The SOFT TIMES

Support Organization for Trisomy 18, 13 and Related Disorders

Come to the Water

By Pam Healey

I spent a spring weekend at a women's retreat at a rustic but quaint mid-nineteenth century Christian revival camp on Cape Cod. We had "Come to the Water" to worship, learn, reflect and socialize. We came to rest from being twenty-first century women doing too much. I considered how important it is to come to the water, literally and figuratively. We slept by a quiet woodland pond, home to a family of geese and goslings. Three times I walked miles on the nearby beach on Nantucket Sound. In late afternoon I strolled by crashing waves and at dawn slowly awakened by walking by the same waters, glass smooth. There was time to hear the roar of white-frothed waves pounding against the sand and pulling back rhythmically, to hear the steady music of water running through the gut beyond the breakwater, and to be soothed by the calm of lapping waves, carrying the tinkle of a blanket of thin shells curling over in water and sand. At mid-day there was the sound of laughing children at play and of bounding dogs disrupting Canada geese, mallards and laughing gulls.

Coming to the water helps us come to our senses, our inner selves, and our own abandoned child, who once carried tidal pool creatures in buckets and made drip castles on low water sand flats. Coming to the water may release the playful child left behind in the responsibilities of adulthood and make us momentary poets and artists. It reveals the sacred. We can be immersed in the vastness, buoyed in moving water and carried to a distant horizon. Coming to the water prepares us to move forward in the coming days and months, when our own tides bring the unexpected, unwanted and even requested. Having come to the water and found rest, we ready ourselves for the flow of our lives, which will pressure and challenge us in the weeks and months to come.

At SOFT we have come to the water. Many times we have journeyed to the water and while spending summer days together found ourselves refreshed, renewed, supported, simply made ready to face the challenges and uncertainties ahead. There has been time for reflection, friendship, laughter, and the catharsis of shared tears. We find time to breathe deeply and well. We metaphorically float for a while. In what we did as a group and in individual side trips for years we have come to the water: salt, fresh and chlorinated, still and flowing, peaceful and dramatic, warm and frozen. We have our own internal dowsers that bring us to the seashore, lakeside, riverbank and cascade, to the waters that refresh us body and soul. Coming to the conference has brought us to those waters.

We have traveled four times to Salt Lake City where courageous pioneers seeking religious freedom found a gap in the mountains and looked down at a shining inland sea and said, "This is the place." It was there that Kris said, "We need to find others" and enlisted John, created SOFT, and provided a mooring for thousands of bewildered and grieving parents in the last nearly three decades. The first SOFT conference was in Salt Lake City. Later, when SOFT came to Salt Lake City for the annual conferences, there were hotel pools and the dancing Olympic fountains, as well as, The Great Salt Lake, best seen from afar. For this family the side trips also meant hiking the Narrows at Zion, spotting the Colorado River carving through the Grand Canyon, walking around Jenny Lake, standing at Jackson Lake and rafting the rapids of the Snake River. Coming to the water was both an Outward Bound and an inward bound experience, and we are better for such excursions.

In Baltimore in intense heat we came to the Inner Harbor, busy with boats, sightseers and sea birds. We stood together and saw fireworks reflected in night water and saw our own stories reflected in new friends. In Chicago we met not far from Lake Michigan. For the first Chicago conference, this family stopped en route in Cleveland, and our preschoolers waded into a reportedly clean Lake Erie. Traveling to the second conference, before

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In this issue…

SOFT Founder, Kris Holladay

SOFTLY SPOKEN
Kris Holladay

"GIFTS OF THE HEART"

Gifts of the heart bring me sweetly and kindly to a gentle place in my soul. It was Wednesday, June 3, 1998 and it marked the 10th anniversary of Kari's death. As a reminder of this special day, I put on a necklace that belonged to Kari and enjoyed a few moments of memories. But, the day was busy and so I moved onto the list of things yet to be completed. Savannah (5 years old) had an appointment with her neurosurgeon, Dr. David Moss. This is one appointment we do not miss, no matter the date. Our son, Nick, 15 years, was helping by going with me to the appointment. We loaded up the wheelchair, the walker, and off we went.

To our disappointment, the waiting was small and crowded! We left our "stuff" in the hallway then moved into the crowded room trying to be considerate to the other patients already waiting. We crammed ourselves into a corner and sat down. A young mother holding her son was talking to Savannah and being so cute with her. Nick, the ever-thoughtful brother took Savannah into a playroom while I visited with the young mother. As we began to talk, she introduced me to her two daughters ages 3 years and 2 months. The young mother was holding her 18-month-old son born with a neurological disorder of unknown cause and an uncertain prognosis. As I listened to this dedicated mother and heard her words of courage and determination to do all she possibly can do for her son, I felt her to be a "kindred soul." She told me of their experiences with specialists never blaming, only looking for answers.

After sharing her story, she asked about our family. I told her we had 3 darling daughters and 3 handsome sons. As I stroked the necklace I was wearing, I explained about Kari and Trisomy 18 and this date was her 10-year anniversary of her death. I explained how we adopted Savannah four years prior. As I shared this with her, this young mother began to cry and she asked in her most hushed voice, "Is it okay to not want my son to suffer? Is it okay not to wish for him a long life? Is it okay for me to not know what I want for him? How long can I do this to him and my family and me?"

As I watched her share her deepest fears with me, a stranger, I realized I was sitting there looking at MYSELF just 19 years before. I, too, had had three small children in three years; our middle child was severely impaired with her future uncertain! Taken back by my realization, I began to gently cry as I held this mother's hand. Because she did not understand the source of my tears, she began to pull away. I continued to hold her hands and in a soft voice I shared with her my fears, my prayers, and my hopes of those many years ago. We hugged an understanding embrace.

Just then, Savannah's name was called and Nick, Savannah, and I were ushered into an examining room. After the doctor's exam, we prepared to leave, or so I thought. As we walked out the door, I heard Dr. Moss enter the next room and overheard my name. I peeked in to see the same young mother and her son. I smiled to Dr. Moss and went over to her and thanked her for her gift of the heart. She was puzzled until I told her that she had blessed me with a gift of seeing myself 19 years before. She and her son were my gift today, especially this day of all days. I told her the gifts of the heart are held in a special place in my soul. As I turned to leave, I told Dr. Moss that "she was me" years before. The young mother then asked Dr. Moss as she pointed to me, "Will that be me in 19 years from now?" Dr. Moss's response, "If you are lucky!" As I drove home, I stroked the heart necklace and again thanked Kari for touching my life and giving me another *GIFT OF THE HEART!*

GIFTS OF THE HEART come to us wrapped in the most unexpected packages! It seems these gifts come to us when least expected and most appreciated.

Hugs…

Kris

"You smiled and talked to me of nothing and I felt that for this I had been waiting long." - Rabindranath Tagore

Kris Holladay, with her beautiful daughter, Kari Deann Holladay.

Book Review by Pam Healey

Almost Home: Stories of Hope and the Human Spirit in the Neonatal ICU, by Christine Gleason, MD. Kaplan Publishing, NY, 2009, $26.95, 244 pages.

Neonatologist Dr. Christine Gleason presents stories of the infants whose precarious survival was literally placed in her hands and of her relationship with the parents, some children themselves, others at the end of their reproductive time, who all held hope in what medicine could accomplish. Each chapter is the story of a different child, and although most have happy endings, all do not. She tells the stories not just of the individual clinical cases but also of her role in diagnosing and treating infants born at the edge of viability who needed answers and procedures faster than seemed possible. Too many times she is responsible for several critically ill infants simultaneously.

