

AS Diagnosis in Children Can Be Difficult To Obtain

After a harrowing night spent in an Orange County, Calif. hospital, Diana and Rick Annett took their highly traumatized 14-year-old son, Brian, who was loaded from a wheel chair into the family van in the exact same condition in which he was admitted, and went home without a diagnosis.

When they had arrived at the doctor's office the previous day, in February 2005, the champion swimmer couldn't walk. He had just worked out the day before. He was ordered to go to one hospital and then was quickly transferred to another, more specialized medical facility.

And he was screaming from the pain all the while. "You couldn't even touch his legs," his mother remembers, her youthful voice cracking. "That's how sensitive they were; we had to carry him to the car and get a wheelchair, and just moving his legs was horrific."

"They were thinking it was maybe something to do with his spinal cord. You can imagine the scary things they were thinking and what I was trying not to think about," Mrs. Annett, who is still shaken when reliving the details, tells *Spondylitis Plus*. Brian had had a few previous trips to the ER, where his pain was diagnosed as "lactic acid build up," even though it is now known that lactic acid is actually a fuel, and not a caustic waste product.

It has been known for a long time that there is a close connection between the HLA-B27 allele and ankylosing spondylitis. The initial treating physician, an orthopedic surgeon, had in fact ordered this very test for Brian, whose sister has psoriatic arthritis.

So armed with the Rosetta stone to the disease—even though she didn't realize it at the time—Mrs. Annett repeatedly inquired of the hospital staff doctors if this positive gene test was related to her son's worsening condition. Everyone, however, was baffled as to his condition. They couldn't find anything physically wrong with him, and his spinal MRS and labs were normal. The neurologist and an infectious disease specialist could only shake their heads at the family as the lanky youth lay writhing in the hospital bed.

Still No Answers....

The next morning Mrs. Annett was told by the doctors that even if their daughter did have psoriatic arthritis, their son did not have the arthritis that was associated with a positive HLA-B27. "They pooh-poohed it when I told them the 'orthopedist' said the test might be important," she said, adding that based on the test, she had requested that a rheumatologist see her son no fewer than three times. Each time, her request was refused.

"Then I had this infectious disease doctor look straight at me and tell me that it was all in Brian's head. 'I think you're putting too much pressure on Brian

with the swimming; he needs time to be a kid,' he told me," recalled Mrs. Annett, who says she took quivering and angry umbrage at the suggestion. "I then looked at this man and said, 'You have just met my son; you haven't even talked to our family.' He had no information about us. None of that. They didn't ask about his daily routines. Had they known, Brian has oodles of time to be a kid. I was ready to scream and yell, but I maintained my manners," Mrs. Annett explained, to this day still emotionally reeling from the family's hospital ordeal.

Mrs Annett Feared The Worse

"When I walked back in there," Mrs. Annett said in picking up the story, "Brian's face was like a ghost. Here's this 14-year-old kid lying there with severe pain. His eyes were half opened. There was something that had been taken from him. I looked at him and I wanted to cry because I didn't know what words had been exchanged. I thought, 'you know what, I've got to get my kid out of here.' They had already done some mental damage to him, making him feel that this horrible pain was in his head. He later told me the doctor made him feel like he was crazy; he had actually suggested that to him."



Tyler Walker & Brian Annett

So the Annett family got Brian to his sister's rheumatologist, Dr. William C. Shiel of Mission Viejo, Calif., the following week. Dr. Shiel diagnosed him with AS after a careful history taking and a five-minute examination where Brian came up quite short on flexibility, plus the positive HLA-B27.

Sometimes Counseling Can Help Sort Out Emotions

Brian had a couple of counseling sessions to help him deal with his hospital ordeal, where he was told that his pain was all in his head, that it was somehow his own fault for giving in to it. "Even though we said both those doctors were wrong, it was helpful to have the counselor tell him that he didn't do anything wrong," Mrs. Annett notes.

