SOFT Lights The Way

By Pam Healey

Lighthouses, iconic coastal buildings, come in different sizes, shapes, colors and patterns and have steady beams or unique flash patterns. The stately lighthouse with the keeper’s cottage, fuel storage building and foghorn house, together, constitute the light station. Earlier, there were some lightships, anchored with tall masts with a beacon atop, in areas not conducive to a permanent facility. Lighthouses stand guard on islands, hilltops, dunes, cliffs and at the end of peninsulas jutting into ocean bays and sounds and into lakes. Some are on little more than a rocky island framing the round or square base. Lighthouses are cylindrical or upside down cone-shaped, round, square or octagonal towers or stubby spark-plugs. Others are skeletal iron frames. They stand alone or are attached to houses. A few top buildings. Lighthouse exteriors were first rubble or wooden, soon were brick, stone, iron, steel and even cement made partially of shells. Boston Light’s over two hundred year old walls are seven feet thick at the base. The towers are punctuated by windows to light the steep spiral staircase once climbed by the keeper several times a day to tend the lantern and look out to sea. Some original lighthouses have been storm toppled and replaced; others have been moved or rebuilt farther inland when coasts eroded. Today, many have been taken from service, but some have been brought back in use by historical societies. Only one in the country still has a keeper. All lighthouses are picturesque features of the coastal landscape, reminders of earlier times and challenges, which stimulate the imagination today and invite photography. We must remember that each lighthouse announces: This is where you are. Think about where you need to be to reach your destination. Decide the route you will take. Stay safe.

Lighthouses have two purposes. They direct mariners to harbors by orienting them to what would otherwise be a coast without distinguishing features. They also warn ships away from dangerous rocks, shoals and islands. They made life safer for those on seas and large lakes by aiding navigation in the days before high tech instruments, when captains looked to the coast to know where they were.

By day the lighthouse’s unique shape and color pattern helps sailors orient themselves to an unfamiliar and seemingly uniform shoreline. These are called daymarks. At night the lanterns send sweeping beams or signature flashes to warn sailors away from treacherous areas. With the invention of the Fresnel lens in 1822, the light could be intensified and refracted by the multiple cut glass prisms, carrying a strong (Continued on page 25)

The Beavertail Lighthouse
Dear SOFT,

A couple of weeks ago, the Lollipop Kids Foundation, a local nonprofit 501(c)(3), gave our family a “new lift on life”, a spoof off the old adage “new lease on life”. Leilani, a sprouting twelve and a half year old princess, is indeed a force to be reckoned with. Not just in the sense of a hormonal pre-teen, but in the literal sense as well. She is 75 pounds of body-stiffening, head thrashing, non-assisting princess through and through. So much so that our family affectionately dub her “the Anti-Helper”. But on a faithful Friday, just a couple of weeks ago, lo and behold, her prince had finally come . . . in the form of a hoyer lift.

Since that faithful day, we have relished in the back-saving learning curve that accompanies such a device. But take it from me, her mother, weighing in at a sleek 120 pounds . . . Lollipop Kids came to our rescue and not a moment too soon! See the enclosed pictures of Princess Leilani as she basks in the arms of her new Prince. You know what they say, a picture speaks a thousand words, and in this story the caterpillar emerges as a butterfly, thanks to her new Prince! See you in Rhode Island in July!

SOFTly yours,
Gerri Meggett
SOFT Chapter Chair-MD-DE
Team Leilani Spokesperson
DO YOU HAVE GRANT WRITING EXPERIENCE? SOFT COULD USE YOUR HELP!

President’s Corner
with the VanHerreweghe Family

Dear SOFT Families:

It seems like the holidays go by so quickly. We barely had time to enjoy our family and friends and back to work we had to go. We did enjoy time with my sister who came in from South Carolina as well as with some of her family. We had some really nice weather right up until Christmas and then the snow started falling. After hurricane Sandy, Andy spent the month of November and most of December in New York City cleaning up debris as part of his job. Little did he know he wouldn’t get that week off when he got home because the snow would start and not stop for several days. He worked endless hours cleaning up the piles of debris in NYC and then the snow in Rochester. The snow was tiring but at least, as his team from AP Enterprises said while in NY, it wasn’t piling up people’s lives in piles like they did there. They piled so many memories. We were so proud of his work but we also missed him while he was gone. Especially Stacy, she loves the way he shakes her up every night when he gets home from work. She is enjoying him being home for a while now.

Stacy is dreaming of palm trees and blue water. We are finally going on another cruise in March and her Dad is joining us for the first time. We fly to Puerto Rico then take off for a 7 day Southern Caribbean cruise. We are so excited and we are always ready by March as we have been in winter long enough. Stacy enjoys the warm breezes and fresh air and just walking around the pool deck. She loves to go to the many shows and enjoy the night life. Dave was in the Coast Guard so has always said he had been on border patrol for long enough. Stacy is looking forward to showing him the ropes of getting around a real boat! The kind she likes being on! Wish you could all be with us.

When we get back from the Caribbean it will be time to finalize all the plans for this year’s conference. We have never been to Rhode Island and we are really looking forward to some of the sites as we travel from New York to Rhode Island.

For those that have never been to a conference I will try and help you understand what you might expect. This is a time for an extended family to get together for a reunion. It is a place where you feel safe and everyone understands what you are going through, whether you have your child, have an angel or you are a friend or family member of either, you are welcome here. No one stares, no one judges everyone learns from each other and they have a great time together. This is the time that you may see wheelchairs spinning on the dance floor with the biggest smiles a child can have from ear to ear. You will see children walking, wheeling or being carried as they participate in the Zion Lint Walk of Fame. It is a time to learn at the workshop presentations and get some opinions from doctors participating in our clinics. You will be able to send pictures to Kris Holladay so your child can be a star on the big SOFT screen. Who could ask for more? We can, because you will find a chance for sharing your story with others experiencing the same things you are. We will enjoy a picnic together and then remember those that we have lost with a memorial balloon release. We watch their balloons fly high to each and every angel we have known and loved. There are tears and hugs as you remember that special face and smile, and the love you will never forget. Then we go back to the hotel and attend an auction of a lifetime. What surprises will be your purchase this year? It is a time to wind down and say goodbye. It’s like a family reunion you really want to attend and can’t wait to get there. So what is your excuse? Make your reservations for the hotel and save the date. Can’t wait to see all our SOFT family new and old. Meet us in Rhode Island.

The VanHerreweghe
Barb, Dave, Stacy and Andy

Patty Dumolyn
Turns 24!

Hi! Patty celebrated her 24th birthday this past November 24th. She continues to be a happy and healthy young lady, and we are so very lucky! Currently she is with a caregiver while I am at work. She practices walking with her walker and doing her physical therapy exercises daily. She likes to go shopping, bowling, and out to lunch in the community. At home she likes to play with paper, water and musical/light-up toys. She enjoys her freedom and likes to crawl around the house, getting into chairs to sit a while, and cruising the kitchen counters. Here is a picture of Patty checking out a Christmas gift—she usually likes the bags better than the presents!

Our Children Live On is a collection of true stories written by parents, grandparents, siblings, friends and caregivers, who have received comforting signs from children who have died. This and the previously published companion book by Elisa Al-Chokhachy Miraculous Moments: True Stories Affirming Life Goes On were more than eleven years in the writing, as the author wrote about what she witnessed as a hospice nurse caring for the dying both in the hospital and as a private duty nurse. Some of her patients were young. For this book she invited, then encouraged the loved ones of these and other children to tell their stories. She believes the accounts can bring comfort to those who grieve. She believes many people have had a transcendent experience related to the loss of a loved one or know someone who has. She recognizes that writing about loss can be difficult for those grieving deeply. Publicly telling their stories also carries a risk of being seen as less than rational. She knows people do not talk openly about what cannot be easily or logically explained. She knows that sharing what might be called angel moments can help others who are grieving by revealing that these brief reunions are not rare, and they send messages that death is not the end of a relationship.

The 88 stories in her first book and 82 stories in Our Children Live On validate the experiences of many people who have witnessed miracles but, uncertain of the reactions of others, have been reluctant to share what has comforted them. The powerful stories may also educate those working with the dying and bereaved, affirming that such opportunities of connecting with those who have died give reassurance that life is eternal. Dying people report spiritual awareness of those who have died. Others believe they have crossed over to heaven in near death experiences. More recount symbols, dreams, visions and a sense of presence from those whom they mourn. The many instances of both subtle and undeniable signs should give hope to both the dying and those who love them. She values each story and sees the experiences as both unique and having a common thread. When interviewed at a book signing, she spoke of particularly liking the experiences of agnostics, because they were forced to rethink what they believed. She believes that the children who have left earth "... come close in times of need. They hear our thoughts and prayers and send miraculous signs of hope. They want us to be happy. These children are our guardian angels, our teachers and catalysts for growth as we struggle to make sense of that which seems senseless and purposeless" (p. 5).

The book is divided into nine sections: Visions, Sounds, Smells, Touch, A Sense of Presence, Signs, Dreams, Angels and Near Death Experiences, each with a thoughtful introduction by the author. She explains some sections have accounts that cover several categories. The number of stories in each section attest to the commonality of each type of experience. The children who have made connections include infants, toddlers, children, teens and adults. Some are born dying; others die suddenly in a crash. Some fight to survive; others take their own lives. There are first borns who die before siblings are born, large families left to grieve a sibling, older only children, the unborn, and a newborn twin. Each leaves a hole in the family fabric but sends signs that separation is not final.