As a young doctor she second guesses her decisions: to involve a teen mother who watches the soaps rather than even ask how her baby is doing, to perform heroics on a baby who she later discovers has little cerebral function, and later to persist with an unresponsive infant taken after his young mother bled to death. She is haunted by unpracticed procedures that took too long, tests not run, and questions not asked, which may have changed outcome. She remains embarrassed by some of her early decisions or failings, but she remembers older doctors who reassured her that they too had been new doctors, and she had done her best. She is elated to make the immediate diagnosis of a rare genetic syndrome, then solemnly remembers what that diagnosis will mean for the parents.

Over the course of twenty-five years of being a doctor she grows in confidence and expertise, but she never presents any infant as routine. She learns to talk with parents whose journey she has not made. With them she watches for the infant to make some of the decisions, letting go when that seems to be what is called for and supporting the baby that heartily fights despite grim odds. Describing sad eyes or intense eyes that follow her, she never forgets the humanity of the unbearably small or impaired child tethered to yards of plastic tubing.

Early in her career when she flinches as the senior resident refers to an infant boy as "she", Dr. Gleason then asks if the baby is a boy and is told "Well, it really doesn't make much difference; it is usually only the parents who really care…." (p. 3) She cares. She reaches out to parents, even when they are inaccessible, and changes their lives when they prefer to walk away. She awakens when she is not on duty and worries about her babies. She names babies who have been abandoned. She collects pictures of infants in incubators and later holding them in rocking chairs the day they go home and displays them with companion pictures decades later. She both changes lives and allows those lives to change her.

Dr. Gleason acknowledges that her book is a celebration of miracles that occur at the beginning of life because of what modern medicine is able to accomplish, but she keeps in mind that there are also failings of modern medicine,even with the advancements that occur over her career. With later cases she comments on procedures that although now common were unknown when she began in the neonatal intensive care nursery. Her book presents what happens when medicine, technology, the expertise of the NICU staff and at times blind luck combine to save the most compromised infants. She sits with parents as they decide how much intervention is enough and together they weigh the small chance of a positive outcome against suffering and decide if the suffering is necessary. She writes of parents who make different decisions and must come to a joint decision, and parents who unexpectedly gain immeasurably from the short time spent with their child. Just as she reported a certain callousness that protected some who dealt with so much potential tragedy, she also remembers the wisdom of her colleagues who believed something positive could come from tragedy, and she presents her own evidence.

Almost Home follows Dr. Gleason's professional journey from The University of Rochester School of Medicine to her residency in Cleveland beginning in 1979, to three years of a neonatal fellowship in San Francisco to her appointment at Johns Hopkins as Neonatal Attending Physician, at a time when the good old boys network limited opportunities for female doctors. Five years later she would become director of the Hopkins NICU. For the past 12 year she has been Chief of Neonatology and a professor of pediatrics at the University of Washington and Seattle Children's Hospital. Throughout her medical career she has been involved with neonatal research, including using fetal and newborn sheep to test drugs and procedures.

Dr. Gleason's own journey is not smooth. After an early defeat she decides to change her specialty, certain the stress of the NICU is not for her. Her next case convinces her to remain, but doubts still intrude. When she cannot make basic payments from what she makes as a resident, she moonlights as an emergency room pediatrician during her research not clinical stints and has more time. Her experience broadens with pediatric and adult patients and both pays her bills and confirms her decision to be a NICU doctor. As a second year resident she spends time in the Pediatric Intensive Care Unit and after the death of a fourteen year old, she realizes that she cannot be a doctor to older children who had a life outside the hospital. Her decision to be a NICU doctor is informed by what is and what is not involved. Dr. Gleason describes the NICU as "a strange and wonderful place where both miracles and tragedies happen every day" (p. ix). Despite her own tears, which she hides to remain professional, the NICU is mostly a place of hope. She carries with her both the successes that encourage her in later cases and the lives

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lost before there was enough living.

Most of the infants she writes about are premature, but some have genetic or other challenges. She follows them from their arrival in NICU and in some cases goes out on transport to bring them by ambulance or helicopter to her larger hospital. She writes of the cases she remembers best. She also carries the lessons of her earliest patients with her as she takes on the challenges of similar patients even years later. She deals with a variety of heart defects, persistent fetal circulation, necrotizing enerocolitis, sepsis, stroke, apnea and bradycardia, hernias, pneumothorax, and babies too big or too small for gestational age. She sees robust babies who are sick and fragile looking babies doing well. She routinely tends to changing oxygen needs, fluid retention, fevers and seizures. The daily tasks to be done are never completed. Too often carrying out what must be done is interrupted by emergencies in labor and delivery bringing yet another compromised infant to her ward. She becomes more confident with familiar scenarios but keeps alert for "the occasional zebra, instead of the more typical horse, when I heard certain hoof beats" (p. 188). Alertness and flexibility are essential. She pulls from her own knowledge and experience in the clinics and research lab and listens to her colleagues and is willing to try something for the first time. Innovative procedures bring hoped for results often enough to outweigh what might seem to be less than certain decisions. She takes well-calculated risks involving surgery and medicine and saves lives.

For those who have held vigil in a NICU, listened in shock to a previously unknown diagnosis, weighed the wisdom of interventions and prayed for a miracle, which may have come in a way not anticipated, this is an in-depth look in a familiar world. For those who have been disappointed by the limitations of what has been offered or possible or by resignation when hope is needed, this book is a look at the other side. This is an account of the doctors who tried to do the right thing. It may not always be a comfortable read, bringing back such a difficult time with an outcome that may not have been satisfactory. For those whose infants were in

Book Review by Pam Healey

NICU decades ago, it raises possibilities of what might have been. With a diagnosis of trisomy 18 or 13 the limitations are different, lines more surely drawn. Judgments made may be different. The book does not address the resistance to intervention so many SOFT members have experienced. Nevertheless, Almost Home brings the perspective of those who must quickly, precisely and compassionately carry out routines in what are never routine situations, make fast decisions and react quickly to unexpected changes. It is both different and what SOFT parents do daily. Almost Home brings the perspective of a dedicated doctor, who tried research but returned to the hospital floor, then mentored others in the classroom and clinic. She imparts wisdom borne of experience, intuition and sensitivity. She brings enthusiasm for a dynamic career, even when hoped for results are not always possible. It is a book that demands curling up on the couch with tissues nearby with enough time to read at length, getting lost in a place that supports miracles, expected and unexpected. The spirit of infants and the optimism of their parents in Almost Home will touch readers. The little ones who begin life so tentatively will be familiar, reminding SOFT parents of their own NICU babies.

SOFT's Website

Check out our updated website and browse through the Medical Articles, Presentations, Family Stories, Resources, Growth Charts, Surgery Tables, and Conference Presentations. After you peruse this sample newsletter save some time to check out our newest additions. There are many new and interesting topics that have been added.

"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.

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 e-mail your interest and address to
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PROFESSIONAL VIEWPOINT: Guidelines for Care in Infants and Children with Trisomy 18 and 13 Syndromes.

By John C Carey, MD, MPH
Medical Advisor, SOFT
and Dr Anna Cereda (Monza, Italy)

In previous SOFT newsletters, I have presented guidelines for routine care of infants and children with the trisomy 18 and trisomy 13 syndromes. In addition, I have summarized the rationale for these recommendations for health supervision and anticipatory guidance in the chapters in the book entitled *Management of Genetics Syndromes*, edited by Drs. Suzanne Cassidy and Judith Allanson, published by Wiley-Blackwell. This book, currently in its 3rd edition, was published in 2010. Please refer to this latest chapter for the details of each of these guidelines. Below is a tabular form of the current version of the recommended guidelines for usage in the hospital and clinic setting.