Dr. Shiel knows Brian loves to swim and he's doing everything in his power to help him achieve his goals. Brian, who turns 16 in September, is now a sophomore in high school and is back on the Mission Viejo Nadadores club team. His specialty is the 100-yard backstroke. This year, Brian has achieved CIF status for Mission Viejo High School, where they just won Division I, CIF. "He got to be a part of that, which was really cool," his mother happily reported.

He recently began treatment with an anti-TNF-a blocker. Ms. Walker told *Spondylitis Plus* that the pain in his lungs is on the wane and that the arthritis in his hips, knees and ankles is also getting better. She said she no longer hears him moaning in pain during the nighttime hours.

"I will fall to my knees and cry if it is all working for him," she swears, getting back to the pre-diagnosis days one last time. "It's just so maddening. I just don't want these people to do to another family what they did to us. I don't want them to look at another sweet child they've just met and say it's all in his frickin' head. It's unfair. It's mean. It infuriates me. It could have been avoided."

A Mother's Story: 'Please don't let this be'

Over a period of weeks, Sherri Walker noticed that when her nine-year-old son, Tyler, got out of bed in the morning, he exhibited an unusual stiffness in his walk that didn't go away. A warning went off in her heart, where she knew what it was, but she wasn't ready to put a name on it—not yet. "Dear God, please don't let this be what I think it is," she would pray. But the stiffness continued unabated, although the happy little swim team member never complained about it.

"I actually watched him get up in the mornings and he would get out of bed stiff-legged," Mrs. Walker recalls. "That alarm kept going off—and I knew what it was because I thought I could have it and my mother had just been diagnosed with it after years of having what we thought was just arthritis and my mother's sister has some form of it and their mother had arthritis."



Left: Tyler Walker at age 5 with Trophy & Medals



Bottom: Tyler Walker Sleeping with Trophy

The "It" Is, Of Course, Ankylosing Spondylitis

The "it" Mrs. Walker refers to is, of course, ankylosing spondylitis, but getting the youngster tested and diagnosed for the disease would be another matter. "First I had to get approval from our primary care doctor who said, 'No, Tyler doesn't have arthritis—he's nine—what are you talking about?'" He really fought me and I explained to him how the disease ran in our family, but still, he initially wouldn't approve the tests," Ms. Walker recalls for *Spondylitis Plus*.

"Finally, finally, finally, he said, all right," the Orange County-based advertising copywriter continues. "The blood test was HLA-B27 positive—and there it was. They did an entire battery of tests, mostly to rule out other illnesses. It took about six months to go from 'something is wrong with my son' to finally seeing an expert who could help us."

That expert was UCLA's chief of the section on rheumatology, Dr. Deborah McCurdy, who Mrs. Walker called "fabulous and wonderful." Dr. McCurdy wrote to Tyler's school, and requested that Tyler be given an extra set of textbooks so he wouldn't have to ferry them around on his back, a move his mother termed "invaluable"; the books should have been provided to him free of charge under IDEA* (see sidebar).

Tyler Wanted That Trophy

Meanwhile, Tyler wasn't letting the morning stiffness and soreness get in the way of his childhood dreams of become a swimming champion. He had been swimming competitively since he was five years of age after eyeing his friend's trophy. "I just thought that my friend's trophy was so cool and I wanted one for my bedroom," Tyler says. So Tyler's career as a competitive swimmer was off and running at the age of five. He started out on the Rancho Santa Margarita Dolphins, a small city local team

The more his parents learned about his diagnosis, the happier they were at his choice of activity. "Tyler's dad was so supportive of his swimming and of me when we were taking Tyler to the doctors who told us there wasn't anything wrong with him," notes Mrs. Walker.

The youngster later joined the prestigious Mission Viejo Nadadores swim club. He also swims for his Tesoro High School team where he holds school records in the 100 butterfly stroke and 500 freestyle. And the scholar-athlete's impressive grade point average has remained at 4.0 for the past three years.