Several of the parents lost infants, a few to genetic disease, including both trisomy 13 and trisomy 18. There are two children with Tay Sachs. One mother beautifully explains the signs she received, saying, "I am referring to the subtle experiences people often shrug off as mere coincidences or seemingly small events. Incidents that, when viewed in the right context and with a receptive mind, provide clarity and insight that enlightens our lives. I call these miracles moments of grace" (p.79). Throughout the books are these "moments of grace" witnessed by those who love children who have died. There is a house covered in ladybugs, a symbol of protection and good luck, a cloud of dragonflies, and a single dragonfly in the rain at a gravesite. There are butterflies, traditional symbols of metamorphosis, en route South or sharing a summer’s day or a winter’s evening. One lands on a bride’s dress, and she knows it is the friend who would have been her maid of honor had she not died. There are brilliant rainbows appearing at significant times. There are heart shaped clouds on an anniversary or an X shaped cloud when a kiss is needed. There are white down feathers appearing inside and black raven feathers that appear outside in unexpected

(Continued on page 5)
(Continued from page 4)

places. There is a single flower blooming at season’s end. Each natural phenomenon is a clear message from the child missed. The appearance of what is a natural sign, often synchronizing with a special date or event, takes on personal meaning and gives reassurance.

A father missing his son murdered in college, listens one sunny April afternoon to a favorite song, “Con Te Parito,” wishing it would snow, as it had the first two times he heard the song. Immediately, a snow squall blotted the landscape, and he was overcome with a sense his son had sent the snow. Later, a psychic, who speaks of things only the father and son had discussed, also mentions the squall and that his son was happy, he “got it.” The translation of the song is “Time to Say Goodbye.”

Numbers are signs: an athletic shirt number, and year or day of birth are seen on clocks, dates of special appointments and pennies found at significant times. Although these could easily pass unnoticed, parents begin to see patterns and find reassurance of their child’s hand in the coincidence. Light appears, mysteriously in photographs, in unexpected warm sunshine, and disappears when the bulb of a disliked lamp explodes; all are significant. Moonlight forever belongs to a son who would say, “I will love you to moon and back,” and comforts his parents, who find the moon rising over their new home.

Beyond the many incidents of children reassuring their parents they are all right, at peace, and yet with them spiritually, are the back stories the parents, grandparents, siblings, and friends tell. The stories will bring tears, but they are also stories of love, triumph and joy. The authors tell about their miracle moments, but they also poignantly express the importance of their child in their lives. They speak of birth, school, sports, college and marriages. They recount ordinary events that are important memories. There are infants born dying, young children who develop cancer, teens who do not survive car crashes, a rejected adult son with AIDS who comes home to die, and troubled young people with depression or drug addiction. Their stories are shared. We also learn what parents, siblings and others have accomplished as they worked through their overwhelming grief to lead productive lives guided by children who died too soon. One mother believes that fostering a sense of “Life is Good” in teenagers may save future car accidents by making teens more responsible drivers less willing to take chances and stretch the limits of speed and alcohol. A babysitter whose carelessness contributes to the death of a toddler reaches out to other young sitters to teach them to be vigilant. Some learn to let go of the heavy burden of guilt and sorrow and reach out.

Elissa is both editor and contributor to this important book. As an author of one chapter, I can attest to her vigilance in editing each piece. Work goes back and forth, with suggestions and changes until it works well, alone and with 81 companion pieces. Her encouragement, recognition of the importance of our experiences and belief that comfort and healing can be brought to those who need it are behind each piece. She understands how devastating losing a child can be. She knows discussing the spiritual connection between the child and family members is valuable. She writes, “Death is not the end. It is simply a doorway to our spiritual home where we will all be together again” (p.5). She brings her sensitivity and her passion for her life’s work to her books and both comforts and enriches her readers.

Miraculous Moments
At SOFT 2013

Elissa Al-Chokhachy, MA, RN, HPCN, FT, is a board certified hospice and palliative care nurse with a Master’s degree in Thanatology. She has been working for two decades in a hospital setting and in private duty nursing with patients of many ages who are dying. She is also a healthcare counselor and faculty member. She knows that being a hospice nurse is a perfect fit for her, because it allows her to take a holistic approach, caring for the physical, emotional, mental, and spiritual needs of each patient, as well as helping those who will be left behind to grieve. She is a winner of the Red Cross Healthcare Hero Award and the Boston College Alumni Award for Excellence in Nursing. She also won the Dr. William B. Stevens Award for “The Nurse Who enjoys her work the Most.”

Elissa has spoken across the country on her books and experiences and will be speaking as the keynote speaker on Friday morning of the 2013 SOFT Conference before the workshops begin. In 2001 at the Boston conference she came with a group of children with disabilities, who acted out her inspirational book, The Angel with the Golden Glow: A Family’s Journey Through Loss and Healing. She has written several more books, since that time, one a children’s book to help understand when a loved one is dying and the two anthologies that affirm that the spirit lives on after death. She looks forward to sharing her experiences and books and hearing from SOFT members who also have had angel moments. I think of Jonathan’s angel cloud, Becky O’Toole’s graveside rainbow, and Paige’s balloon that stayed tree bound until the last balloon was released. I would like those of you who have had an angel moment to write it down and email it to me at healey-lex@aol.com. I will collect these for a project I would like to do for the conference.
Another year has come to a close and a new one begins. Time marches on from days to weeks to months and years. And on difficult days, it is seconds to minutes to hours!

Every January, I am reminded of a moment in time ….

Kari was six years old and was doing well. She was the healthiest “sick kid” around and was progressing slow but sure. Our family had found a comfortable routine and I was content. Each moment was a blessing and every day a pleasure. The challenges of a young family were familiar to us, but it was exactly how I wanted to spend my time! Then it happened! Kari had a seizure; not an “ordinary” seizure, but a seizure that wouldn’t stop called a “status seizure”. Hours passed before the doctors could control the seizure and only then, by following a regimen of medications. Kari was in a hospital bed where she lay motionless except for her quiet breathing. I pulled up a chair and sat next to her, stroking her hair and wondering how everything had changed in a split second of time!

As I looked at this wonderful child, I started telling her why this would not be a good time to die! I explained to her that she couldn’t leave me in January because this is when the new year begins and I couldn’t start each year missing her desperately. But February would never be good because it’s Valentine’s Day and it would truly break my heart if she were gone. Of course, March was kite flying month and the daffodils were starting to bloom & she loves the park. And, April brought Easter and new dresses and new life. I told Kari that May was out of the question because it was the end of school and the beginning of summer and we would play all day. June was too beautiful and the sky so blue and we love to go for rides. July had the 4th with parades & picnics and I told her that she loves the fireworks because they are so loud and bright and I couldn’t look at them without her. August was the end of summer and we always played in the back yard and it was more fun with her there. September was a new school year and that would mean new clothes and pictures on the first day of school. Of course, October brings Halloween and she always looks so cute in her costume. Then there is November and Thanksgiving and I was sure I could not be grateful without her in my arms. And certainly December was not a good month because of all the celebrations and I knew I would never enjoy them if she were to leave me then! No, there just wasn’t a good time for her to die!

She didn’t leave me then, but she did four years later. Oh how I worried that time would take away the things that were so dear to me! But, I know now what I didn’t know then. Kari’s lessons of love are TIMELESS! The memories I carry are TIMELESS! My love for Kari is TIMELESS!

“To everything there is a season and a time to every purpose under Heaven…
A time to be born and a time to die;
A time to plant and a time to pluck up;
A time to break down and a time to build up;
A time to weep and a time to laugh;
A time to mourn and a time to dance;
A time to cast away stones and a time to gather together;
A time to embrace and a time to refrain from embracing;
A time to get and a time to lose;
A time to keep and a time to cast away;
A time to heal and a time to mend;
A time to keep silence and a time to speak;
A time for LOVE …
A time for PEACE…”

-- Ecclesiastes 3:1-8 --

Hugs, Kris
All that we behold is full of blessings.—William Wordsworth

Did You Guess Who I Am?

How many faces did you guess correctly? To participate in future picture pages, kindly submit your photos, identified, to jmgthompson@att.net

Erin Handel
Phillip Serb
Jack Laird
Mark Wright
Rachel Adeye
Kari Deann Holladay
Nicholas Wright
Greta Thompson

DID YOU GUESS?

Conor Healey
Isabella Josephine Wolfe
Annabelle Shelander
Kris Holladay
Greta Thompson

Morganne Dye
Hal Holladay
Stacy & Andy Van Herreweghe
Emerson Garst
Megan Barnes
Judie Laird
Barb Van Herreweghe
Margaret Krause-Thompson

Erin Handel
Baby Blevins

February/March/April 2013, The SOFT Times, Page 7
We’re linked to the internet at http://www.trisomy.org

PROFESSIONAL VIEWPOINT: Journal Club

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


This article by Palomaki and co-authors is the third paper to address the issue of whether studying fetal cell-free DNA from maternal plasma can effectively identify trisomy 18 and 13 in the prenatal setting. This new technology, called noninvasive prenatal testing (NIPT), has emerged as a diagnostic test in recent years. NIPT involves drawing a blood sample from a pregnant mother and identifying fetal DNA material that is now known to be present in maternal blood. The use of maternal sample without the need for an invasive procedure (like amniocentesis) is an attractive approach. The sequencing of circulating cell-free DNA in maternal blood has been shown to reliably identify trisomy 21/Down syndrome in several studies in the last two years. The paper mentioned here applies the same DNA sequencing approach to the identification of trisomy 18 and 13 pregnancies.

The investigators examined almost 2,000 samples taken during pregnancy of known chromosome outcome. This study analyzes the samples that had been taken at 14 or 15 weeks of gestational age and using this technique detected 59 of 59 trisomy 18 pregnancies and 11 of 12 trisomy 13 pregnancies, demonstrating it was an effective test. Their false positive rates (that is, calling the result trisomy 18 or 13 when it was not) were less than 1% but showed an area that needs more investigation.

Currently there are four laboratory companies in North America that offer this new technology of DNA sequencing of maternal plasma for the detection of trisomy 13, 18, and 21 in high-risk pregnancies (mothers over age 35 and families with a previous history of trisomy). Application of this technology as a screening method to replace current programs is not occurring now but is likely to in the future.