Health Supervision and Anticipatory Guidelines for Care of Infants and Children with the Trisomy 18 and Trisomy 13 Syndromes

	Manifestation/Theme	Diagnostic or Screening Test/Referral
Infants (0-1)	Congenital heart defect	Cardiac evaluation, including echocardiogram, in newborn period and later as indicated.
	Developmental disability	Referral to Early Intervention and to appropriate programs for children with disabilities (OT, PT, speech).
	Growth delay	Measure length, weight, and head circumference at every visit; plot on trisomy 18/13 growth curves (available on SOFT web pages).
	Feeding difficulties	Referral to dysphagia or feeding team; assessment for GE reflux; consider G-tube at 6 months; always consider upper airway obstruction.
	Hearing loss	Audiology in newborn period and at 6 months of age; followup as needed.
	Neurologic conditions	Diagnostic neuroimaging in newborns and infants with trisomy 13 as needed; referral to Child Neurol ogy for seizure management if needed.
	Eye abnormalities	Referral to Ophthalmology in newborns with trisomy 13; referral at 6-8 months in trisomy 18.
	Respiratory difficulties	Refer to Pediatric Pulmonology or sleep specialist when appropriate; always consider upper airway obstruction.
	Neoplasia (Wilms tumor/hepatoblastoma)	Every 6-month abdominal ultrasound starting at 6 months in children with trisomy 18 until age14 years.
	Genetic issues	Referral for medical genetics consultation and genetic counseling as needed.
	Family coping	Referral for family counseling and pastoral care as needed; referral to support groups, local & national; distribution of web pages; palliative care team as indicated.
Older Children	Developmental disability	Referral to special education, other educational services (PT, OT, speech).
	Urinary tract infection	High risk of suspicion; evaluate when needed.
	Scoliosis (especially in trisomy 18)	Follow closely clinically and referral to Orthopae-dics if any sign.

Coming Home to SOFT

By Bob Irvin
SOFT Ohio

An important thought struck me at the SOFT 2011 picnic, but I don't think it's a terribly new or especially original one. I just think it was important for me. Something I'd felt in the past became especially true for me once again.

The gathering of a couple hundred people at the picnic was like . . . and here was my thought: like one very big and lively family reunion. A place where old friendships are once again rejoined . . . and where new relationships are made. A place where some old friends are missed, and yet thought of fondly.

Maybe a few people thought that way of us, since we missed for a few years.

After a half-decade of missing the conference — for reasons quite varied, some good, some perhaps not so good — we came back to SOFT for this year's picnic gathering. We knew what to expect, sort of, at the melt-you-where-stand memorial balloon release, and we expected a great setting and things like plenty for the kids to do and great food. These things have come to be quite expected at SOFT picnics and conferences. What I didn't expect to feel so deeply was how much I had missed the gathering and missed the friendships, new and old.

There's nothing quite like the giving nature of Kris Holladay and the genuineness of her hugs, is there? To say hi to Dr. Carey and Barb and the Cantrells, to see the faithfulness of the Cooks and couples like the Wrights and many others who labor to put on such an event. The thrill for Joan and I to see old pal Heidi Herdman from England, her precious (now 19!) Saskia and see lovely once-little Ellie now all grown up and, we hear, appearing in the movies. (BIG-time movies. Think H. Potter.) And to hear of the success of a SOFT U.K. gathering and Dr. Carey appearing there — more great news.

At any good family reunion, you perhaps connect with someone you hadn't talked to in years past. I got to talk to "new people" (but new only to me) like Jeremy Bowers of Omaha and his wife and five kids all wedged from 6 years of age to three months, including T-18 mosaic Dominic, sporting his fancy glasses and a bit of a spiky 'do.

I met Alan and Laurie Poppe, whose Kayla is 5 and T-21 (Downs) and pretty as a prairie flower. Mom worried about her going down the inflatable slide, but as Dad watched on proudly, I think she went down that slide, oh, about 13 times. For the Poppes, it was their first SOFT conference though their Brianna, now 22, had been diagnosed partial Trisomy way back in 1989. They've known SOFT people for many years, though, and have contributed to the organization in the ways that they've been able to, Alan told me. This year was just their time, their year, to come to their first conference. Sometimes family reunions are like that too.

There are always great family support heroes, like Dolly, Cindy Cook's aunt. I asked Dolly if she had helped with the conference in any way. She answered, "Just watching the boys." And we thanked her, knowing that that alone was a significant contribution that allowed the Cooks more of the time needed to put together a fantastic SOFT conference week.

I love seeing some of the most beautiful girls in the world. These are some of those I got to hug and tell them of their beauty, lovely ladies who don't look like they've aged a bit with the passage of a few years: Greta Rose Thompson, now 31; Saskia, who looks in 2011 just as she did when we first met her in Boston in 2001; Megan Hayes, also now 31, sporting some awesome baby blue Converse Chuck Taylors; and Philina Lockwood and Bethany Branch, conference mainstays through the years.

And it hit me who the real heroes are, perhaps similar to the way that, after years of being around your family, you suddenly realize those who have been the real heroes all along—you just never had your eyes open to recognize it. With SOFT, I realized once again who *the real heroes are:* the parents who love those kids with such a passionate, undying love. Who pack all that gear and wait on the lift-buses and spend so much time with their kids dedicating so much love.

Still more things that make for a great, way-above-average Saturday: watching my son go up and down and up and down and up and down that slide . . . and chatting and taking my daughter out in one of the canoes . . . and great food . . . and incredible orchestra music . . . But eventually, with a SOFT picnic, all roads lead to the Cantrell Memorial Balloon Release, the most emotional you can get this side of watching one of your children come into the world. I love the hugging moments by SOFT parents; the girls who've known each other for years also hugging and being there for one another; watching single balloon after single balloon go up; the bouquet representing all those children known only to God being released at the end.

As I tracked our Adrienne's balloon rising higher and higher (something kept it in my vision far longer than I expected), I chose a moment in time to widen my gaze out in points equal distances from Adi's bright yellow orb. It was then that it struck me: Dozens if not scores of other balloons were going up with hers — around hers, under hers, above hers, but every last balloon ascending to the heavens.

She's far from alone, I thought of our Adrienne, who left us in 1998. She's with all these other kids. It's just like being at a SOFT picnic, and just like being at a good family reunion: The last thing you are is alone.

Thanks for having us back, SOFT. It's been too long to miss a gathering like this. Because this is truly . . . family.

The Medical Intervention Debate

by Pam Healey Ph.D.

Increasingly, there are articles in journals, and blogs and conversations on the internet, each related to the need for or wisdom of providing medical intervention to save the lives of infants and children with syndromes characterized by medical fragility and severe developmental delay. There are parents and some advocates who believe everyone should be offered medical services to prolong life. What is offered to otherwise healthy children should be offered to children with multiple disabilities or a poor prognosis aside from the current narrow medical need. Others believe that some children are not worth saving, that nature should be allowed to take its course. They believe foregoing medical interventions will relieve the child of a life of suffering and the family of a life of burden. These two opposing philosophies mean there are two passionate camps with little middle ground.

The most recent article, published in January, 2012, argues for a lack of intervention as the humane course for infants with trisomy 18 or trisomy 13, labeled as lethal or fatal conditions. In "Trisomy 18 and Trisomy 13 Treatment and Management Decisions," by T. Allen Merritt, MD, MHA, Anita Catlin, DNSc, FNP, FAAN, Charlotte Wool, Ph.D. APRN, Ricardo Peverini, MD, Mitchell Goldstein, MD, and Bryan Oshiro, MD. in *NeoReviews*, an online journal of the American Academy of Pediatrics, a group of clinicians consider ethical decisions in the NICU. The paper is a review of the literature on the challenging decisions facing maternal fetal medicine teams, along with other clinicians and parents, when determining care for children with trisomy 18 or trisomy 13. With increased technology, medical interventions have increased. The American Academy of Pediatrics asserts it is "Dedicated to the health of all children" but there seem to be clearly drawn lines according to diagnosis. Studies of the natural history of trisomy 18 and trisomy 13 are used to defend the position of minimal or no medical intervention. Since most infants with these diagnoses do not survive infancy, the condition is considered lethal. Those who do survive seem not to be considered, except in their cognitive limitations as argument for "no cure."

