

The Mother's Story

By Jodi Donathen

Nearly six years ago David's and my lives changed forever. We were blessed by the birth of a beautiful daughter, Alexis. Lexi, we have learned, isn't one for waiting. She arrived nine weeks before her due date. She was an emergency Caesarean section and was sent to the Neonatal Intensive Care Unit. Lexi stayed in the NICU for six weeks.

The week Lexi was discharged the nurses ran a series of tests on her. One of the tests was called an Auditory Brain Evoked Response System (ABR). This test can identify whether a child has a hearing impairment. Lexi didn't pass the screening. Upon discharge we were ordered to have more hearing tests run.

At the age of six months, we were given a clear diagnosis. Alexis had a profound bilateral hearing loss...she was deaf. She was fitted for hearing aides, and we were hopeful that they would be able to assist with her deficit. During this time she also began therapy for her delays from her premature birth. The therapies included occupational therapy, developmental therapy, and shortly after her diagnosis, speech therapy.

By the time Alexis was nine months old there were indications that her hearing aides were unsuccessful. The extent of her hearing loss was so great that the aides were unable to deliver enough magnification of the sound for her to hear. Because of this we were referred to Riley Children's Hospital for consideration for a cochlear implant. Alexis qualified and underwent cochlear implant surgery at fifteen months of age.

During the six months that we waited for surgery, the other interventions remained. Her delays were becoming more pronounced, especially with communication. I remember at a speech session her therapist looked at David and me and asked, "What would Alexis do if you left the room for ten minutes...or even a half hour? Would she notice if you were gone? Does she notice your pets? Does she point to objects or does she simply take you to what she wants?" These questions took my breath away. I felt empty because I knew that Lexi's behavior wasn't typical or so called "normal". Our response was the same – she wouldn't notice if we were gone, the cats are nonexistent, and she fusses to indicate her wants. The therapist then told us of her concerns. She thought that Alexis was exhibiting signs of autism.

Her global delays and lack of communication also peaked the interest of her pediatrician. We were again on our way to Riley to consult with the developmental pediatric group. During the initial visit in the fall of 2002 the doctors were not willing to diagnose Alexis. Because of her profound hearing loss, prematurity and cochlear implant they wanted to allow time for Alexis to develop her skills. Their hope was that the implant would assist with the communication delays. That was our hope as well.

Over the next couple of years we were dismayed to see little improvement in her delays. In the spring of 2005 Alexis was given the label of autistic. The team felt that this most accurately reflected her range of physical and social delays.

From the age of six months Alexis has received therapy to address her delays. It would be an understatement to say that she dislikes these sessions. She has no particular bias; all therapists make her work and conform to their ideas and routines. Lexi does not like to be told what to do and expresses herself very well without words. Therapy is difficult for Alexis and for us. It is a constant reminder that our child isn't the same as other children. She is different and is behind with what is considered "normal" development. Therapists have tried to assist her, but by the same token, have made us

very aware of her shortcomings. Progress has been slow and frustrating. The struggles that she faces are heartbreaking. Sometimes it is easy for David and me to fall into a “poor me” trap. It was during one of these times that a good friend of mine placed a circular in my mailbox. The newsletter had a post-it note attached to it that read, “Read this, thought of Lex.” The article was in a Reins of Life publication. There was a little girl on the front cover, balanced between the slats on a fence. She was overlooking an arena. As I read the article, all I could think about was Alexis. The child in the story could have been her. What excited me the most was that the child was a success story. Here was a person with multiple issues and she was flourishing. She had overcome her challenges while enjoying the time she spent riding horses. I began to feel hopeful for the first time in a long time. This could be an opportunity to make therapy fun and beneficial. I called the phone number listed and spoke to Chris Flowers. The next session was just being formed and she sent me the information. Alexis began riding at Reins of Life in the spring of 2004.

I can tell you that Reins has been everything I hoped it would be when I first read the article. Reins of Life has helped Alexis by providing her a service that is non-threatening and accepting. The volunteers and instructors have worked to ensure that she has a quality experience that addresses her specific readiness level. When Alexis began riding, the entire environment was foreign to her. The smells, sights, sounds and textures of this new place overwhelmed her. She resisted wearing a helmet and would cry when we placed it on her head. This led to continued aggravation, and she would try to pull the helmet off. It would take at least ten minutes to corner her to put the helmet on and secure a fit. Today, after two years of riding, Alexis will still resist, but when she realizes that it is time to ride, she will come to me and lower her head in anticipation of the helmet. Alexis was also having challenges with the floor texture changes. She would not feel comfortable moving from the solid cement floor in the building to the unstable squishy floor in the barn and arena. She would tiptoe around the barn, almost as if she was unsure that the ground was going to hold her. Now she runs freely in both the barn and arena. It is almost difficult to keep her out of this area. When we first began, one of the biggest challenges with sensory defensive behavior was that Alexis would not hold anyone’s hand for a sustained amount of time. She would retract her hand and avoid touch. Today, because of Reins, she has overcome much of this problem. She will hold hands with the volunteers and even touches her horse, Jack. We are still working on petting and grooming, but progress is evident. During the last session for the very first time Alexis began feeding Jack his snack after their ride.

The Father's Story

By David Donathen

Alexis, that girl will steal your heart. The way she looks at you, the way she will all of a sudden just take off in a run, her smile... but most of all, her laugh. She's always had that wonderful laugh. We knew she wasn't normal, that she couldn't speak. But her laugh – as long as she had that, she could make me laugh and I would know she was happy. But I remember the day we found out she was deaf. My wife told me that the laugh might go away for some deaf children go mute. I didn't want her to lose her laugh.

I remember that night standing by her bed, recalling a story in the Bible of when Jesus healed a deaf man by placing his fingers in the man's ears. With tears rolling down my face, I placed my fingers in her ears and I prayed. I prayed for a miracle for her. I knew it was not going to work. I fell to my knees and sobbed.

You know she's still deaf but she still has her laugh. I think that was God's gift to all of us.

Reins of Life has given many gifts to my daughter. The ability to go to a Halloween party, participate in the 4-H fair, and have rewarding therapy sessions with consistency. Something the autistic side of her appreciates.

There is something else Reins of Life gives, not to the children but to the parents. It is a time for us to let our guard down, to be with other individuals who have had the same struggles and fears, and to appreciate the accomplishments of all of the children. Reins give us hope. The hope that the love of a horse may be the key. The key you may ask? What is this key? The key is a hope of all hopes. The key is something that I struggle to find everyday. The key is what I wish I had when my daughter makes eye contact with me and I can, for that brief moment, see her. If I just had that key, I could unlock that door and she could come out to be with us.