

Welcome to the sorority of strong and broken hearts

by Maureen K. Higgins

Many of you I have never even met face to face, but I've searched you out every day. I've looked for you on the Internet, on playgrounds and in grocery stores.

I've become an expert at identifying you. You are well worn. You are stronger than you ever wanted to be. Your words ring experience, experience you culled with your very heart and soul. You are compassionate beyond the expectations of this world. You are my "sisters."

Yes, you and I, my friend, are sisters in a sorority. A very elite sorority. We are special. Just like any other sorority, we were chosen to be members. Some of us were invited to join immediately, some not for months or even years. Some of us even tried to refuse membership, but to no avail.


We were initiated in neurologist's offices and NICU units, in obstetrician's offices, in emergency rooms, and during ultrasounds. We were initiated with somber telephone calls, consultations, evaluations, blood tests, x-rays, MRI films, and heart surgeries.

All of us have one thing in common. One day things were fine. We were pregnant, or we had just given birth, or we were nursing our newborn, or we were playing with our toddler. Yes, one minute everything was fine. Then, whether it happened

in an instant, as it often does, or over the course of a few weeks or months, our entire lives changed. Something wasn't quite right. Then we found ourselves mothers of children with special needs.

We are united, we sisters, regardless of the diversity of our children's special needs. Some of our children undergo chemotherapy. Some need respirators and ventilators. Some are unable to talk, some are unable to walk. Some eat through feeding tubes. Some live in a different world. We do not discriminate against those mothers whose children's needs are not as "special" as our child's. We have mutual respect and empathy for all the women who walk in our shoes.

We are knowledgeable. We have educated ourselves with whatever materials we could find. We know "the" specialists in the field. We know "the" neurologists, "the" hospitals, "the" wonder drugs, "the" treatments. We know "the" tests that need to



be done, we know “the” degenerative and progressive diseases and we hold our breath while our children are tested for them. Without formal education, we could become board certified in neurology, endocrinology, and psychology.

We have taken on our insurance companies and school boards to get what our children need to survive, and to flourish. We have prevailed upon the State to include augmentative communication devices in special education classes and mainstream schools for our children with cerebral palsy. We have labored to prove to insurance companies the medical necessity of gait trainers and other adaptive equipment for our children with spinal cord defects. We have sued municipalities to have our children properly classified so they could receive education and evaluation commensurate with their diagnosis. We have learned to deal with the rest of the world, even if that means walking away from it.

We have tolerated scorn in supermarkets during “tantrums” and gritted our teeth while discipline was advocated by the person behind us on line. We have tolerated inane suggestions and home remedies from well-meaning strangers. We have tolerated mothers of children without special needs complaining about chicken pox and ear infections. We have learned that many of our closest friends can’t understand what it’s like to be in our sorority, and don’t even want to try.

We have our own personal copies of Emily Perl Kingsley’s “A Trip to Holland” and Erma Bombeck’s “The Special Mother”. We keep them by our bedside and read and reread them during our toughest hours. We have coped with holidays. We have found ways to get our physically handicapped children to the neighbors’ front doors on Halloween, and we have found ways to help our deaf children form the words, “trick or treat.” We have accepted that our children with sensory dysfunction will never wear velvet or lace on Christmas. We have painted a canvas of lights and a blazing Yule log with our words for our blind children. We have pureed turkey on Thanksgiving. We have bought white chocolate bunnies for Easter. And all the while, we have tried to create a festive atmosphere for the rest of our family.



We’ve gotten up every morning since our journey began wondering how we’d make it through another day, and gone to bed every evening not sure how we did it.

We’ve mourned the fact that we never got to relax and sip red wine in Italy. We’ve mourned the fact that our trip to Holland has required much more baggage than we ever imagined when we first visited the travel agent. And we’ve mourned because we left for the airport without most of the things we needed for the trip.

But we, sisters, we keep the faith always. We never stop believing. Our love for our special children and our belief in all that they will achieve in life knows no bounds. We dream of them scoring touchdowns and extra points and home runs.

We visualize them running sprints and marathons. We dream of them planting vegetable seeds, riding horses and chopping down trees. We hear their angelic voices singing Christmas carols. We see their palettes smeared with watercolors, and their fingers flying over ivory keys in a concert hall. We are amazed at the grace of their pirouettes. We never, never stop believing in all they will accomplish as they pass through this world.

But in the meantime, my sisters, the most important thing we do, is hold tight to their little hands as together, we special mothers and our special children, reach for the stars.