

Home Port

the newsletter for parents

From Parents Who Have Been There

"I've learned to focus on what my child can do. As we leave Anchor Center and go to public school, they want to help but they go about it in a different way — by focusing on what she can't do. Even extended family does that. We need to get away from the labels and focus on the possibilities."

"I've learned to not let my child use his vision impairment as an excuse for not being able to do something—we don't define our child by his diagnosis."

**"Meeting other
parents has
given me
the strength
to move
forward."**

Making Connections

by Karen Roberts, Parent Consultant

Anchor Center for Blind Children is all about making connections. You arrive at Anchor Center to learn how to connect your visually impaired child with the world. How does your child respond, learn and react to the world around him? It is a shared journey of discovery and learning. But at the same time, most parents, grandparents and caregivers are on a parallel path of grief and acceptance. We are mourning for the child that should have been while loving and learning to care for the unique needs of the child that is.

We are at different places on this journey. We all have different types of family support, we all have very different children with different needs. But no matter our particular circumstances, we must take our time at Anchor Center and use it to build support and connection for ourselves, as it will be up to us to navigate the future for our child. A new dimension has been added to our parenting, one that was unexpected but can be fulfilling and exhilarating.

Isolation, hopelessness and depression can consume us. All of us. It doesn't matter what type of special needs your child has, the difference between the dream and the reality takes time to accept and time to heal. And one thing we don't have, as

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Finding Our Way Out of the Fog

By Marlo Naumer

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I remember the exact moment that our week-old daughter, Claire, received the diagnosis of blindness. We knew after her birth that something wasn't right with her eyes since she didn't open them, and when she did, it was obvious there was something wrong with her left eye. My husband and I went into a fog upon hearing the words, "bilateral microphthalmia." We didn't know how this could happen to our daughter and we certainly didn't know what to expect for the future.

The fog continued. My husband and I did what we were told to do by the doctors. Conflicting medical opinions certainly added to our lack of clarity for her prognosis. Claire had a cataract removed from her right eye when she was a month old. Since then she has been wearing a very high powered contact lens in that eye. It was certainly a very stressful first year worrying constantly if her contact lens was still in since she often rubbed it out; and we simply dreaded the days that we had to remove or reinsert the lens. But we learned to do it, we got better at it and we tried not to make it a torturous process. The left eye has been left

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Children. My first conversation was with Karen Roberts, part of the staff and a parent with a special needs child. I will always remember what she said. "I know, Marlo, the diagnosis overshadows the joy of Claire's birth." That was exactly what I was feeling — guilt, fear, confusion, sadness — and very little joy. I think there was an instant connection for me to Anchor Center before we even entered the building.

We began at the Anchor Center when Claire was 11-weeks-

untreated due to a malformation.

Claire's eye surgeon at Denver's Children's Hospital told us to visit Anchor Center for Blind

old — and have been faithfully attending ever since. At that time Claire was the youngest child at the school. She slept through most of the infant class, but it was such a supportive place for me that we hardly missed a session. I was inspired by what I saw the other kids doing. Plus the staff was such an incredible resource and gift that each time I left, I felt more joyful. The fog was lifting!

We also searched for medical answers. Usually we left those appointments feeling very sad. We went to Seattle to have a vision test that is unique to that region. They attached probes to her head and said they were measuring her brain activity; the results showed Claire's vision as 20/2000-plus — the worst number that they would even bother recording. The only reason that I didn't completely fall apart was that JC (Anchor Center teacher of the visually impaired) had done a different version of that test a week prior and believed that Claire's vision was about 20/400. Her test gave us hope that Claire's functional vision was so much more than what a medical test could successfully measure. I clung to that hope and continued to attend the Anchor Center Infant and then Toddler program.

I was a sponge and soaked up every word uttered by the Anchor Center teachers. I knew that brain stimulation during the first year was imperative for healthy development. I knew that the resources — the visual stimulation provided by the building and the activities that the children participated in — were nurturing healthy brain development. The medical data continued to suggest that Claire's situation was completely bleak and hopeless, but the staff saw all that Claire was capable of and encouraged us on this new journey.

And here we are, more than two years later, celebrating all of Claire's accomplishments. I remember another parent saying early on, "Watch Claire, pretty soon she will start reaching for toys." That was hard for me to believe. And here she is today, knowing her colors, finding ladybugs, turning a book around when it's upside down, picking up ice cubes off the floor and pulling her sister's hair.