The implications of this technology are far reaching: NIPT provides the availability of a reliable test with a noninvasive procedure, that is, a blood sample. It is likely that the application of this technology will replace the current first and second trimester screening programs that include blood sampling and ultrasounds leading to the potential option of amniocentesis. It is also likely that the conditions to be identified will be broadened to more chromosome syndromes and other genetic conditions. I would anticipate more discussion of this topic in future columns.

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 02421.

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**

Donations to SOFT’s general funds
Brian Primeau
Friends who used GoodSearch.com
Ioannis Karmis
Martin Laird
Kaitlyn Gillis, in honor of Trisomy 18 babies
Lisamarie Derosier

**In Honor of our niece, Stacy Lynn VanHerreweghe**
Bob and Sheila Reynolds

**In Memory of Noah Idan Stein**
Joshua Stein: “In loving memory of our son, Noah Idan. We love to you Infinity and Beyond!”
Erik Carr
Jessica Friedheim
Jason Pearlman
Sokunthea Nau

**In Memory of Regan Adeline Lawson**
Joe and Laurie Hetzel

**In Memory of Grace Abigail Ellison**
Brittney Hass
Laura Eichner: “In memory of Grace and in honor of her loving family”

**In Memory of Julia Grace Childress**
Marc and Jennifer Childress
Jodie Sekeres: “In memory of our precious niece and cousin on her second birthday. We love you, Julia!”

**In Memory of Sarah Marcela Poole**
Ileana and Arnaud Desalos
Allison and Mike Hopke
Michael Ross: “Our thoughts are with you during this very sad and difficult time”
Donna Richardson
Gretchen Hoffman
Myrl and Lou Peterson
D’Ann Ederhoff
Joseph Meijide
Deborah L. Gant, MD
Pete and Sandy Morin
Dan, Victoria and Natalia Hata: “You wrote a beautiful tribute to Sarah.”

**In Memory of Michelle Richie**
Kenneth and Renee Richie

**In Honor of Patty Dumolyn**
Mike and Barb Schuster

**In Memory of Elizabeth Schultz**
Friends of Clissold School

**In Memory of Rhys Austin Khoury**
Elias and Amy Khoury: “In memory of our son, Rhys Austin Khoury, whom we lost to Trisomy 13 on 12/14/10. He will forever be in our hearts.”
Margaret and Dick Holman

**In Memory of Claire Carlyle**
Laura Cooper and Radford University Nursing Student Association: “Your sweet child will always be a part of our lives.”

**In Memory of Sebastiaan Xavier Keg**
Antonia Keg

**In Memory of Sophia Ann Allen**
Griffith Family Foundation, Inc.

**In Memory of Judah Benjamin Immanuel Cohen-Mirgon**
Jeff Cohen and Jeanne Mirgon

**In Memory of Jonathan Little**
Scott and Vivian Showalter

**In Memory of Elijah Watson Resler**
Bob and Susan Butler

**In Memory of Thristan Williams**
Mary Botello

**In Honor of Nicholas Wright**
Shannon K. MacMaster

**In Memory of William Thad Thompson**
Stephanie and Benjamin Starr: “We love you and are praying for you”

**In Honor of Teagan Peterson**
Paul and Courtney Vonnahme

**In Honor of Sydney Wise**
Corporate Research International

**In Memory of Marla Kay Parker**
Sara Parker

**In Memory of Ellie Louise Cushman**
Carolyn Branson: “In loving memory of Ellie Louise, such a beautiful baby born to a beautiful family.”

**In Memory of Isaiah Nance Pea**
Bertha Scales

**In Memory of Nathan Patrick O’Maley**
Tim and Susie O’Maley

**In Memory of our baby granddaughter, Jordon Arella Coulombe**
Sally and Ray Boucher

**In Memory of Ella Marohn**
BP’s Fabric of America Fund, recommended by Mike Platzke
You're invited to participate in Color Me Beautiful!

Artists are invited to participate in this winter's Color Me Beautiful event! The Color Me Beautiful celebration and silent auction will showcase original art pieces designed and donated by:

- Individuals with Trisomy and related chromosome disorders
- Current or past pediatric oncology patients
- Other artists, including caregivers, who are simply in support of the cause

The event will benefit Noah’s Never Ending Rainbow and The Jeanie Marie Fund. Both groups give back to children and families in need as a result of the founders' personal losses to Trisomy and to cancer.

Open to the public, Color Me Beautiful will take place February 23rd, 2013 at the Wausau Country Club in Schofield, WI.

For more information on donating artwork, please contact either:

- Dana Tehako-Esser, Noah’s Never’s Ending Rainbow, at dana@noahsneverendingrainbow.org
- Amy Zondlo, The Jeanie Marie Fund, at couragecalendarwisco@gmail.com

Donated artwork may be dropped off at or sent to The Diamond Showcase, located across from the Wausau Center Mall, at 301 3rd Street, Wausau, WI 54403.

The mission of Noah’s Never Ending Rainbow is to educate, advocate, raise public awareness, promote strategic alliances and assist families who have children with Trisomy and related chromosome disorders. Noah’s Never Ending Rainbow along with River Valley Bank and WAOW teamed up to spearhead the ‘Build from the Heart’ project. “Build from the Heart” included building a new handicap accessible home for an area family with the only two children in the world known to have a specific chromosome 3 and 6 abnormality. The specialized home is open to the public and includes a therapy/community room for other special needs families to utilize for playgroups, therapy, and networking. www.noahsneverendingrainbow.org

The Jeanie Marie Fund has been established in honor of those affected by cancer of any form, to any degree. The goal is to take an otherwise tough and potentially dark time and turn into a bright and hopeful future for someone in need. Through its inaugural project, the Courage Calendar, The Jeanie Marie Fund has been able to sponsor several hundred overnight stays at the Ronald McDonald House in Marshfield for families in need. Additionally, The Jeanie Marie Fund has sponsored and coordinated a successful bone marrow donor drive benefiting the ‘National Marrow Donor Program / Be the Match’ organization. The Jeanie Marie Fund has been named the WAOW April 2012 Jefferson Award Winner recipient. www.thejeaniemarfund.com
Friendship is born at that moment when one person says to another: "What! You, too? Thought I was the only one" - C.S. Lewis

Rhode Island Adventures

By Pam Healey

We will be traveling during the conference, leaving the comfort, convenience and luxury of the Crowne Plaza Hotel to explore the area. Rhode Island is the smallest state, only 48 by 37 miles, with water bisecting much of it. Its highest point is a mere 812 feet above sea level. Small is good: many attractions, especially coastal ones, are close by.

Friday night, Family Night Out, will be in Newport, a popular seaside resort. We will travel south by bus across the Verrazano Bridge to Jamestown, Conanicut Island, then cross the expansive Clairborne Pell Bridge (seen on the state quarter) to Aquidneck Island and the city of Newport. You will see islands, lighthouses, boats, seabirds and coastal homes as you travel. Newport is a charming city that dates to the first half of the seventeenth century. It is the birthplace of the US Navy, summer playground of the Gilded Age and home to the Tennis Hall of Fame, and world famous music festivals. Yes, it was here that Joan Baez was introduced and a few years later Bob Dylan was booed for going electric. The plan is for the bus to drop some people a short distance from the center of town, so they may explore the area and walk into town. Others wanting to get right to the serious business of eating and shopping may choose to start their adventure in the commercial center.

Although there will not be time to walk the entire route, strolling along part of the Cliff Walk is recommended. The Cliff Walk, a National Recreation Trail, is a three and a half mile coastal trail that runs between the mansions and the sea. The views are spectacular from the path which rises from cliffs with as much as a seventy foot drop to rocks and surf. The views are equally magnificent across the back lawns of the homes of the nineteenth century rich and famous. Sections of the trail are easily accessible and an enjoyable time to explore.

(Continued on page 22)

In any season, Newport is welcoming.

Color Me Beautiful

"This picture defines what the 'Color Me Beautiful' event is all about...makes my heart smile. This is Stacy who is 31 years old and has Trisomy 18. Stacy’s amazing past aide, Carrie helped her with her masterpiece. And what a masterpiece it is...signed and all. Move over Picasso, there is a new artist in town..." ~ Dana Tehako-Esser of Noah’s Never Ending Rainbow

"This is what the 'Color Me Beautiful' event is all about! My heart is so smiling. Pictured is our handsome artist friend Lane, who is 4 years old and has Trisomy 18, working on his art project for the 'Color Me Beautiful' event with proceeds benefiting Noah’s Never Ending Rainbow and The Jeanie Marie Fund. I HOPE you love it as much as I do. Thank you Lane, I hope it raises hundreds if not thousands of dollars! Remember...HOPE, always." ~ Dana Tehako-Esser of Noah’s Never Ending Rainbow

The 'Color Me Beautiful' artist friends pictured on the attached flyer, previous page, are the beautiful Maya who is 9 years old, is a 2x bone marrow transplant recipient and has AML (acute myeloid leukemia) AND the handsome Simon who is 7 years old and has Trisomy 11q Monosomy 20p due to an unbalanced translocation.
Conference Wish List

**Family Welcome bags**: Boat bags: $1000

**Food and beverage** at Wednesday night welcome: {price not determined, depends on menu and attendees}

**Picnic**:
- Carousel Performing Center and banquet tables: $400
- Field and grove picnic tables: $250

**Binders and inserts**: $600

**Lanyards and nametags**: $300

**Busses**: donations of $300 and up will go toward busses to Newport, the picnic, the clinics and the sib outings.

**Sib t-shirts**: $500

**Awards** for Stroll for Hope: {price not yet determined}

**Walk of Fame** presentation gifts: $500

**Childcare supplies**: $600

**Angels and centerpieces**: done

**General conference contributions**: any amount appreciated

More information to come in the next newsletter

**Fundraising proposal**

Bake sales and garage sales bring limited profits. Money will come in later, but we need funds soon. I have an idea. I am a certified Myers-Briggs Type Indicator counselor working with senior corporate career counseling clients, recent graduates and college students. I have extra time, thoroughly enjoy assessing personality type and need to bring in funds for the 2013 conference. For anyone interested, I will help you determine your personality preferences, then explain what that means and how the knowledge can help you with learning, relationships, career and stress. This will entail a mailed booklet and answer sheet, then scoring, interpreting and giving a 1-2 hour consult by telephone or Skype and a lengthy written report. Myers-Briggs is used by 80% of top corporations with about two million given a year. I will charge $100 and 100% will go to the 2013 conference. This offer is only available until May 30th because after that all free time will be crazy time spent with the conference details.
You gain strength, courage & confidence by every experience in which you really stop to look fear in the face. -Eleanor Roosevelt

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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.
Welcome to the Ocean State

It is time to learn a bit about Rhode Island. In 2013 SOFT families will be in the thirteenth state, the first to declare independence from England and the last of the original colonies to ratify the constitution. Rhode Island is the smallest state and has the second most dense population, most people living in a few contiguous cities. Much of the state is rural with vast tracts of swamp, woods and fields, all dotted with stone walls made by early farmers. Rhode Island, the Ocean State, has a vast coastline, including a rockbound coast, sheltered coves, and broad sandy beaches. It contains more than twenty islands in Narragansett Bay, most inhabited, some protected areas for birds. There are about a million people living in the state: Italian, Irish, English, Portuguese and others. Rhode Island is old and has many firsts. It has signature food, historical places and interesting traditions that SOFT families will enjoy.