The authors consider the conflicting approaches of paternalism by physicians and other professionals and the parental need for autonomy. They discuss possible medical procedures in the context of ethical decision-making and potential dilemmas, immediately, and in the distant future, should the child be given a future. They present perinatal palliative care as the alternative to aggressive medical treatment that parents may request. They carefully delineate what should occur. They begin with the belief by the medical team that palliative care is the treatment of choice. The team shares their position with parents after a diagnosis and include a social worker and spiritual services, along with medical personnel who will be involved. Following prenatal diagnosis a birth plan is developed. The team makes it clear to parents that what will be provided in that hospital includes intensive comfort management, control of symptoms and time for the families to spend with their child unencumbered by medical equipment. Resuscitation is only offered if the diagnosis is not clear or to buy time for family members to reach the hospital and spend time with the infant. The infant remains in the hospital until death or is sent home to die with Hospice follow up. If the family does not accept the limited medical interventions, then they are encouraged to find another hospital, which will provide ventilation, surgery, or dialysis.

The authors acknowledge that their preferred approach can run counter to what parents want, but they also believe that educating parents about their child's diagnosis in terms of medical challenges and developmental outcomes is important, if parents and physicians are to have a dialogue and find common ground. The authors explain their approach is well considered and based on acting in the best interest of the infant and doing no harm.

The authors are concerned that medical interventions, which have been developed in recent years, serve to extend the lifespan of infants with trisomy 18 and trisomy 13, and therefore are contrary to ethical considerations held by many physicians. According to them, the best scenario is when parents and physicians agree and "the quality of the infant's living or dying is humanely supported and is characterized by dignity and kindness" (1). When parent's are unable to take the physician's perspective, the result can be "moral distress, heartache and disappointment" (1). Typically, the problem arises when parents ask for technical support and surgery, and the neonatal professional team opts for palliative care and hospice care, that is, no heroics, just comfort. The authors believe that medical interventions will not cure the child, will not measurably improve the situation. The authors believe that neonatal palliative care provides an opportunity to educate parents to do the right thing for their infant. They believe being lovingly held by parents in the final days and hours of life is what the infant needs, not medical interventions. They see education about "The selective use of intensive medical interventions" (1-2) as a means of reaching consensus for parents and physicians, who each believe they are interested in doing what is best for the infant.

The professionals consider both the infant, including potential quality of life and physical suffering related to interventions and continued survival, and also the lives of family members. They believe the lives of family members will be inevitably stressed with opportunities curtailed in caring for a medically fragile child of limited cognition. Finally, they mention allocation of resources. Limited medical and community resources mean that resources that go to an infant, then child with limited potential are drained from others who might need them, in order to reach their potential which is greater than that of the individual with trisomy 18 or trisomy 13. They cite a study that determines that 1.6% of days in the intensive care nursery are for futile treatment of infants with a lethal condition or minimal cognitive functioning. When there is not enough to go around, first in NICU, later in schools, then decisions are made to support those

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who have the greatest chance of surviving to adulthood, if given surgeries or other medical interventions, living independently and perhaps making a contribution to society. Driven in part by economics, lines are drawn according to diagnosis. Might lines be shifted to include other diagnoses on the no interventions side?

Later, the authors express concerns similar to the concerns one of the authors, Anita Catlin, made in her response to Debbie Brun's article which came from her research with 13 families in SOFT. In "Trisomy 18 and Choices" in the section, Ethical Issues in Newborn Care in *Advances in Neonatal Care*, *Vol. 10, no. 1,* page 32, Catlin raises a number of questions she believes should be considered in deciding on a course of treatment for a newborn which she considers having a "fatal" condition. She dismisses the long-time survivors (ages 8-33) by listing their need for wheelchairs, functioning at infant to toddler level, lack of verbalization and reliance on G-tubes. She believes those advocating for aggressive medical interventions should consider whether the child will suffer during the interventions. She asks whether the interventions will provide permanent correction and healthier living for the infant, or whether ventilation, subsequent hospitalizations, procedures addressing other organ dysfunction will require still more medical interventions. She raises the question of whether beginning medical interventions serves the infant well. She also raises the issue of how the family will contend with demands, restrictions and lifestyle changes stemming from that initial aggressive care of an infant she sees as imperiled and in need of hospice or palliative care only. She wants parents to consider what moving forward with doing all that can be done for an infant with trisomy 18 will do to family life. She sees as real problems: the parents' ability to continue working while the child receives care and later comes home, dislocation of families to be near hospitals, financial concerns with mounting bills, and perhaps disrupted lives of siblings or less attention to siblings. She raises the question of whether the decisions made can be revisited. This mirrors an earlier discussion of ventilating at-risk infants, because removing the ventilator is an ethical decision. Starting ventilation does not mean it is easily stopped, so more problems are created.

The reality may be that a child with a now repaired heart is a healthier child, albeit with the same cognitive limitations. It becomes more difficult to argue against a hands off, palliative care only approach, when the next medical crisis occurs. Finally, Catlin asks parents to consider who will care for the child, when the parents age and when they die. She moves from an infant with days to live to an adult with trisomy 18 who

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by Pam Healey Ph.D.

three decades later needs a caregiving plan. She agrees that there is the technology to save infants with trisomy 18, but emphasizes that does not mean that is what should happen.

Both articles are well written with extensive relevant documentation of studies and opinions from those who also see infants with trisomy 18 and trisomy 13 as being born dying. There are many in the no cure, no hope camp. The authors believe anguished parents can "adjust their expectations" and embrace a dignified death.

Currently, there is a debate occurring about a 3 year old child named Amelia Rivera, who needs a kidney transplant. Her family has been refused treatment at Children's Hospital of Philadelphia. She has Wolf-Hirschhorn syndrome, 4p-, a condition that precludes being on the transplant list, because it carries the diagnosis of developmental delay. The argument is that with limited organs, organs should go to those who can use them best. The greater good is a guiding principle. Some people are more worthy, more deserving, perhaps more human than others. We are not created equal. There is more to the justification to keep Amelia from the transplant list. Amelia is young, which means she will require another transplant in 12 years, and a social worker worries who will make sure she takes her medicine then. The clinicians worry about what Amelia will do in the future and illogically see not giving her a future as a solution. The same doctor who said she could not have the transplant because of her "mental retardation" (his words not mine), later argued that the transplant meant medicine, and the medicine could cause seizures, and seizures could result in brain damage. Somehow, brain damage in a child who already essentially has brain damage is worse than in an otherwise healthy child. Circular logic!

Since the transplant will not improve her cognition, which apparently defines her, and will just keep her alive, then an available kidney must go to someone with more potential. There seemed to be a solution. Her family will provide a kidney, which means no one else is deprived, but doctors have not yet agreed to do the surgery. Perhaps they believe that doing the surgery may create a precedent, which will weaken future arguments for disallowing surgery for future Amelias.

Supporters of Amelia and her family write that this is discrimination against those with disabilities. It is not just an issue of limited resources, as far as organ donation is concerned, but an issue perhaps of limited resources in general, and a belief held by many that some children are meant to live a short time. If they are helped to survive longer, they will use up other limited resources: child care, teachers, therapists, tax dollars. Someone will have to pay for special equipment, hospitalizations if a cold turns more serious, and special transportation to a special school with a low student teacher ratio. This is far more than an assumption that some children will suffer physical pain if they live, and doctors, who hold to "do no harm", believe letting them die curtails suffering. $$$ are getting caught into the ethics discussion. Assumptions about the value, perhaps the humanity, of those with severe disabilities who will use financial resources are getting into the ethics discussion.

