

## Early Warning

Early childhood is a time that is marked with important milestones in development. It is also an opportune, if not critical, time for helping a child with a disability to make improvements in areas where there are deficits. In these articles, two mothers discuss the impact of early intervention and support in their families' experience with apraxia of speech (also known as developmental apraxia of speech, verbal apraxia or dyspraxia), a neurologically based disorder affecting the ability to plan, execute and sequence the movements needed for speech.

# Dealing with A Parent's Worst Nightmare

By Jeanne Buesser

**W**hen my husband, Raymond, and I chose to become parents, we jumped into the unknown. Our children's well-being and happiness became our concern. The first of our three sons, Danny, was a healthy, very active boy. He was a very independent child, smart beyond his years.

Our second son, Adam, was born 2 1/2 years later. Adam was a big baby like his brother, with no obvious problems at birth, although his tongue stuck out and his cheeks sagged a little. No one thought there was a problem, except that Adam never babbled or made sounds as an infant. We just thought he was a quiet child.

How quickly life can change, though. When he was a little more than 3 1/2, Danny contracted Burkitt's lymphoma, a rare fast-growing cancer with few symptoms. This virtually silent killer took the life of our son within hours of his diagnosis. We were devastated, in shock, unable to comprehend how we as parents couldn't save our child. We asked, "Why did we deserve this? Why us?"

Ten days after Danny died, I joined a group called The Compassionate Friends, a bereavement support group for parents experiencing the death of a child. It was the one place I felt I could express my grief and lean on others who had similar tragedies. I learned the benefit of being with others who could share ideas for liv-

ing. I became the librarian and facilitator of my local chapter. I discovered that whatever positive support and energy you give to others will return to you three-fold.

**A new start, more challenges**  
In our grief, we weren't overly concerned that Adam still wasn't talking; we were trying to deal with Danny's death. Wanting to make a new start, we sold the house and moved to another. It wasn't until Adam was 2 years old that a neurodevelopmental pediatrician diagnosed him with a neurological speech disorder called apraxia of speech.

Children with apraxia of speech are unable to produce the sounds for speech so as to be understood, despite having the ability to do so. Intelligence level in most children with apraxia is unaffected. For example, Adam can put together 60-piece puzzles without ever having seen them before. He has a picture-perfect memory, and can approximate the picture to the puzzle box. But it is also very frustrating for him. Adam will have tantrums because he can't respond to our questions with intelligible speech. Adam makes his needs known by pointing or doing some sign language as we ask him a



Above: Adam Buesser (l.) and little brother, Josh. Left: Danny Buesser



yes or no question. If that doesn't work he will show us physically what he means. Adam's apraxia greatly limited his circle of friends. No one could understand what he want-

ed and few children wanted to play because he was "different."

For Adam, as for most children with apraxia, intensive speech therapy was key in helping him once apraxia was diagnosed. Occupational therapy was also necessary.

His intensive speech therapy is three to four times a week and includes brushing his tongue with a toothbrush; trying to get him to blow bubbles, blowing through straws, blowing candles out; getting him to pucker his lips, trying to repeat the sounds p, b, m, d, and others, to strengthen and coordinate his facial and mouth muscles. The therapist recommended massaging his cheeks to tone his muscles.

Adam now says up to 80 words. We don't always understand him because he cannot produce some of the syllables/consonants of

speech. When the therapy first began, the only sound that he could say was “mmmm.”

A few months ago, our family had a frightening experience when Adam got lost while we were on an outing at a large zoo. It taught us an important lesson. I have since gotten an ID bracelet for Adam, since he cannot speak his name or give a phone number or ask for help himself.

Adam is now 6 years old and attends a spe-

Apraxia of speech is an often overlooked disorder with no known cause. In defining developmental apraxia of speech, the American Speech-Language-Hearing Association (ASHA), describes its effect as: “The child knows what he or she wants to say, but the brain is not sending the correct instructions to move the body parts of speech the way they need to be moved.”

cial education kindergarten class for speech. He writes his name and uses a special computer device to help him communicate. His speech is slowly getting better. Sometimes it is very fast and gets garbled.

As a parent, I cannot stress how important it is to educate medical professionals, teachers

and parents about apraxia. When Adam was diagnosed with apraxia I didn't know where to turn for help. If more professionals knew about this disorder, many more parents of diagnosed or undiagnosed children would know there is hope and information that can help them.