Rhode Island has its own favorite recipes and unique terminology for its regional food. Not only is sea food important, so is frying or sweetening what others accept as is. Quahogs (say, koe-hogs), large, slow growing, thick shelled clams whose purple inside was the Native American's wampum, make great chowder. New England chowder is cream based. A clear chowder with tomato was made popular by the Portuguese in Rhode Island and was derogatorily called Manhattan chowder. Quahogs are also used for stuffies (mix chopped clams with bread, onions, peppers, Tabasco, sometimes Portuguese sausage, and stuff them back in the shell to bake). Clam cakes are really clam fritters, deep fried batter laced with chopped quahogs, and amazingly good. Today's ubiquitous coastal clam beds were cultivated by Narragansett Indians before the English settlers arrived. Drive along the coast or walk beaches and see people wading in low water kicking clams free with their bare feet or raking them with special tools. Commercial quahoggers use flat boats and long handled tools with a basket attached. There are also steamers, soft shell clams, that I have been told are an acquired taste (texture), and fried clams, my favorite decadent meal. Rhode Island lobstermen ply the bay, and lobster is a Rhode Island treat, and the most lucrative catch. In the warmer months stripers and bluefish are caught from boats, jetties and beaches. More than half the squid landed in the country is caught by Rhode Island fishermen, then locally processed and frozen for distribution. Eating sea food during your stay is highly recommended.

Johnny cake is a Rhode Island cornbread, unleavened, fried and topped with something sweet. It is great for breakfast or with pea soup, and another gift from the Narragansett Indians. In celebration of being the first colony to break from the British in May, 1776, churches, granges, fire houses and restaurants host May breakfasts with Johnnycake featured. It is believed the Rhode Islander’s pronunciation of journey cake gave the flatbread its current name. Rhode Island is also the home to Doughboys, basically, fried pizza dough rolled in sugar. Go to Iggy’s and try to eat only a few! After standing in a long line with beachgoers you will deserve all you eat. Milk shakes, called frappes in the rest of New England, are called cabinets in Rhode Island. If you order a milkshake in New England you will get shaken milk, no ice cream. Awful-Awfuls are thick ice cream drinks (straw stands up on its own) sold at Newport Creamery, and, tradition has it, if you can drink three, you get one free. One is a meal. Rhode Island pizza is strip pizza, rectangles with tomato sauce and no cheese. When I was in college in the 1960s we called them tomato pies, and they were perfect for a student’s limited budget. Coffee milk is made from syrup by Eclipse and Autocrat of Rhode Island and has been the state drink for 20 years. The runner up for state drink is Del’s Frozen Lemonade, with trucks and long lines dotting the landscape once the weather turns warm. A slim orange hot dog of veal and pork, topped with a spicy meat sauce, onions, mustard and celery salt in a steamed bun is called the New York System Wieners, a century old tradition, unknown in New York or anywhere else on the planet. More than fifty places sell them in the state, so someone is eating them. Their high cholesterol and salt may be contributing to loss of population in the state. Good Italian restaurants are plentiful. Consider the choices and decide what you might be willing to try as a food adventure, and learn the language.

Rhode Island has historical, large and even unique industries within its tight borders. This includes bling and fun. The first spinning jenny was manufactured in Providence in 1787, and a short time later the industrial revolution in America was started at Slater’s mechanized cotton mill in Pawtucket, just north of Providence. A thriving textile industry followed. Clothing, now made in China, was once made in Rhode Island. Jewelry and metal products dominated industry and include Gorham Silver Manufacturing Company, Cross pens and Schaefer pens, costume jewelry companies (one thousand local companies, in the late 1980’s produced more than 80% of country’s costume jewelry) and Swarovski. Alex and Ani, committed to manufacturing at home using recycled products made the US Olympic teams’ charms. Hasbro, one of the largest toy makers in the world is headquartered in Rhode Island. Its first toys were pencil cases, then doctor and nurses kits, but since then it has become famous for Mr. (and Mrs.) Potato head, G.I. Joe, the first action figures, Easy Bake ovens, Lincoln Logs, Nerf, My Little Pony, Transformers and Lite-Brite. Hasbro bought Milton Bradley, Parker Brothers, Playskool, Tonka and Kenner. Monopoly, Scrabble, Twister, Candyland, Clue, Boggle, Dungeons and Dragons, Sorry and other childhood favorites are now Hasbro brands. The Clinics will be at Hasbro Children’s Hospital in Providence. CVS the second largest pharmacy chain in the country is based in Rhode Island. Ann and Hope, a Rhode Island company, was the first

(Continued on page 24)
SOFT’s Utah Chapter
Decorates at Annual Festival of Trees

Over 40 years ago, a group of 15 women from around the state of Utah started a “Festival of Trees” as a way to raise money for Primary Children’s Hospital. It started as a smaller event where there were 60 trees for display. All these years later, it has become one of the largest fundraising events for the hospital. The Festival now has over 220,000 square feet of display space and over 700 trees. Every one of the trees is donated and the proceeds from the sale of the trees go to benefit children in need that are being cared for at Primary Children’s. Almost $1.7 million was raised last year for the hospital with this event.

For more than a dozen years, the families of SOFT in Utah have participated in this event in honor or memory of our SOFT kids by donating a tree, the decorations for the tree, and time for decorating the tree. Every Monday after Thanksgiving, we gather at the Festival to decorate, talk about our special children, and spend time with our SOFT family. We all enjoy having the opportunity to see one another and to do something to benefit our children’s hospital that has done so much for our children and is the home to our own John Carey.

Because of deep love, one is courageous.—Lao-tzu

Can You Guess Who I Am?

#1
#2
#3

February/March/April 2013, The SOFT Times, Page 15
“Hope is that thing with feathers that perches in the soul and sings the tune without the words and never stops . . . At all”

-Emily Dickinson
SOFT’s Symbols

By Pam Healey

In response to some recent discussion of symbols for trisomy community, I thought I would include some thoughts. The butterfly has been a traditional symbol for children who have died. Memorial pieces in the newsletter have been in a section called Butterfly Wings. The butterfly is used by Compassionate Friends, and it has been used by SOFT to represent our children now beyond our grasp. In Florida in 2000 and in St. Louis in 2012 we have had butterflies released at the end of the balloon ceremony.

A butterfly is a symbol of metamorphosis: the remarkable change from caterpillar to butterfly. The butterfly is beautiful, bright, and elusive. It hovers near. In its flight it seems to dance, joyfully darting, changing levels and directions, hopping from flower to flower or being lifted by the wind. Many of us have had butterfly experiences that remind us of our child and in their timing seem to be angel moments. For instance, in creating the logo for the 2013 conference I went through a file of lighthouse pictures I had taken, chose one in which the buildings were angled right, then noticed there was a monarch butterfly overhead that had flown between me and the lighthouse. That confirmed the choice for me.

The rainbow has been a symbol of SOFT since the beginning and is a well chosen one. A rainbow is inclusive, with primary colors and secondary colors working together and still keeping their individuality. The individual parts work together, and the whole becomes greater than its parts. SOFT is made up of many syndromes, but all the children are our SOFT kids. As is true with the rainbow and the separate bands, the whole surpasses the parts. Watch the children on the dance floor on Thursday night of the conference and watch the glow. Last year we had fifteen different diagnoses represented, and they entered the room separately on the Walk of Fame, then joined together in an evening of energy and fun.

A rainbow appears after a storm and brings brightness and a sense of peace. It also only appears when light is at the right angle, so usually late or early in the day. Noon’s glare prevents rainbows, although sun and rain create it. It is a bridge between earth and the heavens, which both starts and ends in the earth. It is also elusive, always ahead of us. We can never reach it. A rainbow is unusual, rare, but not impossible. It is a natural phenomenon, a gift of nature. It presents the idea of a covenant, which carries trust that things will be better.

Balloons are also a symbol for SOFT. Each year at the balloon release those of us who have had to let go of our child, let go once again, but we stand in the company of those who understand. Perhaps each time we let go as his or her name is called, we also release some of the grief, some of the pain, some of the questions that have never been an-

In January 2013, Greta and her family traveled to Ft. Worth, Texas for the 10th Annual Chisholm Challenge Competition. She earned 3rd place in English Equitation and a 4th in Western Trail. This event showcases riders with disabilities and is the precursor to the Stock Show and Rodeo. She is shown astride Chico, an Arabian mix. Her leader is the trusty Chris Reinbarger, and Mom & Dad are sidewalkers! Good job, Greta!