These discussions bring into sharp focus the reality that what parents often want for their imperiled infants and toddlers and what those providing medical treatment are willing and comfortable in providing can

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Book Reviews: Parent Voices

By Pam Healey

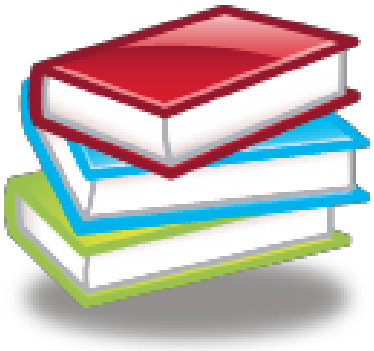
Shut Up About Your Perfect Kid: A Survival Guide for Ordinary Parents of Special Children, by Gina Gallagher and Patricia Konjoian, Three Rivers Press, NY, 2006, 2010, 250 pages, trade paperback, $15.00

My Baby Rides the Short Bus: The Unabashedly Human Experience of Raising Children with Disabilities, Edited by Yantra Bertelli, Jennifer Silverman, and Sarah Talbot. PM Press, Oakland, 2009 344 pages, trade paperback, $20.00.

These are two important books for parents finding their way in raising children with disabilities. The first, *Shut Up About Your Perfect Kid: A Survival Guide for Ordinary Parents of Special Children*, is written by two sisters, who support each other when they find they are both struggling to do what is best for their daughters: one with Asperger's syndrome, the other with bipolar disorder. The particular disorder does not matter. The book addresses the process of letting go of the imagined child and embracing the child that is theirs. It deals with grandparents, neighbors, school personnel, doctors and even the Catholic church. The two mothers share their children's accomplishments, including the victory when a child with autism learns to lie. They also share their own sadness when they watch their children struggle. They tell their stories through admitting their fears, frustration and feelings of inadequacy. They report personal triumphs and growth. They also write funny bumper stickers and make lists. They seem to believe if you allow yourself to laugh, you might not cry!

The book is dedicated to all special parents and other caregivers "who feel sad, overwhelmed, and isolated." Their book is to give others assurance that they are not alone on their journey. With the permission of their teenage daughters, the two moms tell their story as therapy. Although there is certainly anguish and many trials they would probably prefer to forget, they write of incidents, insight and breakthroughs with frankness and humor. In telling their story they pass on what has worked for them and what they have learned from the experts along the way. Although there are tips from professionals, there is also valuable information from the real experts, parents of other children with special needs. The information includes terminology to make medical and educational conversations easier. There is advice about finding the right placement and the best therapists. There is a list of tips from parents to teachers and another from teachers to parents to help those involved prepare for a team meeting. There is also a humorous list from other parents of when you know the therapist you found for yourself is not working out for you. Throughout the book are examples of what people say and what they mean: on report cards, in meetings, on IEPs and even in the supermarket. There are also examples of what parents of children with disabilities can say to others, who are rude or insensitive, to educate them, increase their awareness of disability or, if all else fails, escape from them.

Throughout the book is an awareness



of the difficulty of living in a society that expects perfection. They have started a movement to hold at bay all those obnoxious parents bragging about their perfect children. They give great examples of parents of perfect children saying they understand what the authors experience day to day, because they have just experienced a minor crisis. A parody of a typical family newsletter of accomplishments is followed by their own humorous newsletter. There are examples of business cards to hand to strangers who have an opinion about their child or assumptions about their parenting skills. There are lines to give to provide a sense of normalcy when in conversation with parents of perfect children. If you must gate your child for his protection, that can be rephrased as living in a "gated community." You can brag your money is tied up in pharmaceuticals if you spend as much on meds as food. There is a section on taking care of yourself, relieving stress and finding opportunities to laugh. There is acknowledgement of the courage, resilience and honesty of their children. They note the remarkable contributions to the family made by siblings who do not get their share of parental attention, can be frightened by medical episodes, but develop with sensitivity and love.

This is a book filled not only with invaluable information that provides a road map for those needing extensive services for their children, but also entertainment and laugh-out-loud moments, as the two sisters do their best to silence all the perfect parents of perfect children. They seek others who will celebrate differences, embrace imperfections and grow from knowing children who have their own beauty and spirit and capture the hearts of those who are open to them.

My Baby Rides the Short Bus: The Unabashedly Human Experience of Raising Children with Disabilities, is a collection of contributions by parents of children with a range of disabilities. Many are poignant, some edgy, some angry, but all are informative and carry the reader into the world of parents facing the daily challenges of raising their children. Those writing the chapters are parents, mostly mothers, who do not fit into the mainstream "through circumstance, identity or choice." They define themselves as alternative parents: with liberal parenting philosophies, some with disabilities, many anti-consumer, often in non-traditional, "modern" families. Many were ready to embrace alternative education and lifestyles before their child's disability led them back to public education, hospitals and medication. The essays are well written, honest, often humorous, and usually emotional. There are diaries, poetry, plays and stories.

The first chapter consists of stories based on receiving a diagnosis. One mother writing of her child with cri de chat syndrome (5 p-), says "Some of us come with

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be at odds. Both want what is best for the child, but neither side can agree on what actually is best for the child. There is often not time for discussion to lead to consensus. The stakes are high. Kids are dying. Real kids, adored kids in real families are dying. Doctors see educating parents as a solution. Parents, reeling from a new diagnosis, keeping vigil with a fragile infant or seeking treatment for a child with new problems are hardly in a position to educate doctors. These are also parents of young children, who do not yet know all the joys their children will bring. They just want to have treatment before it is too late. They want their voices heard, but it is an uneven playing field. One side has most of the power. The other side has the most to lose.

There are voices that should be heard. There are many who have had time to know first hand the "burdens" of raising a child with medical challenges and developmental delays. They realize that what their child cannot do matters to some, that the disabilities may preclude full participation in what society deems are important and maybe necessary endeavors. What is important to these parents and to the debate based on mutually exclusive approaches, is the realization of the joys also present in having a child with a chromosomal or other diagnosis.

Day-to-day experience makes the parents the experts, the ones to educate any clinicians who will listen. They have anecdotes, journals, pictures, and videos, that tell not of limited cognition but of development, meaningful interaction and joy. They have witnessed behavior that transcends the diagnosis. They have experienced love that transcends the disability. Those advocating a let-nature-take-its-course position, need to spend extended time with real families and see how much the child with an extra chromosome is lovingly integrated into family life. They need to hear how siblings gain more than they lose by having a brother or sister with trisomy. They need to hear how values are clarified, and how opportunities are opened up. They need to see how confidence increases as challenges are met. They need to see the delight, the possibilities, the triumphs and the love that make any burdens manageable.

The physicians and medical ethicists need to look at a three or five pound infant unable to coordinate sucking, breathing and swallowing, having apnea attacks, and see beyond that infant to a four year old asserting herself by refusing to be compliant, in the full throes of the terrible two's, which should be celebrated as agency. They need to see a ten year old using a walker with determination and perhaps a bit of pride. They need to see a twelve year old with her head thrown back and laughing as she dances, twirled in her wheelchair to a live band. They need to see a fifteen year old flirting, a broad smile her response when given the attention she seeks. Those making the decisions they make in mercy need to see first hand rough and tumble play between young siblings, and the protective advocacy of an older sibling who comes up against the attitudes that devalue those with disabilities. They need to hear shared laughter and be touched by the quiet moments. They need to witness tears, not those that come from frustration with dealing with those in power, but from joy because so often the child in question is the perfect child for that family. Some families believe in fate and accept there is a reason for a special child in their lives. Others rise to the occasion, learning along the way. Some begin by making the best of the situation they find themselves in and become transformed. Some children with trisomy 18 and trisomy 13 do survive and bring their own gifts.

The Medical Intervention Debate

by Pam Healey Ph.D.