Our family believes that Claire would not be doing so well were it not for our faithful attendance at Anchor Center. The teachers and the parents we have met there have nurtured all of us and the fog has lifted. We have found great hope in this new and unexpected world of vision impairment. Anchor Center for Blind Children has been a retreat — bringing peace, joy and hope to us and to so many other families. It certainly wasn't easy at first and we all know there are still moments of darkness for what lies ahead, but not a day goes by that we don't see sunshine.

From A Mother's Heart

By Roberta Curtis

Can any parent ever truly be prepared for the journey of parenthood? Our odyssey began at Abby's 2-week well-child check-up when our pediatrician listened to her heart and heard a strong murmur. We'd known that this was a possibility but had expected it to resolve itself. Our pediatrician sent us to a pediatric cardiologist who told us Abby would require open heart surgery because she had two holes in her heart — a "VSD" and an "ASD." I only remember thinking "Was there something I did?" "Why my baby?" We were told this was a congenital birth defect and it just happens. At Abby's 2-month well-child check-up, we were told by her pediatrician that we should see a pediatric ophthalmologist because her eyes were still "wobbly." The ophthalmologist told us Abby was visually impaired. If ever there was a metaphor for what I was feeling it was like a huge Mack truck kept hitting me — I would just begin to pick myself back up from a hit when the truck would hit me again. With two congenital birth defects the doctors were testing for more. She eventually received the diagnosis of coloboma, a very rare genetic disorder. With each discovery that darn Mack truck left marks all over me. Abby went in for open heart surgery when she was 4½-months old. That was the worst hit by the truck — to hand over my baby and not be able to hold her again for days.

After sharing the news with family and friends, I grew tired of hearing phrases such as, "God doesn't give you more than you can handle," so I went looking for other support. Upon

my search I came upon Anchor Center for Blind Children. WOW! This was the first time I felt a surge of hope amongst the fog of emotions I had been mired in. Due to Abby's medical needs, a teacher of the visually impaired visited her at home until she was well enough to join the groups at Anchor Center. I went from feeling alone on a deserted island to feeling supported and encouraged. I have learned the best source of strength comes from within and, with that, the courage to ask for help when I need it.

Abby has not only survived, but thrived with the wonderful help and support of Anchor Center. She is so much more than a weak, fragile little being. She is a strong, determined and opinionated preschooler that has achieved and overcome so much in her short life. When she was first born we didn't know if she was going to survive. Those days of being hit over and over again by the Mack truck seem like a distant memory. A memory that time, determination and hard work by our family, by Anchor Center and mostly by a little girl with a huge and healthy heart, have put into perspective.

**ABBY IS MUCH MORE
THAN A WEAK, FRAGILE
LITTLE BEING**



L-R: Abby, Elie and Sam

parents, grandparents and caregivers of children with all levels of special needs, is time. What we neglect as we spend the early years searching for answers — from doctors, therapists and other service providers — is ourselves. As we meet the intense daily needs of our children we don't have time to meet our own needs. And so the feelings of despair and the loss of control begin to take over our lives and eventually affect our children and our families.

It's not a *luxury* to take time for ourselves, it's a *necessity*. Otherwise we will enter the world after Anchor Center angry, frustrated and unable to work with people on behalf of our child.

As a parent of a former student and now the parent consultant with Anchor Center, what I have to offer you is a listening ear and a few more years of experience. I've been there — the shock, sorrow, joy, gratitude, emergency rooms, insurance appeals and red tape, sleepless nights, unfulfilled expectations, thoughtless comments, self-pity, misdiagnosis, unanswered questions, inner searching...and daily life. It continues on.

You've found Anchor Center. You and your child are learning together how to live life with a visual impairment. You are learning new terms such as "sensory overload," "ear pointing," and "tactile learner." You are finding that there is a world of possibility beyond the feelings of despair we all initially experience. You are finding your way back to a new "normal."

Connecting with other parents at Anchor Center is a very important step in this journey. All parents find their "new normal" in their own way and in their own time. You will read a few parent's stories in this issue of *Home Port*. Building a support system for you, your child and your family is the

most important thing you can do for the future. This support system will change through the years as your child grows and your needs change.