Stacy is reminding everyone that she is going on a cruise in March and she’s ready to GO NOW!
Remembering Jonelle “Joni” Calderwood

By Pam Healey

Jonelle “Joni” Calderwood of Boise, Idaho, passed away peacefully at home on December sixth. Joni was 24 years old and had full trisomy 18. She was an adorable, lively little girl, full of personality, and she grew into a beautiful young woman. She always seemed to keep an eye on what was happening and reacted joyfully to the fun going on around her.

We saw Joni, her sister Faith and her brother Tanner off and on at SOFT conferences. I think it was Chicago 1993 that we first met. I remember being in a pool with Joni and her grandmother, Norma Horton, and as we adults were chatting and therefore interrupting her pool time, Joni splashed us. When we continued, she splashed us again, and Norma spoke to her to stop. Well, she had her attention, which was clearly her intention. That was when I realized that despite the current wisdom that development would be minimal, Joni had just clearly demonstrated a determined sense of agency. She knew she could make things happen. That understanding and the ability to act on it is what has been labeled the “terrible twos.” I knew then that children with trisomy 18 do survive, and they do develop. They, also, meet important psychological developmental milestones. For her I think it might have been the “terrible fives,” but despite the naughtiness, the behavior was still welcomed.

A few years later the Healeys and the Calderwoods met at a pancake house in Salt Lake City. Patrick and Joni at nine were the oldest of the five kids we crowded around a table. The adults compared notes on our memorable but brief trips to the Great Salt Lake the day before. The water was teeming with some kind of mini briny shrimp, that kept us away, but the sand held its own threats: midges or no see’ums, tiny biting insects, apparently right at wheelchair level. Poor Joni was sporting red welts, but was happily joining the other children at breakfast without complaining much. I remember her as being alert, easily engaged and joining in with whatever fun was going on. I also realized that having three children with one in a wheelchair, that required some logistics, did not stop this family from enjoying themselves and effortlessly doing what all families do.

In 2008 Joni joined us in Denver. She had slowed a bit, but clutching a favorite toy, with a flower in her hair and charm bracelets on her arm she joined in the festivities at the hotel and at the picnic. Many of us will miss seeing her when we head West again. She was one of our “Golden Girls” who defied the odds by decades and was an active, adored part of her family as the big sister and wonderful daughter and granddaughter. She accomplished a great deal. She went to school, right through high school, played enthusiastically, mastered tasks and changed lives. In her obituary her family shared, “She touched the hearts of all that met her, and many lives will be forever changed by the experience. Joni endured and overcame many challenges in her short life, but was tired and heard the call to come home. She will be missed more than words can express.” Thank you Justine, Jon, Faith, Tanner, Norma and Bud for sharing her. Our hope is that all those many years of precious memories will sustain you as you adjust to life without her. Many of us in SOFT also hold special memories of her.
His loved ones are very precious to Him and He does not lightly let them die—Psalm 116:15

A Tribute
To Joni
From Her Cousin

I called my Dad around 6:50pm or earlier and my step mom answers. She tells me of my cousin Joni's death. It was just yesterday. My first feelings are shock. I can't believe it. I call my close cousin Tanner. He does not answer his cell, so I leave a message telling him I heard of the loss and that I too loved and miss her and wanted to talk to him. Next I called Grandma; she too did not answer so I left a message saying that I just heard of the death and that I am still in shock and wanted to talk to her about it. I knew little of my cousin Joni. She had disabilities. She could not talk, walk or eat by herself. She was in an infant mode for 26 years. She looked like a 7 year old girl.

She would laugh when she had a stuff animal or when someone played with her. She cried when she had seizures or hurt. She mostly slept all day and watched the TV.

She had to be fed through a tube that went into her belly that carried liquid food. She had to wear diapers and could not potty by herself.

When I was younger at my grandma's house she would babysit her. And sometimes she would be left in the living room with me. I would listen to her blow bubbles and sometimes I would play with her. I would tap her balloon or made her stuffed animal a puppet and she would laugh.

She seemed to have her own thoughts. At nights she would dream and you knew if it was a bad dream or a good dream. She smiled a lot when grandma or my aunt would take her places in her stroller.

I saw her happy, sad and in pain, she would cry out in the middle of the night when she had a seizure and my grandma or aunt would hear and immediately would go and treat her.

Sometimes you would think she was trying to talk but it was always missed heard bubble gurgle sounds.

I loved her and miss her. She was my cousin and my thoughts will always remain. I wrote this so I could never forget her.

She was always genial. Never hurt anyone.
Tributes to Jonelle "Joni" Calderwood

On July 21st, 1988, God gave our family the greatest gift we could ever receive, Jonelle. Some would say she was born disabled, but if you ask anyone who knew her they will tell you she was born with a gift and was the greatest blessing our family ever received. She taught everyone that crossed her path love and understanding. She eased away pain and sorrow and she brought happiness and smiles to everyone. Sadly, for all of us who loved her so dearly the Lord took his finest angel Joni home, on December 6th, 2012.

Joni is a daughter, a granddaughter, a sister, a cousin, a friend, and the greatest secret keeper ever. She was the sweetest, kindest, and most loving person I have ever known. It didn't matter how bad your day was just seeing or being near Joni would soothe the stress away. She always had a smile, a kiss, and bubbles ready for you. I haven't met a single person that could resist Joni's kisses or her bubbles.

I call her my little secret keeper because she would always listen to me, it never mattered what I had to say, I could be telling her my secret dreams and wishes or confessing to something stupid that I had done. There was never any judgment or disapproval in her eyes, only an overwhelmingly unconditional love. I remember how I used to lie next to Joni on the floor at my Nana's house; I would talk to her and tell her everything. I poured my heart out to her when I was sad, happy, or confused. Often I imagine she was talking back to me and telling me everything will work out and be ok, she comforted me more than anyone could ever know. When I would share my secret desires and dreams with her, I would imagine Joni sharing hers with me. I always imagined that her dream was that some day she would be able to walk, talk, and no longer have to carry the burden of her diagnosis. She would run to us with her arms wide open and tell everyone how much she loved them.

Joni was such a blessing to our family, she was our glue, our pivot, and most of all she was and still is the center and heart of our family. I was so scared to be around her when I was younger, but it was a fear of breaking someone so special and amazing, she seemed so fragile to me. However, as the years passed I came to realize that she was the strongest person I knew. She lived a life filled with pain, illness, and many surgeries. Although, none of this ever stopped her from being the amazing person she was. Even in the hospital after a horrible surgery, Joni had kisses and a smile to share. Joni taught me patience and understanding. She taught me to be strong and she taught me that no matter what obstacles come my way in life, they can be overcome. She helped me to recognize that her diagnosis did not define her, instead she broke the boundaries of that diagnosis and defined it. She proved the doctors wrong so many times because she knew it was not her time to go home yet, she had much to accomplish. She had more strength in her heart than many people I know today. She was not going to give up easily, she fought for her life and to be a part of the lives of the ones she loved. Her strength gave us 24 more precious years with her than the doctors thought we would have.

We all know Joni had her difficulties and struggles, but we also know that she had the most amazing support system constantly surrounding her. Aunt Teen, Nana, Uncle Jon, Papa, Faith, and Tanner you gave her the most amazing life she could ever ask for. You didn't keep her hidden away and only treat he diagnosis. No instead, you treated Joni. You showed her some of the world. You treated her like any other person and you showered her with so much love she could never have a moment's thought of being different from anyone else.

Joni is home with our heavenly father and now she can do everything she wasn't able to do here on earth. Sometimes when I close my eyes, I imagine Granny Great and Joni running through the sand laughing together, finally re-

"From Joni - Started in 2007"

Justine: Nana and Joni were talking one day and the following is what Nana noted as to what Joni would share with you if she were here and could. Yes, some words are borrowed and are familiar.

Yet-
Mommy, do not stand and cry.
I am not gone -1 do not sleep.
I am the breeze that brushes your face.
I am the wind that takes away your breath. The wind that rustles the leaves to remind you -1 am here.
I am the sound of the waterfall and the trickling stream.
I am the diamond glinting on the new fallen snow.
I am the rainbow in the tear drop.
I am the sunlight filtering through the trees.
I am the rain you love so much, look see my face reflecting in the rain drop?
I am the thunder rumbling in your dark hour.
I am the lightning flashing when the agony of the loss seems too great to bear.
I am the dragon you ride through the night sky. The dragon of your fear and
The Legacy of Joni

Growing up in a home where study and worship of God was not practiced, it was hard for me to grasp the concept of celebrating when someone you loved had died. Yet here we are today to celebrate the life of Joni who in her life taught all of us many lessons.

Some would pity Joni and lament on how sad it was for her to be locked up in that poor body of hers. Others comment on what hero's her family are. On the contrary, Johnnie was not a victim to be pitied, but rather to be respected and admired for her tenacity, courage, and steadfast spirit. She loved life and in her own way controlled her life. She wanted certain things her way and in her own time. Her family, are heroes, but more importantly, they are examples of how God expects us to care for and support those we love, especially those who, for whatever reason, are less fortunate than us. Joni did not have the opportunity to run, swim, and play as many others do, yet she was every bit as connected to the world around her.

In her secret world, Joni lived the life she loved. Surrounded by love and care, she responded to life in her pure and innocent way. She never lost the spiritual connection to life that babies are born with... that connection which for many fades in time as we are exposed to life and stress on earth as we age and mature.

Joni found joy in the small and obscure things—things that by many of us are overlooked as we charge through the days of our lives rushing here and there; putting off the time we could and should be nurturing our own souls and relationships, saying to ourselves, "I don't have time, or to our loved ones.... "we will have to do it later". How many times have we put off a loved one who was not so dependent upon us for their care citing another day or tomorrow? Yes, this little angel knew a freedom that many of us could only dream of, a freedom to experience life in pure innocence and connection to that higher realm we all search for; the connection that, we do not slow down and take the time to develop. There are many names for our higher power depending upon the faith in which we choose to worship. For Joni it was God. She found joy in the creations of God. Last year for Christmas one of her gifts was a pass to the local aquarium. This past Thanksgiving she made what would be her last visit. To many this is sad but for Joni it was an experience of delight.

