

SOFT Beginnings

The History of S.O.F.T.

Support Organization for Trisomy 18, 13, and Related Disorders

by Kris Holladay

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As I have spent the past few weeks pouring over my journal and the first editions of the newsletter (1980), I am filled with emotions and memories. Thank you for the opportunity to take a stroll down memory lane and reflect on the beginning of SOFT.

I remember ... Brandy Woodcox. Her name will never be forgotten to our family. It was November 1977 and Kari was just two months old. We asked everyone, including strangers on the street if there were any other families who had children with Trisomy 18. The answer I received was always the same, "No". Finally, as a passing thought, a nurse mentioned a family in Salt Lake City, but she would need to ask around for this family's name. The excitement was overwhelming and when the nurse finally called back with the name of the family, we shouted with joy! She gave me the name of the Woodcox family and their phone number. Yes, another family, another child; we were not alone! I called Debi Woodcox and she shared her story about their daughter, Brandy. Brandy was 2 years old! Brandy smiled! Brandy played! Brandy was happy! Much to our disappointment, the Woodcox family moved to Iowa the very next day so letters and picture became our life-line. But, never ever would we feel alone again!

It took two more years before another family came our way. Out of the blue, we received a phone call from a family also living in Salt Lake City. Pam & Tim Watson had also been looking for another family with a child with Trisomy 18. Pam recalls the day a stranger noticed her daughter, Rachael. The stranger said that she looked a lot like a little girl she knows named Kari. To this day, we do not know who this stranger was, but she brought us together in nothing short of a miracle! Rachael & Kari were the same age yet no one had ever thought to introduce us! How sad to have lived for two years so close to each other, and yet be so far away. (The Holladay's lived in a small town (Tooele) about 45 minutes from the Watson's who were living in Salt Lake City!) The meeting of our two families left an impression never to be forgotten and a promise was made to create a way for others to meet and share their stories.

Within a few weeks, I was told by our geneticist, Dr. Bruce Buehler, that a new, young and very handsome doctor had just accepted a position at the University of Utah Medical Center. This doctor had just completed his work in San Francisco. And, not so coincidentally, he had expressed concern for families whose children were born with Trisomy 18 and Trisomy 13. As I recall, Dr. Buehler said that this young doctor expressed the predicament for these families and expressed it much like being "caught between a rock and a hard place." Yes, that young doctor is our very own Dr. John Carey! The day we met Dr. John Carey was memorable. His compassionate blue eyes and warm conversation were exactly what we needed. In September 1979, Pam, John and I decided to get busy and get organized! Dr. John Carey, Pam Watson, and Kris Holladay were going to become an "official" parent support group!

Pam & I made an appointment with Legal Services for the Handicapped. The meeting was encouraging and productive. The lawyer explained our responsibilities and recommended we first decide on a name for our new organization. Now, that sounded like fun! Hal and I decided that an acronym would work best and would leave a good impression without having to repeat the longer name of the organization. What we didn't know then, but came to understand in time, the name of the organization grew longer and longer as the days and months went by as more families came into SOFT with numerous genetic conditions. We tried all sorts of combinations of words only to end up with a senseless word we couldn't pronounce. Then Hal said he had figured it out! He said to write down the first letter of each word as he said the "new" name. It went like this-- Families And Relatives of Trisomy. Oh no! I just couldn't visualize letterhead with the acronym F.A.R.T.! He laughed and I crossed it out and we started over again! Somewhere in the combination of words we finally found the perfect acronym and S.O.F.T. was created. On September 10, 1980 we officially became SUPPORT

ORGANIZATION FOR TRISOMY 18/13 (S.O.F.T.), INC. Our first governing board was President: Kris Holladay; Vice-President: Dr. John Carey; Treasurer: Pam Watson. The sound of SOFT warmed our hearts and we knew it would stay with us. John, Pam and I signed all the necessary legal papers and we were incorporated through the State of Utah. (Note: The original name was changed for accuracy at the Philadelphia Conference in 1988. The "/" was replaced with a comma. Later, "and Related Disorders" was added to the organization's name.)

Now that we were official, it seemed like a good idea to find some members! We had articles put in the newspaper, Dr. Carey told his friends about the group, and we talked to anyone and everyone who would stop and listen! When Pam received a call from a family in Henefer, Utah with a daughter with Trisomy 18 who was 11 years old, we were stunned and amazed. The Grant & Emma Richins family along with their daughter, Kimberly, soon became our fellow "pioneers" as we ventured into unknown territory!

During this time of reaching out, we decided to print a newsletter and the first one was created by my sister, Karen. The newsletter still brings understanding, information, and connections. The original format is carried on today with the family's letters linking us through the miles. For the first edition, we printed 25 copies even though we only had 14 names on our address list (which included grandparents, aunts, uncles, and friends)!

At last, we had a few members and we held our first "Gathering" on May 31, 1980 in Salt Lake City, UT. The meeting of new friends was memorable! We took pictures and shared stories. The second "Gathering" was held on February 21, 1981 and the family that traveled the longest was Pat Farmer and her family! She drove 3 hours and their family received a standing ovation for their sacrifice. Again, we shared pictures, stories, memories and more! We had more "Gatherings" and our address list grew longer and longer and we started to hear from families all around Utah and in California, Arizona, Montana, Idaho. Our growing bigger meant growing pains. I appreciated the referrals from medical professionals, but couldn't believe the mail and phone calls it generated! SOFT continued to grow and we applied for a bulk rate mailing permit. I spent so much time at the Post Office that I think the Post Master thought I had a crush on him!

