. A VSD is the most common and the simplest structural cardiac defect. Some patients had a combination of all these problems. Twenty-five percent of these infants had surgery. Survival at the age of one month was 56%. There was survival from two to 216 months with the median age at surgery 1.8 months. With cardiac surgery pulmonary hypertension improved in 57% of the young patients. This is a condition that ultimately can lead to death, if pressure becomes too great in the lungs.

In the past trisomy 18 has been seen as a lethal condition. Parents are told they will not have much time with their child. The old approach of “don’t expect much time with your child” is changing with surgery being offered. Survival estimates are significantly higher for those who had surgery, than for those infants who did not. If the protocol is changed and cardiac surgery is offered to more infants with trisomy 18, then outcome is better.

There were 27 patients with trisomy 13. Twenty-three of the patients, or 85% had coronary heart disease (CHD). Twenty-two percent had an atrial septal defect and 17% had a ventral septal defect. A double outlet right ventricle was found in 13% of the patients with trisomy 13. Half had pulmonary hypertension. The surgery took place from the age of four days to nine and a half years. Those who had surgery had longer survival.

Conclusions were that cardiac surgery resulted in better life outcomes, particularly with children with trisomy 18. Mortality rates were still higher than in similar non-trisomy cases. It is unclear if overall prognosis improves, since the numbers are too small. Those who survive still have medical and developmental issues, and lower life expectancy. Their prognosis will not necessarily improve. Cardiac surgery may be indicated for relatively simple coronary heart and/or extracardiac complications. Physicians and parents should discuss options and respect varying opinions in decision making. It is important that physicians explain options and make recommendations and not judge. It is important in speaking with parents that they be open, not sugar coat the situation and give realistic information about possible outcomes.

Palomaki et. al., 2011, reported on prenatal diagnosis, a topic of current interest. It focuses on what is and is not changing. At this time DNA sequencing of maternal plasma reliably identifies trisomy 18 and trisomy 13 as well as Down syndrome. This study is an international collaborative study of prenatal diagnosis that will change the way doctors will work with families. Prenatal screening includes Maternal Serum Alpha Fetal Protein (MSAFP) and nuchal translucency tests. MSAFP are given by drawing maternal blood between weeks 14-22, preferably between weeks 16-18. There is 60% detection with low false positive. The screen can only indicate the child to be at risk for aneuploidy (trisomies) or spinal bifida. A positive finding raises concern that can lead to the recommendation of an invasive test, such as CVS or amniocentesis before a decision can be made based or an accurate diagnosis attained. Invasive testing carries the risk of fetal loss.

Now there is non invasive Maternal plasma cell free DNA sequencing procedure. In this test given in the late first or early second trimester little bits of circulating fetal DNA (4-10%) are looked at and compared, arriving at a ratio of what DNA is from the baby.

This test is excellent for Down syndrome but not as successful in detecting trisomy 18 or trisomy 13. Findings were that with fetuses with trisomy 18 in 59/62 samples at high risk, the child had trisomy 18, 100% accurate with too little DNA to predict in three cases. With trisomy 13 there was one child with a false positive, but the rest were positively identified.

The recommendation is for this noninvasive procedure to be given as a secondary screen after the MSAFP is positive for a trisomy. If this also indicates an abnormal finding, then an invasive procedure should be considered.

The maternal plasma cell free DNA sequencing tests has several advantages. It can be done as early as ten weeks. It has a higher detection rate than biochemical tests now being used. It may avoid invasive procedures which carry the risk of fetal loss. Disadvantages include that it may increase anxiety, since there is less confidence in the new method, and expectant mothers may then go directly to amnio. It is expensive and insurance may not cover the costs or may not cover the new procedure but will cover amnio. Insurance may cover one or the other, not both. The cost may then be out of pocket. It takes ten

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Trisomy 18 & 13: What’s new in 2012

(Continued from page 13)

days for results to come back. This test is not good for a twin pregnancy. This new technology is here to stay, and we must consider what we do with it. The doctor’s job is to make families understand what tests are available and what each can do, that is what results actually mean.

