

Ataxia Telangiectasia

Look into the eyes of that beautiful newborn baby. The pink skin, the sweet smell, the captivating yawn that ends in a smile.

Watch him grow. First steps. First words. He's a toddler, playing with trucks, trying out his first riding toy. Then he's two. He starts to wobble a little when he walks. Then that jabbering you sometimes wished would stop turns into a jumble of slurred words. He has a cold...constantly. And his eyes. Instead of gazing lovingly into yours, they bounce around the room. Fearfully you go the doctor. Something's wrong. The doctor says don't worry, we'll run tests. Then he calls you back. He doesn't know what's wrong. More doctors, more tests. Another phone call. Your son has ataxia telangiectasia (ay-TACK-see-uh Teh-LAN-jick-TAY-sha). Frantically, you search for any information you can find. Your heart plummets.

A-T is a genetic disease that attacks children, causing progressive loss of muscle control, immune system problems, and a strikingly high rate of cancer, especially leukemia and lymphoma. People with A-T are frequently wheelchair-bound by their teens and the disease is generally fatal by the time they reach their twenties.

Camp Barnabas has become a haven for children with A-T and their families. And, in return, they've shown us what it means to embrace each step of the miles they walk every day.

For Kris and Beth, the journey began when Emily's babysitter noticed her walk was very unbalanced and she fell a lot. It happened that their pediatrician also used the same sitter and asked them to bring Emily in for tests. It took 19 months to find a diagnosis. "Part of that time, though, was that we were not doing anything to find an answer. Denial is wonderful," Beth admits. When they learned she had A-T, "We were both relieved and devastated at the same time. We finally knew what she had, but A-T is not a diagnosis you ever want for your child." At first, Beth says, she had to grieve all the things Emily might never do...first kiss, driving, prom, marriage. "Once I got through that, I was able to receive each day for the gift that it is. God chose me to be Emily's mother and I am so fortunate."

For Carol, diagnosing her son took a bit longer. The doctors thought Jeremy had cerebral palsy because of a cerebral hemorrhage at birth. But by the time he was 9, "I kept noticing a regression in his balance and gait. It was like he was drunk! Finally, we went to a different doctor and, after several tests, we got the diagnosis.

"It was a Friday afternoon, over the phone, and I didn't know anything about it, just that it was real bad...We looked it up on the Internet and I was devastated." The doctor offered little hope, "There's nothing we can do." But he did give her the toll free number of the Ataxia Foundation where she was referred to the A-T Children's Project.

David and Mary have also found help and hope through the families and people associated with the Children's Project. "This has been an invaluable resource as far as connecting with other families. When you first go to the site, they will connect you with another family so you have someone to relate to, to ask questions." This especially helps, Mary says, because "A-T is an orphan disease. Only 500 kids in the U.S. have it."

Two of them are her daughters, Kate and Olivia. "I was getting ready for a dinner party when Kate was close to two. I sat her down in the floor and she tipped over. I remember yelling at my mom and saying 'This is not right' and sweeping Kate up from the floor and taking her to the doctor." He kept telling her you're a teacher, you're just looking for something because you see so much at school. But she and David kept searching for answers. They even read about A-T and thought, "How awful. Can you imagine having this disease?"

Two years later Kate was diagnosed. They were getting ready to take her to the Mayo Clinic for evaluation when David typed the symptoms online and A-T came up. They took her to Johns Hopkins instead where the diagnosis was confirmed.

"Our toughest moment, though, was realizing Olivia had it, too. The initial diagnosis with Kate was tough but to have it again with Olivia...When she was born we were sure she didn't have the disease. But when she was one we were vacationing. She was sitting on the floor and tipped over.

"A-T is like having the worst symptoms of cerebral palsy, muscular dystrophy and cystic fibrosis rolled together in one disease...Getting the diagnosis and knowing life as we know it is going to change forever...watching other kids who have it suffer and knowing...it's tough watching other children do things and knowing your kids can't do that."

It's hard for big sister, Abby, too. "I don't think it's the first thing she would tell you right off the bat," Mary explains, "but she would eventually tell you, 'My sisters have a disease that makes it so they have a difficult time walking and talking.' Abby goes to school and nobody really gets it. Most people don't have siblings that have a disability."

But they have found a place where it's a different story. "Camp Barnabas has been a huge support. My girls see kids that have A-T and kids with other challenges. They see they're not alone. And for Abby it's huge to connect with other siblings who go through the same thing, who have a sibling with a special need."

Camp has helped Jeremy to look at things from a fresh perspective. "One year he came home from camp and said, 'Guess what?' And I said, 'What?' He replied, 'When I get to heaven I won't be in a wheelchair!' I was floored. I had no idea he didn't know. The wheelchair had been such a part of him he never imaged life without it. That memory rates almost as great as the year he came home with another guess what. 'I got saved this week!' "

But walking with A-T has it's moments. Sometimes, Mary says, Kate's just real honest about it. "It sucks." The parents all agree, though, that as a family they work hard to live every moment of life and keep things in perspective. Other kids have tough situations, too, they remind their children.

"I tell a parent with a new diagnosis of A-T that right now is hard, but it does get better," Mary explains. "Your life will return to normal. It will be okay. You are going to experience so much joy. I try to tell them to be positive. Treasure every moment. Get your kids involved. Educate the kids around them. There are a lot of questions. Let other people know what you are dealing with. They are curious, they want to know, it makes it so much easier."

Just the other day Emily and her mom were talking about her not being able to walk by herself anymore. Beth says, "I asked her if not being able to walk made her sad. She said she misses being able to walk at school sometimes, when a store isn't handicap accessible, and at church on occasion. But, she said, 'I miss it, but I'm happy.' "

Mary agrees that the being happy is the important part. "The greatest moment – to see them smile – to see them happy. When they've done something that other people take for granted and you can see the success in their face. To hear them laugh.

"We are thankful for every day. The little things become big things. It has really changed us. We are definitely better people than we would have been without this disease."

Note: To protect the privacy of our campers we only use first names in our materials. If you have a newly diagnosed family member with A-T, visit the A-T Children's Project web site (see information at www.campbarnabas.org/ataxia_telangiectasia) and they will connect you with another A-T family to walk with you through these first steps. And connect with Camp Barnabas where your child has the opportunity to fly through the trees and laugh with friends who walk in the same shoes you do every day.



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