It is the people living with the long-term survivors who have the answers about the future, not the neonatologists or pediatric surgery teams that have never spent real time with older kids with what some call a fatal diagnosis. Questions should be raised not about a life of suffering but about whether cardiac surgery can mean better (but still limited) cognition, because a healthier heart means better circulation, thus less fatigue, better sustained attention, and more energy for exploring, thus more learning, and better development. It may be that the medical interventions now denied or discouraged, when given will make a better future and a different quality of life. Maybe having to decide way down the road about a group home or residential facility is an amazing outcome, not a problem worried about for 30 years and used as an argument against medical interventions in infancy. Parents are asking for weeks, months, maybe a few years with their child. Imagine getting decades!

SOFT Mission Statement

SOFT is a network of families and professionals dedicated to providing <u>support</u> and understanding to families involved in the issues and decisions surrounding the diagnosis and care in trisomy 18, 13 and other related chromosomal disorders. <u>Support</u> 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.

Meet Me in St. Louis July 18-22, 2012 Update

By Steve Cantrell

The conference is coming together with some great surprises. Friday night features the World Champion Cardinals against the Chicago Cubs at Busch Stadium. The Cubs and Cards don't like each other and when they meet anything can happen. .A block of tickets has been reserved which will go fast. Not a baseball fan, how about a Cabaret just for SOFT or a night of dining and shopping within walking distance. Mom and Dad's night out with baby-sitting provided by the NICU nurses from Mercy hospital.

Two Sib outings are planned. The younger gang will visit the St. Louis Zoo in the morning followed by the Science Center Omnimax in the afternoon. Older Sibs are in for an adventure they won't believe, The City Museum, an ever-evolving art project that is unlike any museum you have ever seen. In fact, calling it a museum is a bit of a stretch. Instead, this museum features a 10-story slide that whizzes guests of all ages from the roof to a cave, a Ferris wheel and airplane on the 10th floor roof, and the feeling a mad scientist lives here. This is more like "organized chaos, play it by ear and see what happens."

Workshops include Trisomy 18, 13, 9, and related disorders along with first time topics. Learn how to correctly lift your child without injury. Also hands on therapy for the care giver by trained clinicians with take home tips. The Mom's Only and Dad's Only workshops will be expanded so everyone has plenty of time. This will be a day filled with: "WOW I didn't know that!"

Wednesday evening features an old fashioned ice cream social by the pool, sit back and catch up with new and old friends over a root beer float.

Thursday begins with the Stroll for SOFT followed by Dr. Carey's clinic- at Cardinal Glennon Children's Hospital. Dr. Carey along with colleagues from Glennon will offer consultation on a number of important topics. See the registration form for details.

And don't forget Saturday morning with Kris. Kris Holiday's annual video featuring all the kids along with time for sharing.

Come join us for a wonderful time with friends and why not

THE CITY MUSEUM: photos shown above and below-
Site of the older sibling outing, you have to see it to believe it!

At the St. Louis World's Fair in 1904, Richard Blechyden, served tea with ice and invented iced tea.

Missouri is known as the "Show Me State."

The state animal is the Mule.

State insect--honey bee July 3, 1985

Come and visit old & new
SOFT FRIENDS

Meet Me in St. Louis?
July 18th - 22nd
2012

YOUNGER SIBS WILL VISIT THE SCIENCE CENTER OMNIMAX IN THE AFTERNOON AND THE ZOO IN THE MORNING

We Need Your Help

Dear SOFT conference attendees,

One of the true blessings of this wonderful organization is supporting our families fully across the broad spectrum of economic circumstances and financial challenges. The larger SOFT family is here for you as we strive to do what is best for those we love, cherish and fight for. As we prepare for this summer's SOFT conference in St. Louis, conference planners are striving to bring you the most affordable, educational, entertaining and high-quality experience possible. In that spirit we ask for your trust and best judgment in addressing room bookings at the Frontenac Hilton for the conference.

Our contract with this fine hotel requires us to book and guarantee occupancy of a block of rooms. That simply means in order to avoid thousands in charges for SOFT that would hurt us all long-term, we're encouraging attendees not to book accommodations individually. While booking individually might save you a few dollars up front, the advantages of working through SOFT include free Internet, 15 percent off hotel restaurants as well as a free continental breakfast. This approach may well save you money over all. By booking through SOFT you help us avoid charges for the meeting space and ball rooms that will be better spent supporting you at the conference and throughout the year.

It's truly an honor being on the SOFT board, serving people who live the values of sacrifice and devotion on a daily basis. In these tough financial times we respect your tremendous efforts to do your best to meet every challenge with courage and dignity. Courage and dignity that is only matched by our precious trisomy angels and survivors. We sincerely appreciate your understanding and support as we work together to make the 2012 SOFT Conference in St. Louis the best ever.

The Conference Committee

CAN YOU COME OUT AND PLAY?
St. Louis Zoo younger Sibling outing set for the conference

World Champion Cardinals vs Chicago Cubs Busch Stadium July 20 2012

Come to the Water

(Continued from page 1)
reaching Illinois, we stood on the Indiana Dunes on the south side of Lake Michigan and looked lengthwise into a lake that appeared as vast as our familiar ocean. For the third conference we flew to Chicago, drove to Minnesota and played in the Wisconsin Dells and hours later stood for the first time on the banks of the Mississippi, not so mighty in Minnesota but still inspiring. This past year SOFT families filled a party boat and traversed the Chicago River a few times, then ventured out into Lake Michigan to look back at Chicago's skyline against the setting sun. Our hotel curved around a large pond that swelled after a record breaking rainfall; we had certainly come to the waters. At the Chicago conferences we played at Navy Pier, looking east across the lake and down at the Chicago River, and later stopped at Buckingham Fountain.

In Central Florida the bouquet of balloons representing all unnamed children was launched at the end of an early evening balloon release, less than a year after the death of our oldest survivor, Paige Barton, who had mosaic trisomy 18. We watched Paige's yellow balloon release itself from the tree that had held it since the beginning of the ceremony. It floated upward and in the timing seemed to follow protectively the balloons of all our children. Paige, although one of the SOFT kids by genetics, could also be a protective aunt. Her balloon sailed out over a pond that was suddenly arched by a double rainbow that held us longer at the water's edge. We stood by the water until the balloons receded, the rainbow faded and night and the mosquitoes came.

In 1991 early SOFT members came to Seattle "out of the rain and into the rainbow," and Seattle was the conference host city again in 1995 when families arrived into the rain. Seattle, an isthmus between Puget Sound and Lake Washington has water everywhere. It provides awesome vistas of ocean and lakes against a mountain backdrop with water passageways and water recreation at every turn. Water is at the heart of the seaport city, which is "One of God's best creations," according to Margaret.

In Denver from our hotel we looked out at snow fields that glimmered on the Rocky Mountains in the strength of the summer sun and reminded us that, as Camus knew, we carried within us an invincible summer even in the depths of our winter. Glaciers are rivers of ice, and snow fields are crystalline water not yet warmed. We had come to the High Plains but we had come to the water. Our teens tempered by love and loss, braved icy, fast moving and heart stopping river rapids, again proving their resilience and their youthful ability to just go with the flow, however unexpected.

In Toronto and Rochester, on opposite sides of Lake Ontario and an easy drive to Niagara Falls, we stood by water, one vast and at times peaceful, the other, awesome in its roar and power, draining four Great Lakes into one. Both are international boundaries, shared water. SOFT is international, our shared experience transcending nationalities.

In Pittsburgh we met at the convergence of three rivers. The Bargs with Aaron, the Donohues with Mary, and the Healeys remembering Conor created our own SOFT triangle. We took the Duquesne Incline and stood atop Mount Wash-

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Book Reviews: Parent Voices . . .