Nelson et al. Pediatrics, May, 2012 report on inpatient hospital care of children with trisomy 13 and trisomy 18 in the United States. Information is gathered from national databases over fifteen years. They looked at hospitalizations for those with trisomy 18 (1036,615) per year and those with trisomy 13 (846,907 annually) with two-thirds being non-birth admissions. The procedures at a Catholic hospital may have been more frequent with a mind set to help all children. There was an equal payer/Medicaid mix. This is complicated since the child with family insurance ends up on Medicaid, so combined insurance is often the case. There are changing dynamics with more surgical procedures and for those with trisomy 18, longer hospital stays over the duration of the study. There were 2765 procedures with those with trisomy 18 being 64% female and those with trisomy 13 being 52% female. Six percent of procedures were for esophageal sphincter creation, 4% for ASD/VSD repair, 4% for tendon release or tightening, 3% for a tracheostomy. There were few out-patient procedures, probably because it was not clear how the child would fare with anesthesia. Most procedures occurred after the child’s first birthday. Specifically, 41% of those with trisomy 13 and 32% of those with trisomy 18 were less than a year. The exception was heart surgery in those with trisomy 18. Heart surgery needed to be performed in infancy. More parents are advocating for their child, requesting more medical procedures denied earlier, and more physicians acting on their requests. We are in some ways moving away from paternalistic medicine. It was exciting when cardiac surgery was performed without resistance. This is encouraging when geneticists do not ask about long term outcomes before approval of the surgery. Some cardiologists do not accept the inevitability that 90% of those with trisomy 18 or trisomy 13 will die in the first year.

Another observation from the data is that there was an increase of discharges of children with trisomy 18 to home health care or hospice care. The rate doubled. This meant a decrease in the rate of death in the hospital, suggesting the child was better at home than in the hospital. There were no changes in either the disposition home or in hospital death rates for those with trisomy 13. A small but significant number of children with trisomy 18 and trisomy 13 survived past the age of one. This is evidence that generalizing the lethal label to a diagnosis of trisomy 18 or trisomy 13 is inappropriate. Dr. Braddock added that life is lethal, and every one will live long enough will die of something.

The findings of this study underscore the importance of being a parent who advocates for medical procedures for his or her child. Doctors should work with a team, including parents, learn the answers and practice medicine by being a well informed advocate for the patient. There will not always be agreement but discussion is a starting point, and the increasing incidence of both surgical procedures and longer survival support more aggressive interventions, regardless of the high mortality of those with trisomy 18 and trisomy 13.

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Giving Thanks
by Author Unknown

Giving Thanks
For the hay and the corn and the wheat that is reaped,
For the labor well done, and the barns that are heaped,
For the sun and the dew and the sweet honeycomb,
For the rose and the song and the harvest brought home - Thanksgiving! Thanksgiving!

For the trade and the skill and the wealth in our land,
For the cunning and strength of the workingman’s hand,
For the good that our artists and poets have taught,
For the friendship that hope and affection have brought - Thanksgiving! Thanksgiving!

For the homes that with purest affection are blest,
For the season of plenty and well-deserved rest,
For our country extending from sea unto sea;
The land that is known as the “Land of the Free” - Thanksgiving! Thanksgiving!

Thanksgiving! Thanksgiving! Thanksgiving! Thanksgiving!
Friendship is born at that moment when one person says to another: “What! You, too? Thought I was the only one” – C.S. Lewis

Once again, our SOFT Utah family met together for our annual pool party and barbecue. We all had a great time, some new friends and some old, but, like last year, we had over 70 people attend for an evening of great conversation, SOFT children, siblings, food and swimming. We love this annual tradition and are grateful for our large chapter. Thanks SOFT OF UTAH.

We will again get together the Monday after Thanksgiving for our annual tree decorating for the Festival of Trees to raise money for Primary Children’s Medical Center. We’ll follow up next newsletter with an article about our tree.