When we lose a loved one, especially during the holiday season, it can be difficult to make sense of the loss. Some might say, "This is testing my faith, why did God have to take her now, why couldn't he wait until after Christmas?"

It is important to remember that this was Joni’s journey and her time to accept God’s invitation to live with him in a state of restoration of her whole being. It was her time to go to be with others who had gone before her and to wait for those yet to come. Joni was a smart young lady, she knew instinctively that once she was gone, the people she loved, but left behind would be okay - that they would miss her terribly - but that they really would be okay — with this knowledge, she took her journey.

The Bible tells us in the 23rd Psalm that we “walk through the valley of the shadow of death”. It does not say over or under, or around, but THROUGH. The pain that many here today feel is our earthly loss, but it is important to remember that as Joni walked through her own valley, it is now our turn to make our own journey and to try to understand the purpose of Joni’s life and the lessons she came her to impart to each of us. One thing about a “test of faith”: Someone once said that God doesn’t allow things to happen to us so HE will know how strong our faith is. HE already knows exactly how strong our faith is. Tests come so WE will know how strong our faith is - and then take steps to strengthen it.

(Continued from page 20)

Tributes
To Jonelle
“Joni”
Calderwood
July 21, 1988-
December 6, 2012

(Submitted by family and friends)
Rhode Island Adventures

(Continued from page 11)

get some exercise, breathe clean ocean air, and take pictures.

Those who choose to walk part of the Cliff Walk can then walk down Bellevue Avenue into town in front of many of the famous Newport Mansions, such as Marble House, built at a cost of $11 million in 1888, Rosecliff, where Gatsby, 27 Dresses, True Lies and Amistad were filmed, and The Elms with its French interiors and furnishings and exterior sculpture gardens and fountains. Nearby is Chateau-sur-Mer, the earliest of the opulent “cottages” that ushered in the Gilded Age, and was surpassed 59 years later by The Breakers, the 70 room Italian palace with its magnificent friezes, columns and sculptures. These homes which cost millions of dollars to design and construct more than a century ago were the summer estates of the Vanderbilts, Astors, Morgans and other industrialists. They found Newport’s perfect summer climate and magnificent vistas to their liking. We, too, may enjoy the climate and views.

For the lowly tourist, the view from the street is remarkable. We can look through iron gates across expansive lawns to marble, brick or limestone architectural wonders and world famous landscape design that includes exotic trees, topiary, a variety of roses and lush floral gardens. Many of the estates are now maintained and opened for tourists by The Preservation Society of Newport County, but some remain private summer homes. We will not be there early enough for tours, but those staying longer in Rhode Island may be persuaded to return to Newport to complete the Cliff walk or get an up close view of how a historical elite lived and a few still live today.

A short walk from the mansions lies a bustling village of quaint shops, galleries and charming seafood, burger, and ethnic restaurants nestled on cobblestone and brick paved granite wharves jutting into the harbor. Enjoy looking out at yachtsmen taking a sun-set sail or at commercial fishermen ending their day. There will be time for dining al fresco or inside cozy restaurants. There are many unique shops and boutiques. Some may prefer enjoying a smoothie, cookies or locally made ice cream, Italian ice, or chocolate from specialty stores, leaving more time to wander from shop to shop. Bannister’s Wharf, a commercial center that predates the Revolutionary War, is a favorite area, and includes the magnificent Clarke-Cooke House, The Black Pearl Restaurant, Black Dog General Store, the Newport Mansions Store and several galleries. Where else can you find stores featuring the latest in yachting clothes? Bowen’s Wharf, an even earlier commercial center, features centuries old commercial buildings. There are galleries for fine art, model ships, coastal photography, stadiums and scrimshaw. Shops feature international hand-crafts, hooked rugs, resort wear, locally made jewelry, and unique gifts. Walking around Newport is relaxing and entertaining, and picture postcard perfect, so don’t forget the camera.

The Saturday picnic will be in Potowomut, a section of Warwick, at the magnificent Goddard Memorial Park, an eighty year old 490 acre public park of fields, groves, a golf course, trails and specimen trees from around the world. It includes a mile of sandy beach with warm, calm water. It is the former grounds of the estate of a prominent Rhode Island Civil War officer, industrialist and U.S. Senator, Charles Ives Goddard. It is the home of the annual Oh My Goddard Sprint Triathlon, numerous regattas, equestrian events and invitational cross country meets. On summer weekends it is the site of many family reunions, weddings and charitable events. We have secured the octagonal Carousel Performing Arts Center, which overlooks the beach. Tables will be set up inside, but those wishing to eat outside can enjoy picnic tables nestled in a dense grove. We also have the nearby field for both recreation and the Balloon Release. There is a possi-

(Continued on page 23)
Rhode Island Adventures

(Continued from page 22)

bility of pony rides. We have rented the picnic tables at the field’s edge. The beach is close enough to visit to build sand castles, wade at the water’s edge or swim. It offers great views across Greenwich Bay. We feel certain that people will appreciate this unique location only 15 minutes from the hotel. A special project is now being planned that will be a first for SOFT and take advantage of the serene and varied setting.

A favorite event will be in the hotel, but with the cooperation of SOFT members will finance the other destinations. We hope those coming to the conference and our supporters are thinking of this year’s auction donations. The auction is always a great way to buy unique gifts and to showcase your talents. It is the main fund raiser for the conference. Start now to knit, crochet, quilt, nail, solder, string or paint a work of art. Approach local businesses for donations. Make baskets of products that define your local area. Convince older relatives to clean out their attics and find a treasure to donate or get busy creating a one of a kind item. Regift: what you do not appreciate, may be perfect for someone else, or at least should be worth some chuckles. Bring a few things that will make us smile, make us think, make us relaxed, make us warm, make us look good, or make us laugh. This is a challenge. Make this the best auction ever. Consider less expensive items for the silent auction. Wow us with your contributions to the live auction. Wonder what Craig and Marie will bring and save up some money to buy raffle tickets. To make auction arrangements or volunteer to help please contact Patrick Healey at <rnkt1188@gmail.com>.

The view from the carousel

The beach at Goddard Park

Dive into fun in Newport

Through our reactions we create delusions. Without reactions the world becomes clear. - Buddha
discount department store in the country. Ocean State Job Lot continues that discount tradition and is always a retail adventure.

Rhode Island is home to the Quonset hut, galvanized, corrugated steel forming curved buildings with plywood ends that could be easily shipped around the world and put together quickly. They were first made at Quonset Point Naval Station in North Kingstown. More than 170,000 were made during WWII. Today the area is the fifth largest port for auto importing in North America, a docking facility for Audis, Suburus, Bentleys and VWs: 100,000 cars a year. Quonset is the home to the SeaBees, the US Navy’s construction battalion, established just after the attack on Pearl Harbor, but still active building infrastructure where we have troops.

Newport is the home of the oldest library building in the country. The oldest synagogue in North America is the Touro Synagogue, built in 1763 in Newport. It houses the oldest Torah on the continent. The 1673 White Horse Tavern in Newport is the oldest still operating tavern in the country. The longest running Fourth of July celebration and parade dating to 1785 is in Bristol. The first circus, oldest masonic building, first open golf tournament, the first incidence of being jailed for speeding—all in Rhode Island. The first Baptist church in America was founded by Roger Williams in 1638 and those in that church later founded what became Brown University.

Providence Plantation was founded by Roger Williams, who had been sent south from Massachusetts for his heretical beliefs. He founded the first settlement in which church and state were separate, and his separatist ideas and language were reflected a century later by those writing the first amendment. Having outlawed slavery in his colony, he was the country’s first abolitionist. He learned six languages before he left England, and soon learned the language of the Indians. He wrote the first dictionary of native language. With William’s support the followers of Anne Hutchinson settled on Aquidneck Island, soon named Rhode Island. Today, the name of the state is officially Rhode Island and the Providence Plantation. In Williams’ lifetime the colony became a haven for Baptists, Quakers and Jews, those not welcome in other colonies. He developed a deep admiration for the Narragansett and saw them as superior in many ways to the colonists. His tolerant views made him an enemy to other colonists in New England. Coded notes in his books are currently being translated by an undergraduate at Brown.

In Providence see the capitol building and visit museums at Rhode Island School of Design and Brown University. Stroll along Benefit Street, a few blocks west of Brown University. It is a restored Georgian, Federal and Victorian neighborhood slated for demolition in the 1950s and brought back to life with renovated houses, brick walks, gaslight and small gardens. It also boasts historic churches, museums and libraries. It is both a residential neighborhood and an outdoor architectural museum. The more opulent houses were built by the prosperous Providence merchants. The house the Brown family lived in for five generations, thought to be the continent’s largest wooden home from the eighteenth century, was renovated by Brown University with the $11 million sale in 1989 of an eighteenth century carved mahogany block-front desk, once in the home. Come to Providence and step back into the past. Modern Providence includes the Providence Place Mall in the heart of downtown, Trinity Repertory Theater and in Federal Hill fine dining, brick oven bakeries, boutiques and galleries, and in 2013 a celebration of Italian culture.

Our hotel is in Warwick, part of metropolitan Providence. It is the retail capital of Rhode Island, with malls, clusters of national chains and boutiques. Warwick, which consists of 37 villages, boasts 37 miles of coastline, including many beaches, light houses, marinas and coastal parks. Not far from the hotel is the site of the 1772 sinking of the Gaspee, the first violent attack of colonists on the British. It is also the headquarters of Ghost Hunters, winner of the Truly Terrible Television Award. Nothing in Rhode Island is far. Enjoy the many attractions close by before, during and after the 2013 SOFT Conference.