Eventually the staff at Anchor Center will be replaced with a public school system. People who are just as warm and caring will continue to educate your child, but the resources will be tighter and the rules stricter. As you become more adept at working the system and being an advocate for your child, your need for friends and allies who understand your child and who are facing similar challenges will continue to be just as great. That's why it is so important to spend these early years reaching out to others and building a web of support and stability. Because those skills you learn, as you build alliances and support, will be the foundation on which you can build a very happy life — for your child, no matter his or her level of need, your family and yourself.

People seek out support differently. Once you realize how important it is to connect with others the way you do it will depend on your circumstances. I am only a phone call or e-mail away. As you explore your Anchor Center Welcome Book, you will learn of many ways to meet other parents facing similar challenges. It's a long road — treat it like a marathon, not a sprint. Pace yourself and know that while some opportunities will be more appropriate further down the line, other ideas are perfect for this moment. Take advantage of what we at Anchor Center can offer you now and begin to explore the possibilities beyond. Happy sailing and stay in touch!



Mother's Day

By Doreen Sternkopf

I was looking forward to celebrating my first Mother's Day with Yande, when from nowhere my 4-month-old baby boy turned blue and stopped breathing. Thankfully he started breathing again almost right away, but when it happened again that day we went to the emergency room only to be told that our baby was just fine and to go back home.

On Mother's Day we took him back to the emergency room because this kept happening every two hours. On the examining table he had another episode and that is when we were told he was having seizures. He was admitted to the hospital for three days. The Ketogenic diet has helped his seizures, but the different medications have had side effects. It has been hard trying to find the right medication mix for him.

We were referred to Developmental Pathways and they connected us to Anchor Center. Anchor Center has been a blessing to me and my family. Since Yande's immune system was low due to his medications, Anchor Center arranged for monthly home visits with a teacher of the visually impaired. Then, as Yande stabilized, we made the long drive to the school for Infant class. We are so glad we did! My son and I love it here because we have been able to meet other amazing parents and share our experiences. The Anchor Center staff is the best one could ever hope for. The doctors still do not have a diagnosis for my son, but we are hopeful.

I would like to offer help to other parents — I am available to answer any questions parents in a similar situation may have. I hope to meet you at an Anchor Center parent group.



Yande and his sister Ivwa

From Parents Who Have Been There

"I have learned that I can't be afraid to express emotion; I don't always have to be heroic."

"I wanted to try to learn all I could about my son's vision impairment—the internet can be a helpful tool but it can freak you out. It gives all the bad possibilities, there is no filter. I would rather do it the old fashioned way and talk to our doctor."

"Take time for yourself — if you have someone you can leave your kids with, do it!"

The Importance of Emotional and Mental Health Care

By Carol Puchalski, Developmental Psychology Consultant

When children are diagnosed with a vision loss, the question soon arises as to how each child's specific vision will impact motor development, speech and language development and cognition and learning skills. Of equal importance is the impact of visual impairment on social/emotional development and the mental health of both the child and caretakers.

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For all children, emotional health can be impacted by illness, repeated hospitalizations, separation or relationship difficulties, attention problems, poor sleep, poor eating... and the list goes on. Children with sensory integration problems often demonstrate social/emotional difficulties making it hard to distinguish whether behaviors have a physical cause or an emotional one. Parents frequently ask, "Is Eric acting this way because of his vision loss, or is it a behavioral problem?"

Generally when trying to sort this out, I will make sure that parents have first consulted with their pediatrician to find out if underlying physical health or medication effects can be impacting behavior. We can then set up a strategy or

approach for dealing with disruptive behaviors or negative emotions.

Parents can have many of the same situations influence their emotional health. Poor sleep, poor eating, relationship difficulties as well as financial stress and change in routine and/or working status. It is imperative that parents develop and use good self-care and coping skills with effective ways to de-stress.

I am available to discuss these or any other topics involving you or your child. Individual consultation time can be scheduled by contacting me at Anchor Center. Also Anchor Center is adding an emotional/social screening to our current base of transdisciplinary assessments. Called the *Ages & Stages Questionnaire: Social/Emotional Scales*, it will help teachers and parents identify potential emotional and/or social issues early in your child's life. We are looking forward to using this tool in our ongoing effort to do the very best we can for you and your child during your time at Anchor Center.



Anchor Center for Blind Children teaches visually impaired infants, young children and their families, providing hope and a nurturing environment where children reach their highest potential.

2550 Roslyn Street • Denver, Colorado 80238
303.377.9732 • anchorcenter.org