By 1981, growing bigger was our biggest obstacle for our new organization! Once the word was out that there was a parent support group, medical and educational professionals trustingly referred families to SOFT. Phone calls and letters shared heartfelt stories of new families. The familiarity bonded us together, yet each story was unique! It truly felt as if we were "old friends who had just met." The newsletter remained our link of friendship and we tried to distribute an issue every other month. (I still have a copy of all the newsletters from the first one to the present!)

Our hearts would break whenever we were notified of the death of a precious child; it was felt deeply by everyone reading the newsletter. Through the thoughtfulness and generosity of families, SOFT often received memorial donations from families and friends. Sadly, without this financial support, SOFT could not have continued. I always felt a sad irony that through the memorials of a cherished child, SOFT continued to survive. With every memorial check I cashed, I shed a tear. "Thank you" never felt adequate when expressing appreciation for donations when given by a grieving family! How grateful I was and still am for your kindness and generosity!

SOFT always enjoyed hearing from a new family and appreciated the medical and educational professionals contacting us. However, I found responding to the vast amount of mail was becoming overwhelming and each time I would "catch up", it generated more mail and more phone calls. Through this period of time, our daughter, Kari began a struggle with seizures, especially status seizures which often lasted for hours. She would be hospitalized and when released, we would begin rebuilding her lost skills. When Kari was six years old she suffered a stroke which left her the diminished use of her right side. Kari continued to smile and play with her same enthusiasm and these setbacks didn't diminish her spunky personality! The Holladay's were a busy young family with Tricia, Kari, and Bryce. Then in 1983, our family welcomed a newborn son, Nicholas. Kari was fascinated by this new "doll" that made sounds and she would roll, or scoot towards the new baby and watch with fascination.

Changes were on the horizon. During this period of SOFT's history, Dr. John Carey and the University of Utah were my lifeline and sanity. John could see I needed help in sharing the responsibilities of this growing organization. In 1985, Debbi Stutz was hired to assist with SOFT's growing needs. We slowly transitioned the paper work and communication for SOFT to her home. Each week, I would drive an hour into Salt Lake City and meet with Debbi to bring her stacks of

mail and talk SOFT stuff. She had a fancy new computer and was able to bring SOFT into the digital age. Although Debbi didn't have a child with a chromosome disorder, she was compassionate and felt an immediate love for our children and families. She worked long and hard for SOFT. Through this time, Debbi began to dream a dream for SOFT.

From 1979 to 1985, SOFT members were "long-distance" friends sharing stories through the newsletter and phone calls. Our only personal contact was through our "Gatherings", which was convenient for only the few families living in Utah and Idaho. Knowing how desperately families wanted to see another family or child, Debbie began to dream about bringing families together from all over the United States for a family conference. Dr. Carey had started the idea by sharing his experiences with other support groups having national conferences. This gave us the confidence to believe we could really "pull it off"! Debbi plotted and planned, talked and thought, searched and screened, worked and worried until her dream began a reality. Plans for the first SOFT FAMILY CONFERENCE was set for the "Summer of 1987". Planning for the conference was made more difficult when the Holladay family moved from Tooele, Utah to Mesa, Arizona in July 1986. Debbi continued to oversee SOFT even after I left Utah. We kept in constant touch through letters and calls and she met regularly with Dr. Carey. I did my best from Arizona, but the logistics of the conference fell to Debbi and John. Pam & Tim Watson, and the incredible families in the Utah Chapter were the planning committee that put special touches on the conference. Debbi would call to update me on the progress of the conference. And, with great excitement she would tell me that another family just signed up to attend! We were actually shocked! Their hard work brought the first ever SOFT Conference to go from a dream to a reality!

Opening day of conference was a terrifying day for everyone! Families from the east coast to the west coast, boarded planes, trains, and cars with only a hope that other families were coming too! In Utah, we all waited at the front doors at the Little America Hotel & Conference Center. We actually wondered if these families would show up!

History was unfolding before our eyes! Parents brought their precious children either in their arms or in their hearts. Photo albums were carefully carried and shared openly. Tears came first, then smiles and laughter. When it was all over, we shed tears again. Everyone's dreams were realized in just a few short days. No matter what your situation, someone understood, cared and shared. We were no longer alone! We found a safe place with each other!

During the business meeting, we held an actual election and elected a President and a Board of Directors. (Contrary to rumor, we did not force anyone onto the board. We may have begged and pleaded, but never force!) Our first board meeting was held in the hallway next to the hotel's kitchen. The membership voted to have a SOFT Conference each year, which is a tradition that continues to the present time.

Thank you to all those "early pioneers" in SOFT's history!

A final note: Our precious Kari celebrated the first conference with us in 1987 in Salt Lake City. But much to our sadness, she died just 8 weeks before the 1988 conference in Philadelphia. She was 10 years and 9 months old when she died.

If we could "see" with our hearts, I believe that Kari and Rachael and all their SOFT friends are at the conferences, too. We are truly watched over by angels!

The Holladay Family is eternally grateful for this extraordinary journey!

Hal & Kris, Tricia & Ryan (Rayna, Ella, Joshua), Kari (our angel), Bryce & Tiffany (Hannah, _), Nick & Tara (Reese, Nash), Devin & Miya, and Savannah.