Be thou the rainbow in the storms of life. The evening beam that smiles the clouds away and tints tomorrow with prophetic ray. - Lord Byron
Sadness flies on the wings of the morning and out of the heart of darkness comes the light. -Jean Giraudoux

SOFT Lights The Way

(Continued from page 1)
beam miles farther out to sea. The speed of revolution of the lantern and the number of flash panels and light colors create patterns of light and dark, enabling many different flashes or characteristics. There is a different signal for each lighthouse, which allowed a mariner to identify the lighthouse by its signature flash and determine its exact location. Lights have specific range, sequences of flashes, colors of flashes and time between flashes. Fl 10s means flashes white every 10 seconds; Fl G 5s means flashes green every 5 seconds; WR 8s, means flashes white, red every 8 seconds; VQ (3) 5s means 3 very quick flashes of white every 5 seconds; Occ means steady light briefly darkened. Some have specific multiple flashes; not far from Boston Harbor stands Minots Ledge Light, whose 1-4-3 flash says, “I Love You.” Lighthouse keepers have served to keep travelers on course and safe.

Lighthouses are now run automatically, but they once required light keepers to trim the lamps and maintain first the whale oil supply, sometimes lard, then kerosene. Eventually electricity ran the light. Some now have LED lights run by solar panels. The keeper made sure the fuel was supplied or electricity flowing and the bulbs working. They kept the windows and lens prisms clean to maximize the beam. Light keepers kept a daily journal of weather and sea conditions, fuel consumed and other notations.

Being a lightkeeper was not without its challenges. Work was strenuous, often dangerous, and conditions could quickly become deadly. There were more than eighty women lightkeepers, each inheriting the job when her husband died or was injured, many on the job. Entire families were wiped out by severe storms. Trips to the mainland from island lighthouses were dangerous, and the round trip journey was not always completed, especially during evacuations. When the deadly hurricane of ’38 hit Rhode Island, the Beavertail keeper’s children were in school a few miles away. The bus carrying them home crossed by Mackerel Cove, and a wave breached the narrow area between beach and marsh, toppling the bus. The young daughter was drowned. Her brother survived.

The oldest lighthouse, the Pharos of Alexandria, was also the tallest, about 45 stories tall. It stood for 1500 years, destroyed by an earthquake. Our oldest, Sandy Hook, NJ, is 248 years old, the earlier Boston Light having been blown up by the British and replaced after the war. Only Boston Light still has a keeper, a Coastguardsman. The first lighthouse to use electricity was the Statue of Liberty. Thirty-one states have lighthouses, including all six New England states. Michigan has the most; Maine is second. Rhode Island has 21 lighthouses, 13 of them active.

Lighthouses stand straight and tall. They weather all conditions. They help everyone who needs their help and heeds the signal. They bring light to the darkest night and most dangerous storms. They direct and protect. They endure. They also draw attention to themselves and expect others to note their presence. They know there may be no second chances for those who miss their beams. Lighthouse keepers endured isolation, worked uncomplainingly with tedious routine that must be completed. They were often called upon to act courageously. They were prepared for the unexpected and knew a turn in the weather can be deadly. Many were witness to tragedies when ships were wrecked and lives lost. Lighthouse keepers worked for little pay and long hours. They accepted hardship and rose to challenges. Undoubtedly, they found beauty in the sea and sky, in shore birds and sea life, in changing weather and peaceful solitude. Perhaps, they found some nobility of purpose, for many held the position for decades.

SOFT has been a beacon of light for families with children with trisomy for three decades. The conferences have created a light station for 27 years. Those who have learned to care for their children and live with uncertainty educated others who came behind them. They shared information about willing, knowledgeable physicians, special diets, valuable medical procedures, useful therapies, and helpful equipment. They insisted on medical interventions traditionally denied babies with what was seen as having a minimal chance of survival. They discovered stimulating toys and activities and established educational initiatives. These parents have been the beams lighting the way for others. Siblings spoke of the blessings their brother or sister has been. They encouraged parents to not worry that their child with disabilities would mean a younger sibling’s life would be compromised. They too have been the beams. Each year families attend the conference clinics and provide invaluable opportunity to physicians who would have limited contact with long-time survivors with

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SOFT Lights The Way

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trisomy. Their beam announces possibility. Across the coun-
try parents address medical students, so they learn that chil-
dren do survive, develop and become important members of 
their families. They learn what parents will expect from 
them. They learn to see a child, not just a diagnosis. They 
will become part of that safe harbor.

When a family gets a prenatal diagnosis or a diagnosis 
soon after birth and contacts a chapter chair or Barb, they 
find they are not alone. They are given information to guide 
them in their decision-making and encouragement that sup-
ports them at an emotional time. Those who have been 
where they are and understand will help them get their bear-
ings. The conversations, the family packet and the newslet-
ters will orient them to where they are and where they need 
to go. SOFT members help them make informed decisions.

Today, there are technical navigation tools readily avail-
able, but once it was a family telephone and mailbox, a short 
newsletter from a kitchen table in Utah and a few member 
families. We know that as a young mother with a child with 
what had been a previously unknown diagnosis, Kris consid-
ered there were other families “Somewhere out there.” Like 
a beam scanning the open water, she found others, and 
they found her. SOFT families, joining one by one, became 
that safe harbor. Through the new support group she 
founded with John Carey, she directed them into a safe har-
bor, so they could learn together and find strength in num-
bers.

SOFT Lights the Way by presenting possibilities. SOFT 
Lights the Way by changing language, which then changes 
expectations. SOFT Lights the Way when members work to 
effect legislation. SOFT Lights the Way when they address 
problems with DNR orders, increase palliative care initia-
tives and define treatment pathways that change accept-
able protocols. SOFT Lights the Way when parents releas-
ing a balloon stand side by side with rainbow children and 
their parents, letting them know it is possible to survive. 
SOFT Lights the Way when parents gather in lobbies, 
friend each other on Facebook, email each other, create 
slide shows and on-line family stories.

Beavertail Lighthouse is the symbol for the SOFT Con-
ference. Beavertail Light is a gray, square cylindrical granite 
tower in Jamestown on the tip of Conanicut Island at the 
southern end of Narragansett Bay. It warns of a deadly 
rocky coast and orients ships to Narragansett Bay’s West 
Passage. On this site was erected in 1749 the third light 
house in America. It was wooden and financed by fees paid 
by boat owners. Earlier, there was a watch house in 1705 
and a lighted beacon in 1712, and in 1719 a gun shot used 
in fog. The current structure was built in 1856, along with 
the keeper’s house. The assistant keeper’s house added 
later is now a museum. The current lighthouse has a rotat-
ing light which gives a white flash every six seconds. It is 
about fifty yards from the original octagonal light house, 
whose base remains. Restoration of the original base be-
gan in 2012 and saved the artifact from destruction by Hur-
rricane Sandy. Work continuing in the spring of 2013 will 
result in an accessible cap with a compass rose insignia 
and a protective railing. Beavertail Lighthouse will remind 
us that SOFT has been a beacon for thousands of families 
for three decades and helps them find their way through 
storms and uncertainty to safe harbors.

A man should learn to detect & watch that gleam of light which flashes across his mind from within.-Emerson
Darkest Days, Light Within

By Pam Healey

Sometimes, even a beach walk is not calming enough, distant enough, expansive enough, even with no one in sight and only solitary footprints marking the sand. In mid December, 2012, I walked six beaches on Friday afternoon and Saturday morning. It was the time of the shortest days in the Northeast, the time when the long nights and newly arrived cold seem to carry melancholy and fatigue. The air was damp and seasonably frigid, but there was a greater chill. One state away, only a few hours drive, 26 people had been executed, twenty young, very young children and their protectors. I walked not able to process what I had just learned. On the second beach I found a brown shard, not nearly done, with an eagle wing emblazoned, and I thought of the scriptural promise it carried. The shine remained and the edges were still sharp, so I tossed it back into the sea. The words of Isaiah and the 91st Psalm stayed with me.

The next morning I walked a sheltered cove with others, then a small private beach alone, and I looked up at a Christmas tree attached to the end of the boatyard dock, its lights off. I then slipped through rocks and jumped over a spongy blanket of seaweed onto a broad nearby beach accessible only at low tide. I found scattered pieces of weathered glass, most quite old. I looked in the distance to a fort and a lighthouse. The broad fort had guarded the island since the last year of the eighteenth century as a simple fort that soon provided protection in the War of 1812. Decades later, rebuilt, it was the premier fortification in the Western Hemisphere, and it was garrisoned through five more wars. No defensive shot was ever fired from it. Today, as a state park, it hosts Newport’s jazz festival, folk festival and the America’s Cup.

Seen across the cold bay, its thick stone walls retain a presence that reflects its military history. It stands as a reminder that fortification can be necessary. Now schools are fortified. I went through lock-down and evacuation drills with my students and saw police daily in my open multi-building suburban school. At what was my children’s elementary school, when we vote in the gym, police stand guard at the entrance into the classroom section. Coastal forts have become parks; schools have become inadequate fortresses.

The bleak stone symbol seen across the bay was a reminder of threats, but some threats are not always expected, so not met. To the south at the island’s rocky tip stands another sentinel, a Romanesque stone light house, whose red light flashes to those entering the East Passage of Narraganset Bay. Not far behind me, seen from the cove I walked earlier that morning stands Beavertail Light at the broad rocky southern coast of Jamestown. We reached the island driving across a bridge between two more light houses in the West Passage. I considered that there are threats light houses cannot warn against. Their beams and signals are inadequate. They brighten the night with strong, sweeping light, but we have been made aware that in daylight danger is now too real.

On the most isolated beach, I collected scallop shells, gathering more than two dozen, scoured clean by the late autumn ocean. They had washed ashore in abundance after Hurricane Sandy, most still hinged but open and holding animal remnants. I had picked up a few and tried to scrape them clean, but decided letting the tides do the work was better. On this sad morning they caught my eye and gave me focus but were not distraction enough. The cold air, brisk walk and time alone were necessary but also inadequate to soften my mood or bring any sense of understanding of the events that have absorbed a nation.