Many parents whose children don't talk by age 2 or 3 may not think there is a problem. I was reminded of that by relatives. They counseled, “The child will talk when he is ready, don't worry.” If the child isn't diagnosed and doesn't have intensive therapy early, valuable time may be lost and the speech patterns can be very hard to correct. As the child gets older, other problems can arise.

### C.H.E.R.A.B. Foundation

C.H.E.R.A.B. (Communication Help, Education, Research, Apraxia Base) Foundation is a nonprofit organization whose goal is to improve the health and welfare of all children with speech delays and disorders, with a special focus on apraxia or other severe neurologically based speech conditions. The group describes the “cornerstone” of their efforts as bringing “professionals from different disciplines together to provide the most comprehensive evaluations and treatments for these children.”

The Foundation, with the help of the Consortium for Fatty Acids, Omega-3 Research Institute, Inc., held the first conference for therapy of verbal apraxia/dyspraxia, “Verbal Apraxia/Dyspraxia and Essential Fatty Acid (EFA) Supplementation: A New Potential Therapeutic Intervention” in July 2001. According to Lisa Geng, president and founder of C.H.E.R.A.B., “We are currently exploring working with one of the leading teaching/research hospitals here in New Jersey, which has shown an interest in coordinating clinical trials involving the use of essential fatty acids (particularly omega 3 and 6) in children with severe multi-faceted speech/communication disorders.” Says Geng, “We are all very excited about the tremendous potential this research would hold for our children's future to help bring them a voice.”

### Gaining strength from support

How did I learn more about apraxia? A relative sent me a newspaper article about apraxia and a support group here in New Jersey, the C.H.E.R.A.B. Foundation, headed by Lisa Geng. Lisa had also founded the Children's Apraxia Network since her son, Tanner, had been diagnosed with apraxia. After talking to Lisa,

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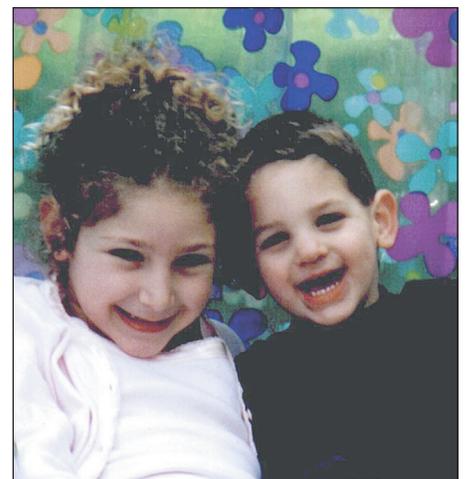
## Evan's Story

**T**he question that everyone seems to ask me is, “How did I know there was a problem at such a young age?” My son Evan is our second child. As an infant, he babbled normally. When Evan didn't have any words by his first birthday, we didn't panic. We tried not to compare him to our first child, Carly, who seemed to be born talking and has always been very advanced. When Evan started saying a few words at 15 months, we were thrilled. Those words had simply vanished at 18 months! People tried to tell us that boys talked later, and that Einstein didn't talk until he was 5. I knew in my gut that there was something wrong.

A very dear friend who is also a neurode-

velopmental pediatrician sat down with Evan at a barbeque, and determined that Evan had a severe delay in expressive language, but at 20 months, was at or above age level in ALL other aspects. He handed me the number for Early Intervention, and the quest for answers began.

Early Intervention evaluated Evan at 21 months and determined that his expressive language was at a 15-month level. We started speech therapy at 22 months. The therapist started with the “withholding” approach. We would model the word “pretzel” and Evan would have to repeat the word to get the pretzel. Evan got so frustrated he kicked me in the shins! He could not imitate a hand motion, let alone a sound. After a week or so



Evan loves his sister.

of this, the speech therapist realized a different approach was needed. She suggested that Evan had apraxia of speech. I made her spell it, and I hit the Internet before she

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*Evan's Story Continued*

pulled out of the driveway. After all the research I did, all I could do was cry!

I followed up the therapist's diagnosis with a hearing test and a trip to another neurodevelopmental pediatrician that my friend had recommended. Apraxia of speech was confirmed. And so started our journey to remediation.