Soft Utah Chapter

‘Let us remember that, as much has been given us, much will be expected from us, and that true homage comes from the heart as well as from the lips, and shows itself in deeds.’

Theodore Roosevelt

To speak gratitude is courteous and pleasant, to enact gratitude is generous and noble, but to live gratitude is to touch Heaven.

~ Johannes A. Gaertner
“So interwoven are the threads of human life that no single contact is trivial. Even in our most casual moments we entertain angels. Around the humblest of us are the influences which touch eternity.”

A counselor experienced in helping families during crisis spoke on television and shared his experiences and wisdom. I heard this message when Kari was just two years old. I was impressed by it then and I am still impressed by it today. This counselor stated many facts and experiences, but I remember only this one poignant statement … “The common thread between families that withstand the challenges of a crisis, such as the birth of a child with disabilities, are those families that believe deeply in ‘something’. What that ‘something’ is was not as important as the fact that they believe deeply! The ‘something’ could be a life philosophy, a religion, a value code, or whatever as long as it is extremely important to them. The result is very stabilizing for the family.”

I believe in LOVE! Our children are our joy and our grandchildren are our delight!

I believe in LIFE! Kari taught me to enjoy life and “seize the moment.” I treasure the memories her life has given me. Her influence is still with me today!

I believe in FRIENDSHIP! It is true what they say about a friend… “A friend is someone who understands your past, believes in your future, and accepts you today just the way you are.”

I believe in JOY! "Happiness is not a state to arrive at, but a manner of traveling." – Margaret Lee Runbeck

I believe in FAMILIES! Hal & I have been blessed beyond our dreams with children who are honorable and courageous. We have a proud heritage in our parents and theirs before. We have pleasure from siblings that we love. We have hope for the future in our children and grandchildren.

I believe in ETERNITY! I believe there is a place beyond this life! I believe death is not the end. I believe families can be together forever! I believe that I will see Kari again!

Time is
Too slow for those who Wait;
Too swift for those who Fear;
Too long for those who Grieve;
Too short for those who Rejoice;
But for those who Love,
Time is Eternity!

Hugs…Kris
There are two ways of spreading light: to be the candle or the mirror that reflects it. - Edith Wharton

Cairns

By Pam Healey

In 2010 I fell simply crossing a road in Southwest Harbor, Mount Desert Island, Maine, smashing my camera into my knee, ribs and cheekbone. My palms and forehead hit the pavement. I looked as if a truck had been involved. Last year we returned to Acadia National Park and in the spirit of getting back on the horse, I took my battered but still working Nikon up the 2.2 mile North Ridge Trail to the top of Cadillac Mountain. There, from October 6 to March 7 the sunlight first hits the continental United States. We missed the sunrise, but did climb, not drive to the top. Cadillac is one of seventeen mountains in the park, all created eons ago by shifting tectonic plates and volcanic eruptions. All were sheared off and smoothed by later glacial action, the fate of all Eastern mountains. Subterranean upheaval and massive ice movement create dramatic landscapes that now beckon, astound and capture the imagination.

The hike to the summit of the 1532 foot mountain, the highest peak on the Atlantic seaboard, is a moderate trek over pink granite dressed in gray-green lichen, bordered by short spruce, scrub pine and scarlet weather-shaped bushes that add a decorative accent. There is a remarkable view of the park, Bar Harbor and the offshore islands during most of the journey. On this day the Acadian lakes were slate blue, the foliage yellow and a dusty red and the clouds soft gray with light found only at the continent’s edge. It was a good place to experience fall in New England.

With age, creaky joints and shortness of breath telling me time’s winged chariot was hurrying near, I also needed to be the one in hiking boots, whose head popped up from below the parking lot, not one who walked off a tour bus. It will be tour bus jaunts soon enough. At the bald summit, to the Northwest can be seen the Hundred Mile Wilderness and five thousand foot Mt Katahdin, the northern terminus of the Appalachian Trail, looming more than a hundred miles away. Further south and west can be seen the Presidential Range of the White Mountains, including the majestic and treacherous Mount Washington, the white scar of Tuckerman’s Ravine facing us. There is something remarkable about vistas that include both mountains and sea. Looking northeast across a silvered ocean, we can see maritime Canada.