(Continued from page 9)
our troubles right on the surface at birth. The important moments arrive when parents decide what to do next" (5). She learns to be a different mother than she had imagined. She is tired from three years of little sleep. She thinks about what she does not know about her daughter's future, and she gets angry at people who offer sympathy. Another mother writes about learning what she does not know and doing things she never imagined she would like medicating her toddler and moving to the back burner what once seemed so important. Another mother with a child with a form of dwarfism says first she could not imagine living with a child with disabilities. She emphasizes that she could not imagine living without her and "How life with her is amazingly, overwhelmingly good" (27). A father chronicles the development of his son, matching expected milestones against his son's slow development, eventually getting a diagnosis. A mother complains that people who admire young children with disabilities, eventually grow uncomfortable with a child who becomes "loud, awkward and odd." She worries people judge her parenting skills by her son's behavior. She believes her quiet daughter is evidence that her parenting skills are fine. Another mother writes of her child with life threatening medical problems, who she does not consider disabled, but admits she readily waves the ADA flag when necessary. Parents write of hidden diagnoses, such as a serious heart defect, and chronicle their battles fighting for educational services. One mother earned a Ph.D. in research and set about to do the research that she needs for her son. She wonders where she fits on the parenting map, as she tries to provide the support he needs. She realizes she has become an ally for other parents with both similar and different challenges. One parent says her child does not ride the short bus but gets to school by walking up hill both ways in the snow.

One parent who at 23 becomes a foster parent to a 15 year old and later adopts an infant, then a toddler with special needs learns about authentic advocacy and shares her insight. Still another chronicles her experience seeking and keeping child care for her child who cries for weeks on end and requires perhaps inordinate attention. She knows Mary Poppins is not out there. She just wants someone who will show up on time, make sure her child does not catch on fire and does not make her cry. Other accounts deal with school relations, or navigating the IEP and school placement maze. Parents give advice, but more importantly, write of experiences readers share.

Both books are informative, entertaining and thought provoking. They can be read in snippets or at length. Readers will nod in recognition as they read, gasp at some situations, and laugh appreciatively at others. They will know they are not alone. Parents considering writing their own stories may get ideas about approach or content and may be inspired to start typing.

Join SOFT in beautiful St. Louis for our 26th annual family conference aka SOFT Family Reunion. You'll see old friends and make new ones too. The medical clinics, workshops, side trips, sibling outings, welcome dinner and pool side gathering are sure to leave you refreshed and tired, all at the same time. For the veterans among us, saying good-bye is the hardest part. The packing, traveling, and forgetting things is all displaced by the joy of not having to explain anything to your SOFT family. We get it!

Come to the Water

(Continued from page 13)
ington and looked down at the Golden Triangle formed by rivers that had powered industry and created a city. Our boys spotted Three River Stadium, but high above the rivers we also looked down at watery ribbons, the south flowing Allegheny and the north flowing Monongahela joining to form the Ohio, which flows southwest to Cairo and empties into the Mississippi. In St. Louis, in 1990, pioneering SOFT families met by the mighty Mississippi. A year earlier they had met by the Pacific in San Francisco. Before that in Philadelphia SOFT first went to rivers. The original SOFT families came to the water for their first conferences.

In Boston we met on the banks of the Charles eight miles from the Atlantic. From balconies outside the rooms, we enjoyed the peaceful wildlife area known as The Lakes, where the river widens. SOFT families reported they traveled to Walden Pond, Boston Harbor, the Concord River, Cape Cod beaches, Plymouth Plantation and Mystic Seaport, all important historical places defined by water.

In San Antonio we stepped from our hotel to the winding Riverwalk, which brought a sense of peace during early morning walks and festivity later in the day, even when we got drenched. We braved a morning deluge our first full day and waded through ankle-deep puddles to get to the workshops. The water had come to us. Later, several families met at the Gulf of Mexico in a hotel on the beach. Seven years earlier SOFT families met inland in North Carolina, while the remnants of a hurricane battered the coast and brought rain. That year, 1996, and in 2009 some families took a side trip to the Outer Banks. On the way home from Raleigh, this family ferried across the mouth of the James River, our Tara a four year old proudly wearing her Pocahontas costume. Thirteen years later, the day before the Roanoke conference, the adults stood on a bridge over the same river, deep but narrow, cutting through the Shenandoah forest.

In 2010 we travelled to Sioux Falls, South Dakota, where the Big Sioux River tumbles over a series of falls, giving the name to the state's largest city. The river and falls brought pioneers and industry to this gateway to the desert west, and in 2010 it brought SOFT families for renewal and a great time with a hospital that looks like a magical castle, a Corvette and a Harley rally, and an auction that began with a rainbow at the storm's end.

SOFT members have traveled across rivers to reach the conferences and traveled on rivers for entertainment. We have had two sunset architectural cruises on the Chicago River and a dinner cruise on the Erie Canal. At the Magic Kingdom we rode in boats to see first that it is a jungle out there, later that it is a small world after all. Enjoying the attractions near or at a reasonable distance from the conference often meant making water a destination. We are a nation from sea to shining sea with vast coastlines. Seventy percent of our planet is ocean, but less than 3% is fresh water, most glacial. But even inland we find our way to water, to see a moving vista, to be carried by the sounds of rushing water, to wade, swim and boat. We stand by the water and think, reflect, pray, wonder, hope, believe and relax. Time and again we have come to the water and alone and in community we have been refreshed.

If you joined us at any of our water destinations, look back and fondly remember your time there. If you did not join us, you were still with us in spirit, your children held precious in our hearts. We know you for you have shared your stories. Once again this summer we will come to the water. We will gather by the storied Mississippi just south of where it meets the Missouri. We will see the Gateway Arch and paddle boats and much more. We will laugh, cry, learn, play, and maybe gain new understanding of life's surprising journey, our resilience and our good fortune in having each other. We will come to the water and be renewed, not just with our friends, but renewed because we are with our friends, some of them newly made.

Pam Healey

Professional Perspective: by Debbie Bruns

Trisomy family

Family is such a multi-meaning term. It can be the family you are born into. It can be the people you surround yourself with. It can be a group or organization you are a part of. Most importantly, family is how you define it.

My work as Principal Investigator of the Tracking Rare Incidence Syndromes (TRIS) project has brought me a wonderful new family. A family that is so giving and genuine and shows love in so many ways.

I attended my first SOFT Conference in 2006. I was extremely excited and extremely nervous. I was so excited to meet families but so nervous that I wouldn't be accepted. I am not a parent of a child with a rare trisomy though I was in a way. Years ago, in the early 1990's, I worked with three preschoolers with full trisomy 18. Two were in my classroom and the third was across the hall but I worked with her at lunchtime every day. The school was located in a skilled nursing facility. The children lived there so Educational Therapists (my job title), Assistant teachers, Paraprofessionals, nurses and therapists were surrogate parents. My "trisomy triplets" as I called them were my girls. So, yes, I was a parent of sorts though I did not receive a prenatal diagnosis or spent sleepless nights at the hospital but had to listen to doctors recommend limiting or forgoing treatment due to their diagnosis and therapists dropping them from their caseload because of little progress. I watched them struggle to achieve milestones. One in particular tried so hard when we did art and sensory activities. Another was particularly drawn to music. All three used smiles and sounds to express themselves. I learned to interpret their wants and needs.

The best part of my first conference was when several parents let me hold their child. I know I wouldn't let just anyone hold either of my kids when they were younger (they are 13 and 10 now). Someone was entrusting me with their special child. I also felt I was part of the family when I cried at the balloon release. There were no words to express that experience. I still cannot fully describe it to my family or TRIS project staff.

Each year I look forward to the conference to see old friends and make new ones. It isn't about recruiting families for the TRIS project, which is part of the reason I attend. It is more, so much more, about making connections and learning about each family's lives during the other 362 days of the year. I want to hear Craig Donaldson's new adventures with Carey Ann, chat with Jude Wolpert about Kamie's school year, catch up with Kelly Freeze about Akaiya, the list goes on. The hugs are also so wonderful when we reconnect after a year apart. Though connected by email, Facebook and the tri listservs, being face to face doesn't compare to anything else.