Tyler, now 17, just broke his own school record in 100-yard butterfly on Saturday, May 13 at the CIF Swim Finals in Long Beach. He swam a 52.87; his school record last year was 53.27.

He says the hardest thing about having AS since he was a little boy is not always being able to do what the other kids do: "I remember back in the sixth grade—they all went out and jumped rope on the basketball court. I did it, too, but then I had trouble walking the next day from the pressure and the pounding on my body. I had to eventually get out of PE because I couldn't do the same activities as the other kids. But I could swim. That's what's great about swimming; it's not that much pressure on the body and it doesn't take a toll."

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“Not That Many People Know About AS”

Tyler says that naturally his teammates don't know about ankylosing spondylitis so he refers to his disease only as “arthritis.” “Not that many people know about AS. The disease name sounds so technical that it's not even a ‘human thing’ anymore so I tell people that I have arthritis, which everyone understands. I've always felt like I was the same as everyone else, but that I just have had to be more careful. I've had more things to worry about and I've had a few more setbacks,” he mentions.

Although Tyler's symptoms are mostly controlled with prescription dosage nonsteroidal anti-inflammatory drugs, he still gets occasional painful flare-ups that can sideline him from his swimming meets. Recently, although he says he has built up a “good resistance to pain,” he had to bow out of a couple of important swim meets that caused his coach and teammates to think he was malingering, something he wasn't comfortable with defending.

“We had a big high school meet and I hurt my neck and it was really stiff. Somehow, I must have pulled it,” Tyler recalls. “I think the arthritis made it worse. I was just having a lot of trouble moving. You never realize how important something is till you don't have the use of it. It's amazing how little mobility you have when your neck is injured. I couldn't swim. I told my coach I was sorry I couldn't make it. He understood but he was very frustrated; he said they needed me.”

The next time was a league meet the following week. This time his hip was involved in the pain cycle. He couldn't walk. His mother let him sleep in the morning of the competition, thinking they could evaluate his condition after a lengthy rest. But he realized he couldn't swim due to the agonizing pain. He had to notify the coach. The coach bellowed into the phone, “You've got to be freakin' kidding me! The line-up is built around you!”

“We Need You, Tyler...”

Within a few minutes, Tyler started getting calls from his teammates. “Tyler, we need you,” they pleaded to him. Tyler says he “felt horrible” not being able to be there and support his team. “It was so disappointing to let my team down. I wanted to be there. I just couldn't; I was in a lot of pain and I couldn't move.”

Today, Tyler is in a different swim group and Ms. Walker was thrilled when the new coach asked her for literature and information on AS. She tells us what happened: “Tyler's new swim coach, Ryan Purdy, actually asked me to send him info on the disease so he could read up on it and know what he's dealing with. That's never, ever happened with any other coach. I sent him the info and he e-mailed me back, thanking me, and I'm sure he will be incorporating some of this new knowledge into Tyler's swim training. It's very encouraging.”

Tyler's bedroom walls are now lined with prize-winning swimming trophies. “Swimming has been a great experience for me,” Tyler says, and yes, he notes that he will most likely continue swimming in college where his sights are set on attending UCLA.

He notes, “Swimming is a team effort and I enjoy the social aspect—and the whole team roots for you, too.”



Tyler Walker in his teens

What A Great IDEA: Individuals with Disabilities Education Act

But parents need to know about it. Mrs. Walker tells *Spondylitis Plus* that she had no idea about IDEA. “I've been borrowing these books and purchasing these books for Tyler all these years,” she laments when informed that the books should have been provided for him under the Act.

The individuals with Disabilities Education Act (IDEA) provide funds to states for the education of children with disabilities; ankylosing spondylitis qualifies for the funds. It assures that each child with a disability receives a free appropriate public education (FAPE), usually between the ages of three and 21. Each child receiving services has an individual education program that spells out their needs. Parents are involved in the planning of the services. Currently, all states receive IDEA funding in the form of federal grants to each state.

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