

For reasons that are, frankly, unknown, 10-year-old Alivia Watson is ...

Doing Great

ABOUT A YEAR AGO, CINCINNATI CHILDREN'S HOSPITAL RHEUMATOLOGIST T. BRENT GRAHAM, M.D., NOTICED SOMETHING DIFFERENT WHILE EXAMINING THEN 9-YEAR-OLD ALIVIA WATSON: THERE WAS NOTHING UNUSUAL ABOUT HER.



By Jeff Shmase



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his startling development took the doctor aback. For three years, there had always been some issue with Alivia, who was just 4 when she was diagnosed with Raynaud's, and in 2005 was later diagnosed with scleroderma, the systemic form. Most of the time, Alivia, of Hamilton, Ohio, had problems with digital ulcers, joint pain, or tight skin.

During this visit in February, 2007, however, Graham could not see any physical issues with her. But he wanted to be sure. So Graham suggested to Alivia's parents, Scott and Charmaine, that they get a second opinion from Thomas Medsger, Jr., M.D., the University of Pittsburgh rheumatologist who sits on the Foundation's Medical Advisory Board. His verdict: He agreed with Graham. Alivia could be safely taken off the drug methotrexate, and she no longer needed quarterly IVIG (intravenous immunoglobulin) infusion treatments and frequent trips to the hospital.

"It was as if a huge burden had been lifted," Charmaine said. "She has this spring in her step she did not have before."

The Genesis

When Alivia was 4, Charmaine began to notice that her daughter's hands were always cold. She took Alivia to a pediatrician, who referred the case to a cardiologist, and then, ultimately, to Graham. He explained the disease was probably secondary Raynaud's Phenomenon, which meant she probably had either lupus or scleroderma, the latter with which she was unfamiliar.

"To be honest, when we heard what could be the diagnosis, we did not take it seriously because Alivia did not look or act sick," Charmaine said. "It was sure, whatever you say, and that was it."

But Graham had a different mindset, one that Charmaine is thankful for. He suggested Alivia be monitored very closely. At the time, she had mild inflammation in her wrists and her skin looked as if it was a classic case of scleroderma.

Blood tests revealed that her ANA (Anti-Nuclear Antibody) test was positive. Soon, instead of being seen annually, he wanted to see her every six months, and then that was followed by every three months.

In February, 2005, Graham said the protein SCL-70

showed up in Alivia's blood. He informed the Watson's that Alivia had limited systemic sclerosis.

"That day when he told Scott and I what was up with Alivia, it was almost unreal to us," Charmaine said. "We went to my in-laws and none of us talked about it as we were all in shock.

"But I said to Scott that we needed to tell Alivia something, so when I tucked her into bed I told her she had to start taking some medicine and get some treatments and be at the hospital a lot more. She was only 7 at the time. Less than a week later, she asked me about it again. She asked me if she was going to die, and that was pretty rough because Scott and I never talked about that in front of her."

At the time and even now, Alivia has not met any other children or adults with scleroderma. A protective parent, Charmaine had read some frightening information on the Internet about scleroderma and she did not want to scare her oldest child.

Family, Religion Important

Now 10 and in fifth grade, Alivia never defined herself as a scleroderma patient. Rather, titles she likes better include big sister to brothers Tanner, 8, and Riley, 5, drama queen, and more.

Family and God, Charmaine says, have helped the Watson's manage with the stresses of having a chronically ill child. Scott's parents live nearby and treat Charmaine as if she was the daughter they never had. Charmaine's two sisters live within 10 minutes of the Watson's, and always offered to watch the two boys while Alivia went to the hospital.

While Alivia was undergoing the IVIG treatments, which were not covered by health insurance, one of Charmaine's sisters, a cousin, and a niece organized a benefit auction to help pay for the treatments. "It was amazing," Charmaine said.

Most important in their lives is the role that God plays.



The title of Alivia's Web site (www.helpalivia.com) is "Keep on Shining Alivia!"

"As Christians, we put God in the center of our household," Charmaine said. "So many miracles have happened since Alivia's diagnosis. Things that weren't supposed to be possible have worked out. We believe that these things are not accidents; rather they are God ordering our steps. He has given us comfort and peace and filled our hearts with love and blessings through the support of our family and friends."

"We may never know why God chose to allow Alivia to have scleroderma, but we do know in our hearts that He made her special."



About Alivia

Likes:

- Making up stories
- Music
- Drawing
- Playing outside

Favorites:

- Animal – cat
- Food – macaroni & cheese
- Color – pink
- Cartoon – Tom & Jerry
- Movie – *Hillary Duff*