The ascent was an easy one, and the journey, not the destination, was the point, even with the summit views. The entire time there was so much to capture my attention in the distance from my new vantage point and at my feet. Not all was natural. I was fascinated by the more than twenty cairns strategically placed on the trail. On the granite face of the mountain, they were easy to spot, and many times redirected us to a twist in the trail that crossed through vegetation or through, up, or around rock outcroppings. Cairns dot Scandinavia and the British Isles. Inuit cairns mark northern hunting trails and predate European settlement in North America. Archeological finds include African and Asian cairns. Strategic rock constructions are universal.

Near the trailhead there is a sign admonishing those who might rearrange existing cairns or build their own. To do so could bring disaster. The cairns are carefully placed rocks that trail crews had built, some as early as in the first decade of the twentieth century. Ridge runners rebuild cairns and destroy those made by hikers. The cairns I saw are made in the style of Waldron Bates, and use stones large enough not to topple. They are placed so they are easily seen silhouetted against the sky and against the granite mountain face. Cairns mark trails and guide hikers who might find themselves in a snowstorm, fog or waning light, when the blue paint trail markings become invisible. Even on a clear day they give a literal heads up, since they can be seen before the paint mark is apparent. That day the blue patches directed us, but the cairns captured my attention.

(Continued on page 18)
Several signs along the way told us that adding to cairns, or building additional rock objects detraets from the natural landscape, reroutes hikers, which causes plant loss, then soil erosion. The pathway is critically important. In large letters it was printed, "Leave the mountain and the rocks as you find them." That is a strong message, repeated often enough along the trail to get one focused on the business of cairns. So, on a clear morning with blue trail marks leading us on, I thought about cairns and photographed each one. They were all different: simple architecture, cryptograms in stone, their age suggested in lichen patches. A few seemed to have random small stones placed by people who could not read and had little artistic sense. The ridge runners would soon make adjustments.

I thought about the cairns and decided that we need cairns in our everyday lives to guide us: concrete symbols to make sure we took the best path and reached our destination when the journey was unfamiliar and danger possible. We need cairns to assure us we are where we are meant to be and have not lost the trail, when what needs to be done is ambiguous or stress shrouds the obvious. Each cairn is different; each one constructed to assure the right turns are made when the trail grows dark.

Life does not often have concrete markings to keep us on track. We need to rely on spiritual, experiential and intuitive cairns on our individual journeys, when circumstances are not what we expected or wanted and the usual guiding markings become obscured by unfamiliarity, confusion, other voices and conflicting interests and beliefs.

SOFT has its own cairns to help guide parents who find themselves on a journey they never envisioned. We have the surgery data base of success rates and hospitals that give parents information that can lead to often denied surgeries to extend their child’s life or improve quality of life. We have parents with advice about nutrition in G-tubes, the best doctors in the area, adaptive equipment, stimulating toys, technology and therapies. Our health care professionals give information about innoculations so parents can insist on them. They give information about the need for regular ultrasounds to detect cancers of the kidney or liver. We have growth charts, charts of developmental milestones children with trisomy typically meet, and evidence of exceptional achievements that extend the possibilities. These are the guideposts that keep often bewildered parents moving forward when crises, stress and fatigue cloud the landscape.

The trail crew consists of parents who have learned what works and doctors who value our children and do what needs to be done, despite the diagnosis that has historically carried labels of "incompatible with life" and "incompatible with life." They are the ridge runners who clear away misperceptions, unfair judgments and policies and protocols that thwart not just progress but survival.

Some cairns, found at historical landmarks, mountain tops and religious sites are built slowly with individual rocks reverently or triumphantly added. Each SOFT parent can leave a rock helping to build a unique cairn by contributing another voice in a research study, by sharing their family story in the newsletter or the SOFT website or by having a conversation with other parents through e-mail, phone calls or Facebook. They take care to add only what is helpful, free of judgment and within their expertise. Their rocks are carefully chosen: advice, not prescription, the authority of parenthood not medical school.