We upped the EI speech therapy to twice a week and had an occupational therapist evaluate Evan next. We discovered that Evan had sensory integration dysfunction. Just an added bonus! I read on the Apraxia-Kids LISTSERV that it is common for this combination to be present. With the occupational therapy in place, we trudged on. Evan was asked to leave his preschool at 26 months. He had been hitting or, as I called it, "communicating with his hands." We replaced preschool with gymnastics and swimming, as the gross motor activities produced the sensory input Evan needed. The hitting continued, but we could never pre-

dict when it would happen.

When he was 30 months old we felt that Evan needed more. We added a session of private speech therapy and temporarily replaced OT with a group speech/OT session given in a preschool environment. Evan's speech exploded! He went from 40 to 100 words/approximations in about a month! He also started to combine two words, which requires more motor-planning than he had ever been able to accomplish!

We have him attending twice a week a very small, home-based toddler program, with normally developing children, that he absolutely loves! He doesn't seem to be any more aggressive than any other 2-year-old boy in this setting. We had determined that his aggressive behavior gets worse as the number of children increases, so we were careful to select a program that was small enough to meet his needs.

It has been a very tough year! There were

times that I felt like a shut-in, never leaving the house in fear that Evan would hit other kids in frustration. There were times that I felt that the hitting must be due to bad parenting. Although I know in my heart we are doing everything we can for Evan, I can't help but blame myself for not always having as much patience as I should. And what about the future? The prospects of further learning disabilities, as stated by the experts' statistics, scare me to death. We will just have to take it one day at a time.

While looking for more information and support, I stumbled upon the Children's Apraxia Network. My EI SLP came with me to my first meeting. While I am generally not a group kind of person, I found the information disseminated invaluable. I also felt a kinship with the people attending the meetings, as no one else I knew had a child with apraxia. I have since agreed to become the group's secretary and have been known to be seen taking the minutes in crayon!

While my original objective for becoming part of the group was totally selfish, the roller coaster ride has brought me to a point of wanting to help other parents in line for the ride.

**Update**

Now 4, Evan is doing extremely well. He identifies all the uppercase letters and most of the lowercase as well. He knows his address and phone number. He writes his name better than most kindergartners. He spent last summer at regular day camp, three full days per week. It was a huge self-esteem builder for Evan and his connected speech improved as well. He is still difficult to understand at times, but he can usually get his point across.

He attends two preschool programs—Pride, the district's preschool special program, as well as a regular preschool—and is succeeding in both. At school, Evan also receives individual speech therapy twice a week and group therapy once a week. To address his sensory integration needs, he receives one individual occupational therapy session and a sensory motor group.

He will attend camp once again this summer, this time with his sister. He will be fine, in fact, he will have an even better time, as the camp has even more to offer than last year's camp, But I will probably worry all summer! **EP**

HDIS

*Worst Nightmare Continued*

attending the Foundation's meeting and feeling inspired by the help I received through The Compassionate Friends, I decided to start a support group in my area.

Though we are without Danny, my family lives on with Adam and Josh, who is almost 3. I hope someday Adam and Josh will ask about their brother. Josh is speech delayed and has been diagnosed with pervasive developmental delay (PDD) with autistic tendencies. The comfort and help that we get from our support group is extremely beneficial to us and also encourages us to help others. **EP**

*Jeanne Buesser is the President/Founder of the Apraxia Network of Bergen County, NJ (Web site: <http://community.nj.com/cc/apraxianetworkofbergencounty>).*

Tips from Jeanne for starting a support group

- ◆ Find a public place to meet.
- ◆ Write a press release—who, what, where, when and why—to help promote your group, to be placed in as many local papers as possible.
- ◆ Find relevant articles for eventual distribution to other parents.
- ◆ Start a Web page, if possible.
- ◆ Maintain a contact list with names, phone numbers, addresses and e-mail.

Resources

A S H A

10801 Rockville Pike, Rockville, MD 20852  
(800) 638-8255 · <http://www.asha.org>

C.H.E.R.A.B. FOUNDATION

657 Valley Rd., Box 339, Gillette, NJ 07933  
(732) 871-6013 · <http://www.apraxia.cc>

Childhood Apraxia of Speech Association of North America

123 Eisele Rd., Cheswick, PA 15024  
(412) 767-6589 · Fax: (412) 767-0534  
<http://www.apraxia.org>  
<http://www.apraxia-kids.org>

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(877) 969-0010 · (630) 990-0010  
Fax: 630-990-0246