I thought of the scallop shell angels my mother had started making a dozen years earlier to represent those children who had lived with extra genetic material and died, many of them as infants. By July when the shells, transformed with wings, haloes and faces, and adorned with lace and gold ribbon, were given to parents before they released their child’s balloon, she had made 117. She stood with me as Conor’s name was called, and I released his balloon into clear blue skies. My angel hangs over his picture still. I smiled, remembering she began by looking for scallop shells on a Cape Cod beach, then started scooping a few from the area around the entrance to the local fish market, each time she bought fish. Soon a sign was erected saying not to take the shells. Angels seemed a better fortune than being trampled by boat shoes and sandals.

The scallop shell is the symbol of the apostle St. James, who, although martyred in Jerusalem, was buried in the distant Spanish seaside town where he preached, named Santiago in his memory. Although there are legends about masses of scallop shells that covered the ship carrying and even losing his body, the shell itself is metaphorical. From Medieval times, pilgrims travelled to his shrine in northwestern Spain. The many grooves of the scallop, which all end in a single point, represent the many routes to one destination. Scallop shells, which usually wash ashore intact, are also thought to be a symbol of God’s protection on our journeys.

I held a shell and studied it. It was thick, and the deep, even ridges perhaps served the same purpose as corrugated cardboard, giving the shell sturdiness and resilience. I spread out the shells in my hands, having first nested them one by one as I stooped and collected them. They varied in size and color. Some were bleached white from more time beached. Some were black, a few yellow, two mahogany, and several held various streaked or

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Darkest Days

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I am now collecting scallop shells to replicate that stark ornament, which carries only its natural beauty and a message of strength. The shells are to be symbols of the resilience of families with medically frag-

ile children of limited developmental potential but unlimited worth and love. The grooves radiating from the broad top to a single spot on the narrow bottom will represent the journey so many families will take in July. They will leave as many as 30 states by car and plane, and will travel from several countries and come together for an important reunion of those with shared experiences of heartbreaking loss and immeasurable blessings. Like St. James they will come home to a distant seaside land. Like Carol Hamblet Adams, they too may find renewal at the continent’s edge.

Light Within

On my beach walks I carried a tall plastic jar to hold the beach glass I hoped to find. In it I placed more than two dozen pieces of beach glass, including an elegant piece of cut glass, its facets frosted, a smoothed chunk of a mid century Coke bottle and a few lavender pieces, colored by the sun. The glass spoke of transformation through turmoil and time. Each piece announced that brokenness is not permanent.

As I reached the end of the beach where a steep granite-faced hill reaches the sand, I stopped and looked out over the bay. There were few boats so late in the year. Gulls roosted on the small rock islands, and eider floated, a study in black and white on gray water. I looked down and saw what appeared to be a black rock, but its shape suggested another origin. I turned it with my toe. Flipped, it revealed a hollowed inside. I bent and picked it up. It was black glass, my favorite, the rare treasure of beach glass. It still looked rocklike in its color and texture, but its shape revealed the hand of man. There was no bright sun to test it against. In winter’s gray light I could not see through it. Later, I would hold it against a lamp, and it would glow green through its thickness and patina. I held it cupped in my hand and marveled at its size and shape, despite its age and long watery journey.

The thick bottom of the ancient bottle was partially retained, and it has a high arched wall at one end. Tipped, it could still hold water. I thought of an old northern New England farmers’ legend that the month’s precipitation could be determined by the angle of the slim crescent moon. It was a matter of how many imaginary buckets could be placed on the moon before sliding off. If the crescent appeared nearly vertical, there would be little rain or snow. The more horizontal the crescent appeared to the farmer, the more buckets would be held, and the more moisture would be provided to his crops over the course of that lunar month. I always check bucket moons. I tipped the black piece away from its open end. This piece could hold many tears.

Black beach glass, the remnant of ancient glass vessels first brought to early settlements by wooden vessels, is made with a high ferrous content. It was made to keep out light to protect what was inside. It is barrier glass. Newer black bottles are marketing strategy, not a necessity for precious liquids. I have one not so ancient black Champagne bottle that traveled through Narragansett Bay intact, losing its shine and its smooth surface and gaining coral markings. I have many pieces of old black beach glass,

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Darkest Days, Light Within...

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some with bubbles from glass blowing, that I have found near centuries old villages. Black glass holds both iron and irony, carrying light within what looks so dark.

It is always a good day when I return with a piece of black beach glass, because it is rare, old and usually overlooked. It resembles rock, ordinary, grayish, pitted black rock. It requires a different way of looking to identify its true origins. It demands a belief that things are not as they appear. It holds light deep within without giving any suggestion that is the case. It humbly announces there is hope. The light it carries assures there is still light when everything that has happened has darkened the world. It reminds us to hold to light deep within when expectations have been dashed and trust and faith waver. It carries light within when there seems to be no logic, no understanding, and certainly no acceptance of what is only unacceptable. The ancient back glass which has completed its journey in storm and turbulence, which has been softened by grit, then left by an outgoing tide, announces that life is not as bleak as it may seem. There will not be logic, but acceptance may come. The light black beach glass carries within will shine until the dark days give way to light.

I hold my piece of old black glass in my hand as I walk back. I run my finger over its surface. Only its weight and shape announce its identity. It feels like rock, looks like rock. A tiny line inside the perpendicular interior planes retains the shine of glass. I turn it over and faintly I can see, then feel, lettering. Held at the right angle it reveals part of the glassmaker’s mark, “Jame”. I return from the shore with coquille de St. Jacque, the scallop shells of St. James in my pockets, and in my hand an antique shard from a black bottle with a James connection. James, one of the first apostles, met Jesus at the seashore and with his brother John, followed him. He was present at the Transfiguration and at the Garden of Gethsemane. He was the first apostle to be martyred.

My spirits have not been lifted enough by my time at the water’s edge, but my treasures take on meaning. My walk has given me an opportunity for prayer and reflection. I know of the hole that has been made in the heart of each of those parents. I am familiar with their pain but not the suddenness or horror. I also know the difficulty of their long journey ahead, which involves both missing a loved child and trying to understand why death came so early. For them it is not nature which brought such tragedy upon them for their safety and that their loss will remain with them always. Their identity will be changed. The numbers of those who died and the many left behind to mourn mean the identity of a community will be changed, as it has in too many other places. The hope of those of us who have travelled a similar journey is that over time and through the tumultuous process of grief that they too will be both toughened, softened and enlightened by grit and force. The hope is that these parents, who have lost their future and are now broken, will emerge like beach glass well-weathered with a new beauty and inner light. Like the scallop shell, they will be resilient. Like us, they will find their way to others who understand, hold their pain and celebrate their children.

I will love the light for it shows me the way. Yet I will endure the darkness for it shows me the stars.- Og Mandino

Resources

Other support groups for specific chromosomal disorders

Links are provided for information only and do not constitute endorsement by SOFT. Please help SOFT maintain current links.

Contact barbssoft@rochester.rr.com to report an inactive link.

Support Groups for Chromosomal Conditions lists contact information for specific disorder groups. Website: www.kumc.edu/gec/support/chromoso.html

Chromosome 3q Registry family information and support Website: http://members.cox.net/chromosome3/index.htm


Trisomy 9 (9TIPS) International Parent Support Group 9TIPS is an international support group for families dealing with Trisomy 9 covering all variations. Website: www.trisomy9.org/9tips.htm Alice Todd 4027 E. Piedmont Ave., Highland, CA 92346 Phone: (909) 862-4470 Email: atotdna@sprynet.com

Trisomy 13: A support website for families with Trisomy 13 Website: www.livingwithtri13.org

Chromosome 15 Betty Hane Email: user-ha8039@aol.com

Disorders of Chromosome 16 Foundation (DOC16) Website: http://www.trisomy16.org Email: doc16foundation@yahoo.com

The Chromosome 18 Registry and Research Society is a 501(c)(3) non-profit, tax exempt public charity that helps individuals with chromosome 18 abnormalities. Website: www.chromosome18.org Email: jmcging@dm.net 7155 Oak Ridge Drive, San Antonio, TX 78229 Phone: (210) 657-4968

The Trisomy 18 Foundation Website: www.trisomy18.org

His high endeavors are an inward light That makes the path before him always bright. William Wordsworth

None of us can predict when the causes we support will capture the public imagination, and our once-lonely quests become popular crusades.- Paul Rogat Loeb

“Remembering the person I have loved allows me to slowly heal. Healing doesn’t mean I will forget. Actually it means I will remember.” Alan D. Wolfelt Ph.D.
Don't forget to renew your SOFT membership!

PARENT Name(s): ____________________

Mail Address: ____________________

Phone: ____________________ (800) 716-SOFT (7638) 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.

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): ____________________

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 Declined shot series

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

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: __________ / __________

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.

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)

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I thank God upon every remembrance of you.-Philippians 1:3

Remembering
SOFT
Angel Wings

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<td>Lauren Beth Price</td>
<td>December 18, 1987</td>
<td>April 8, 1988</td>
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<tr>
<td>Elizabeth Ann Hilmes</td>
<td>July 13, 1987</td>
<td>April 8, 1999</td>
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<td>Conor Michael Healey</td>
<td>April 2, 1986</td>
<td>April 9, 1986</td>
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<tr>
<td>Garrett Stephen Twardowski</td>
<td>April 9, 1992</td>
<td>April 10, 2001</td>
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<td>Dominic Allen D'Aprile</td>
<td>April 13, 2006</td>
<td>April 13, 2006</td>
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<tr>
<td>Patrick David Showalter</td>
<td>February 6, 1987</td>
<td>April 18, 1987</td>
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<tr>
<td>Nathaniel Troy Popielarz</td>
<td>April 24, 2012</td>
<td>April 24, 2012</td>
</tr>
</tbody>
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Email Jack Laird for family contact info at jalird@rochester.rr.com
Deadline For The Spring issue of The SOFT Times Is 15 April 2013

27th Annual SOFT International Conference
Providence, Rhode Island
July 17-21, 2013
Crowne Plaza Hotel at the Crossings
Hasbro Children’s Hospital

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