I attend the conferences to share TRIS project data and always return to SIU Carbondale campus with renewed excitement for the project. Thanks so much to my trisomy family. I hope I can give back to you a fraction of what you give to me.

Debbie Bruns is Principal Investigator of the TRIS project and can be reached at dabruns@siu.edu and the project website is http://web.coehs.siu.edu/Grants/TRIS/

Pictured right: The annual SOFT auction is always a crowded, noisy and fun affair. This year there was a bidding war on children's clothing, a SOFT guitar and of course, Craig Donaldson's mystery box!

SUPPORT ORGANIZATION FOR TRISOMY 18, 13 AND RELATED DISORDERS Membership join/renewal

PARENT Name(s):_____

Mail Address: _____
Street City/Town State/Province Country Zip Code

Phone: (_____)_____ **E-mail**: ___ _____

CHILD's Name: _____ **Sex**: (circle) M _ **F**_ **Date of Birth**: _____/____/____

Cause of Death: _____ **Date of Death**:_ ____/____/____

Affected Chromosome: 18 ☐ 13 ☐ Other: _____ (please specify)

Diagnosis: Full ☐ Mosaic ☐ Partial ☐ Translocation: _____ (please specify)

Other (please explain): _____

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

Growth: (Circle all that apply)
How is (or was) your child fed? **Tube Bottle Breast Cup Spoon other** Is (or was) your child able to self feed? **YES NO with help**

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

Current date: _____Current Weight: _____ (lbs/oz) **Current Length: _____ (inches)**
If your child is no longer living please provide **last known measurements** at what approximate age _____

Immunizations: (circle answer where applies)
1.) Is your child or, if no longer living, was your child up-to-date with your state recommended immunizations? **YES NO Don't Know**
2.) Is (or was) your child on a delayed immunization schedule? **YES NO**
3.) Did you decline (refuse) any immunizations? **NO ALL SOME** (explain) _____
4.) Did your child receive the Synagis series for prevention of RSV? **YES NO Declined shot series**
5.) Does (or did) your child receive a seasonal flu vaccine every year? **YES NO Declined vaccine**
6.) If your child had any **reactions** to any vaccines/shots, please explain which immunization and reaction. _____

Surgical Information: SOFT receives frequent inquires about surgeries. If additional space is needed, use ***'add surgery'*** button first to make as many lines as needed on web registration, then fill fields ***or send requested information on separate page, if filling out a paper form.***

#	Date	Name of Surgery	Name, City, State of Hospital	Name of Doctor	Successful?
1					
2					

SOFT Survey: (Circle answer where applies)
1.) How did you learn about SOFT? **Health Care Provider Another SOFT parent WEB site Other** (explain) _____

2.) Barb Van Herreweghe 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 near-by state that is your state's local SOFT chapter chair? **YES NO**

~ SUBSCRIPTION INFORMATION: U.S. = $25; All Other Countries = $35 in U.S. Funds ~
MULTIPLE YEAR SUBSCRIPTIONS ARE WELCOME!

We now accept either VISA or MasterCard

VISA _____ MasterCard ____ Card #_____ **Exp. Date:**_____/_____.
month / year

Last 3 digits on back of the card: _____

Signature:_____ Date:_____

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 fees.

Joey Watson Fund: _____ (amount of donation)

PLEASE SEND THIS FORM AND PAYMENT 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 unless you specify otherwise.

FOR U.S. FAMILIES ONLY: WE DEPEND ON SUBSCRIPTIONS TO SUPPORT PUBLISHING AND MAILING COSTS, BUT IF YOU CANNOT AFFORD SUBSCRIPTION AND STILL WISH TO RECEIVE THE NEWSLETTER, PLEASE CALL BARB VANHERREWEGHE AT **(800) 716-7638** FOR INFORMATION ABOUT A **LIMITED NUMBER** OF SCHOLARSHIPS.

Membership Renewal.doc [07/14/2009]

~ IF YOU HAVE RECENTLY SENT YOUR RENEWAL, PLEASE DISREGARD THIS NOTICE ~

SEE SOFT'S HOMEPAGE FOR INFORMATION ABOUT SOFT AND THE NEXT CONFERENCE: http://www.trisomy.org

(800) 716-SOFT (7638)

Resources

Other support groups for specific chromosome disorders
Links are provided for information only and do not constitute endorsement by SOFT. Please help SOFT maintain current links. Contact barbsoft@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
4P- Support Group Website: www.4p-supportgroup.org Wolf-Hirschhorn Syndrome, Deletion 4P, A Guidebook for Families , Schaefer et al, 1996 University of Nebraska, Myer Rehabilitation Institute Christine Kleimola, SOFT member, initiated and helped to write this book.
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: atoddna@sprynet.com
Trisomy 13: A support website for families of children with Trisomy 13 Website: www.livingwithtrisomy13.org
Chromosome 15 Betty Hane Email: userha8039@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

RELATED DISORDERS

The following are SOFT member contacts for a specific chromosome:

Chromosome 2
Dana Tehako-Esser
7737 6th Avenue
Kenosha, Wisconsin 53143
262-605-3690
dana@noahsneverendingrainbow.org

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734-482-4027
chriskleimola@sbcglobal.net

Chromosome 8
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vamjam1@mchsi.com

Chromosome 9
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Phone: 02 49822812

If you want to receive the SOFT Times newsletter simply fill out a membership form and send in your dues.
Jack Laird or Barb Van Herreweghe 1-800 716-SOFT

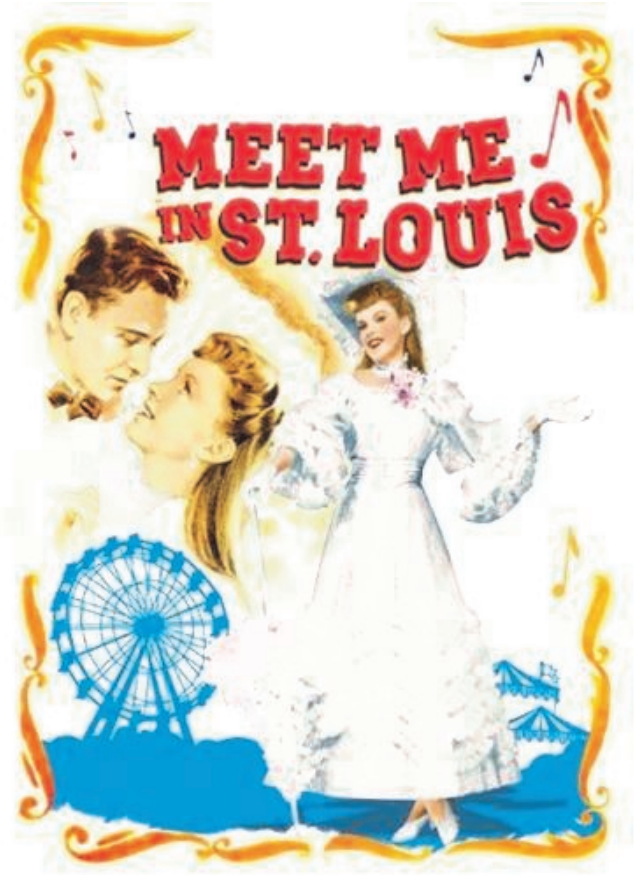
We're linked to the internet at http://www.trisomy.org

Support Organization for Trisomy 18, 13 and Related Disorders
2982 South Union Street
Rochester, New York 14624

Join SOFT Today And Become Part of our Family

Potential SOFT Member
1234 Main Street
Anywhere, USA

POSTMASTER: address correction requested



SOFT Conference 2012

July 18-22

St. Louis, MO