Many parents benefit from those cairns left by others as they journey up a long mountain others have climbed before. Those cairns not only guide decisions and many times extend the journey, they give assurance that what does not appear a well walked passage has been shared over time and geography. They are guided as they move on with time to stop and enjoy the scenery, relishing the time with their child as an important part of their family. They can move forward with important knowledge left by others, feeling more empowered and competent to meet the day’s challenges and work toward a better tomorrow. Those parents whose journey ended too soon in sorrow also leave cairns that assure others, at a time of feeling most lost that their route is shared and they will prevail.

Denver
Bio-Ethics Conference

In early October in Denver, a group of SOFT parents professionally involved within the trisomy community joined other professionals, including neonatologists, pediatricians, genetic counselors, palliative care doctors and nurses, a hospital chaplain, a pediatric cardiologist, a writer who is a developmental psychologist working with parents with the most vulnerable children, and geneticists. There were researchers and those on the front lines. All had both passion and wisdom. Individuals had extensive experience with different aspects of medical and counseling support. One goal was to move away from the silo approach with each specialist working separately to a collaborative approach with clinicians working together.

The task was to determine the pathways that should be defined to best meet the needs of infants with trisomy 18 and trisomy 13. The pathway might start at prenatal diagnosis or immediately after birth when a diagnosis is suspected. Just as there are cairns along a mountain trail to the summit, there are decision points along the

(Continued on page 19)
Cairns

(Continued from page 18)

way, the summit being longer survival or more comfortable survival for a shorter time. The pathways might be determined by letting go or holding on. On each pathway are specific tasks that can be undertaken, decisions that may become the cairns for the best route. The goal was to find the right pathways between doing too little and doing too much for children with an extra chromosome and significant medical complications.

We met in our large group of more than thirty people, and shared our ideas. We were not coming together to settle an argument, to determine winners or losers within a philosophical argument. Our mandate was to share ideas and determine specific recommendations we could agree on. Our model was to be an interdisciplinary team considering what is best within certain cultural, fiscal, legal, technological and ethical constraints.

We built on what was said, disagreed some, elaborated initial ideas and worked to be specific and realistic in recommendations. We learned from each other, collaborated and became engrossed in the difficult work of integrating so much experience and so many ideas. We sat in a banked circle in an impressive new amphitheater in the Bioethics and Humanities Center at the University of Colorado Anschutz Medical Campus. We introduced ourselves and defined our experience relevant to the trisomy community, were educated by presentations, challenged by tasks. We used information from the presentations about recent research in meeting the demands of the mission ahead of us. As a group we shared insight, asked questions and narrowed our definitions and suggestions. We filled many pages of newsprint that were taped across the room.

Later, we broke into smaller focus groups to define specific pathways and what needed to be considered and done. We returned to the larger group and shared the details of our discussions. We spoke of what small and large actions needed to be taken and who should be involved. We tried to consider those whose voices were not included: surgeons, labor and delivery nurses, parents who chose to terminate, siblings and the infant with trisomy 18 or 13. I was part of the diagnosis after birth group. We discussed language, procedures, both the information given and its timing. The point of view shifted within our group of parents, doctors, nurse, genetic counselor and chaplain. We saw the situation differently but shared common concerns and outcome. We learned from each other and began to build our pathway, each decision point a cairn marking our path. We acknowledge the importance of calling each newborn by his or her name. We acknowledged that the birth was a celebration, despite a looming probable diagnosis. We talked about language given to describe the disorder and how genetic results would be shared. We considered interventions along the way and what they meant, including intubation, nutrition, medication, and surgeries. We considered the power structure and the need to empower parents by giving information and listening. Together we added individual perspective gained by experience and education, and collaboratively built our pathway which would best provide care for newborns with trisomy 18 or trisomy 13 and support for their parents.

Together, in each focus group we built cairns that will guide parents and their doctors, nurses, counselors, psychologists, and chaplains in the future, so fewer stray from the optimal pathway and meet with avoidable disappointment or second guessing. Through the two days we acknowledged that despite the best efforts of all those involved with doing what is best for a newly diagnosed fetus or infant, the diagnosis remains a medically serious one, even if it is not necessarily universally lethal. No one’s pathway is easy, direct or predictable. Knowing the possible challenges, areas of disagreement and probable unclear outcomes helps all those involved move forward. The work we did was an important beginning to a process that will continue.

I left Denver’s blue skies and cold mornings and the magnificent views of 14,000 footers capped in snow. Two weeks later we returned to Acadia for our annual visit. Saturday, we awoke to driving rain and a local weather report of partly cloudy. A few hours later the rain let up, and we drove through the park. The narrow roads are bound by granite blocks and ragged granite precipices, which had become a showplace of temporary waterfalls, all eye catching, some dramatic. The streams were flooded and spilled over their banks and roared over rocks now hidden by white froth. We stopped more often for photos on the Loop Road.

There was no point in stopping at scenic overlooks but many reasons to pull over as we cut through the woods. The clouds lifted a bit in places, and there were views across meadow and ponds to yellow woods softened by mist and truncated mountains lost in low clouds. We walked Sand Beach, and each brought out an armful of trash washed in at high tide during the last night’s

(Continued on page 21)
Thank you, 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**

Donations to **SOFT’s general funds**
- Ioannis Karmis
- Joseph Cannizzo
- Scott Crosier

Donations to the **Joey Watson Fund**, Established to help financially challenged families attend the annual SOFT conference

**In Honor of Gabby Horner-Shepherd on graduating up to high school**
- R. Gupta
- Rick and Sandy Horner

In Memory of **Isabella Carolyn Powell**
- Sharon Pitstick, friends and colleagues at ASML
- Jenny, Marc, Sydney, Isaac and Cohen Childress
- "Isabella now plays among the stars with our Julia."

In Memory of **Regan Lawson**
- Elliott and Patty Lawson and family

In Memory of **Nicholas Wright**
- Sharon K. MacMaster

In Memory of **Jackson Paul Kutzik**
- Martin Carcache
- Friends and family of Jamie and Ryan Kutzik
- Anita Reed
- Jamie Lee Cruz
- Bay Area BleachBright

In Memory of **Evan Thomas Gallen**
- Karen Patterson
- Edward and Anne McAssey, with loving thoughts and prayers

In Memory of **Rebecca Van Cruyningen**
- Tobi Burch Rates

In Honor of **Madison Cadieux**
- Jessica M. Reynolds

In Memory of **Matthew Corbett Chambers**
- Andrew Herzig
- Sam and Amy Scaling, with deepest sympathies
- Sheena Taylor
- Margaret Schwirian, in loving memory of Matthew

In Memory of **Adalyn May Scholz**
- Troy Care and Rehabilitation Therapy Team

In Memory of **Claire Josephine Carlyle**
- Jodi Evans, teacher
- Kim and Chad Leggett
- “I had the pleasure of working with Grandma Stef at school. She adored Claire. We continue to lift your family up in prayer as Claire watches from above.”
- Sandy Sykora
- Melissa Sindelar
- Karen Livingston “Thank you, SOFT, for touching the lives of Kyle, Lauren and Claire Carlyle. Your organization is greatly appreciated.”
- Mary and Gary Grimes “God Bless your Little Angel”
- Sue Fjelstad

In Memory of **Noah Idan Stein**
- Aunt Iris and Allen, in memory of Noah, the cutest angel in Heaven.
- Aunt Marian and Uncle Allen Warmbrand
- “Your beloved son, Noah, was blessed to have been shown such love, care and devotion.”
- Marina and Anya Ilinskaya
- Debbie Surendra, Talbott Springs Elementary School
- Judith Barr

Page 20, The SOFT Times, November/December 2012/January 2013
Thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, thank you, 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**

Vulnerability Research Lab, Virginia Maria Fejes
Ed and Vicki Olszewski
Julie Stover
Jimmy and Sarah Choi
David Tucker
Kinley and Andrew Bray
“In loving memory of Baby Noah and his brief time here in our world.”
Lucy and Frank Anton and family
“Noah is an angel looking over you both.”
Christine Skarvelis
Pete Palmieri
Dana Garner
“May God hold Noah tight and give you peace.”
Diana Nam
“In Honor of Noah Idan, who was born Sept, 2012 and passed peacefully on Sept. 27, 2012.”
Stephen Cosenza
Katie and Jeff Thorn
Scott Stevenson and Sarah DeStefano
“We are so inspired by your strength and love for Noah.”
Colby Moore
Laurie Ressler
“May God’s peace be with you all as you remember your son’s life.”
Jennifer Lynch
Christine Skarvelis
Dana Davis
Doni Ernst
Eleanor and Paul Rostoker
Eileen Monford
Megan Knysak

In Memory of Alexis Alves
Jim and Susan McCallum

In Memory of Faith Isabella Ford
Barbara Lersky
Holly Carr

In Memory of Brandon Maxwell
Tammy Maxwell

Cairns

(Continued from page 19)

storm. Later, we drove the three and a half mile winding road to the top of the mountain, but soon we found ourselves in thick fog. There is no turning back, so we continued to the summit, where the fog was being blown horizontally from the sea. We could see the car in front of us, nothing more. It would be a day for cairns, but finding them might be challenging.

We returned to Bar Harbor and took a seaside trail and hopped over deep puddles. The tide was high, and the waves crashed against the sea wall. Someone had built a cairn on a boulder at the water’s edge. A disappointing day had turned into a new experience. The park was redefined, and brought new wonders after the storm.

The next day we awoke to perfect blue skies and planned to hike a different trail on Cadillac Mountain. The puddles in the parking lot suggested the trails might be wet. The ranger, a former colleague of mine, said the mountain would be slippery and hiking should be postponed another day while water drained. We joined the tour bus people and drove to the top and walked the well traveled summit paths. The views were extensive, the light magical and the air crisp. Water lingered in depressions and drained over rocks, the only evidence that a day earlier the mountain belonged to the clouds. Our landscape changes, the familiar is lost, new situations engage us. We address challenges, make adjustments, look for beauty and find it. We survive storms and welcome what comes next.

- Pam

Whether our children are in our arms, by our side, in our hearts or waiting to be born, may we all give thanks for the joy they give us, the lessons they teach us and the possibilities they carry to bring us all to a better place.

**CONFERENCE SPONSORS NEEDED**

If you are considering making an end of year charitable donation, kindly think of SOFT. There are many ways to assist us in our mission to provide support and understanding to families involved in issues and decisions related to trisomy 18, 13 and related disorders. Our annual conference needs sponsors in order to keep expenses as low as possible for families. Your sponsorship will be noted in the conference manual as well as promoted at the conference. If you would like to assist SOFT in this way, please contact Pam Healey at healeylex@aol.com or Barb VanHerreweghe at barbssoft@rochester.rr.com

SOFT is a 501c-3 charitable organization
SUPPORT ORGANIZATION FOR TRISOMY 18, 13 AND RELATED DISORDERS  
Membership join/renewal form

**PARENT Name(s):**

**Mail Address:**

<table>
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<th># Street</th>
<th>City/Town</th>
<th>State/Province</th>
<th>Country</th>
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**Phone:** (  )

**E-mail:** ____________

**CHILD’S Name:**

**Sex:** (circle) M F

**Date of Birth:**

**Date of Death:**

**Cause of Death:**

**Affected Chromosome:**

18 ☐ 13 ☐ Other: ____________ (please specify)

**Diagnosis:**

Full ☐ Mosaic ☐ Partial ☐ Translocation: ____________ (please specify)

Other (please explain): ____________

---

**Child Health inquires:** Providing SOFT with information about your child’s growth, immunizations and surgeries is **optional**. This data might be of help for other families or for medical studies concerning our children. We would appreciate your input.

**Growth:** (Circle all that apply)

- How is (or was) your child fed? Tube ☐ Bottle ☐ Breast ☐ Cup ☐ Spoon ☐ other ☐
- Is (or was) your child able to self-feed? YES ☐ NO ☐ With Help

**Birth weight:** ____________ (lbs/oz)  
**Birth Length:** ____________ (inches)

**Current/Last Weight:** ____________ (lbs/oz)  
**Current/Last Length:** ____________ (inches)  
**Current/Last date:**

If your child is no longer living please provide last known measurements and at what approximate age: ____________

**Immunizations:** (Circle answer where applies)

1.) Is your child or, if no longer living, was your child up-to-date with your state recommended immunizations? YES ☐ NO ☐ Don’t Know

2.) Is (or was) your child on a delayed immunization schedule? YES ☐ NO ☐

3.) Did you decline (refuse) any immunizations? NO ☐ ALL ☐ SOME ☐ (explain)

4.) Did your child receive the Synagis series for prevention of RSV? YES ☐ NO ☐

5.) Did (or was) your child receive a seasonal flu vaccine every year? YES ☐ NO ☐

6.) If your child had a reaction to any vaccines/shots, please explain which immunization and reaction: ____________

---

**Surgical Information:** SOFT maintains a surgery database to help families needing information. When reporting surgeries using a mailed paper form, use a separate page if more entries are needed. When reporting by Web, if additional space is needed, use the ‘add surgery’ button to make as many lines as needed.

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**SOFT Survey:** (Circle answer which applies)

1.) How did you learn about SOFT? Health Care Provider ☐ Another SOFT parent ☐ WEB site ☐ Other: (explain) ____________

2.) Barb VanHerreweghe is the contact person for states that do not have a local chapter chair. Have you been in contact with Barb? YES ☐ NO ☐

3.) Have you been in contact with someone from your state or nearby state that is your state’s local SOFT chapter chair? YES ☐ NO ☐

---

**Circle Card Name:** VISA ☐ MasterCard ☐ Card #: ____________ Exp. Date: / month/year

**Signature:** ____________ Date: ____________

**Annual Membership: U.S. = $25; Other Countries = $35 in U.S. Funds. Multiple years are welcome. Enter Amount:** ____________

**Joey Watson Fund:** This fund was established to help financially challenged families attend the annual SOFT Conference. If you wish to donate to this fund, please add a donation to your membership fee and enter the amount here: ____________

---

**Donations:** If you wish to make a donation to SOFT to help with operating costs, please enter the amount here: ____________

**TOTAL AMOUNT:**** ____________

---

**PLEASE SEND THIS FORM, AND PAYMENT (if paying by check or money order) to:**

**SOFT Membership Committee, c/o Barb VanHerreweghe, 2982 South Union St., Rochester, NY 14624**

We assume that your name may be shared with other SOFT members (only) unless you specify otherwise.

For U.S. Families Only: We depend on annual memberships to fund the newsletter, but if you cannot afford a membership and still wish to receive the newsletter, please call Barb VanHerreweghe at 800-716-7638 for information about a limited number of membership assistance scholarships.

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**SEE SOFT’S HOMEPAGE FOR INFORMATION ABOUT SOFT, CONTACTS, MEDICAL AND FAMILY INFORMATION, AND THE NEXT CONFERENCE:**

**http://www.trisomy.org** (800) 716-SOFT (7638)
I thank God upon every remembrance of you.—Philippians 1:3

**Remembering SOFT Angel Wings**

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<td>Christopher Timmothy Goodrich</td>
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</tr>
</tbody>
</table>

Email Jack Laird for family contact info at  jlaird@rochester.rr.com
Deadline For The winter 2013 issue of SOFT Times is January 15, 2013

POSTMASTER: address correction requested

Happy Thanksgiving

Join SOFT for the 27th Annual Conference Providence, Rhode Island July 18-21, 2013