

Raising awareness

Teenager organizes walk for skin disease

by Matt Gypin
write the author



Julie McCawley, left, reads Braille with Adams County School District 50 instructor Michelle Chacon at Flynn Elementary School in October 2010. McCawley, who has Stevens-Johnson syndrome, has helped organize a walk to raise awareness of the disease on Saturday at Lake Arbor Park in Arvada. Photo by Matt Gypin/METRONORTH News.

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When Julie McCawley was 11 months old, she was diagnosed with Stevens-Johnson syndrome (SJS), a disease caused by an adverse drug reaction that burned her skin from the inside out and left her nearly blind.

Now 17, McCawley, a 2011 Westminster High School graduate, has started a foundation for children with SJS, and has helped organize an SJS Awareness Walk to be held at 10 a.m. Saturday at Lake Arbor Park in Arvada.

"Julie is always spreading awareness of Stevens-Johnson syndrome," said her mother, Jean McCawley, who started the SJS Foundation after her daughter was diagnosed and is trying to get state governors across the country to proclaim August as SJS Awareness Month. "She even slipped Michelle Obama an SJS fact sheet past the Secret Service at a luncheon in 2009."

First discovered in 1922 by pediatricians A.M. Stevens and F.C. Johnson after diagnosing a child with a severe drug reaction, SJS can be caused by almost any medication and can happen to anyone, McCawley said. As head of the foundation, she said she hears from people all over the world who are battling the disease.

"Nobody knows why it happens, and there's really not enough research into it because they consider it so rare," she said. "And it's not rare – far from it. We hear from people every single day, all day. We get emails in the middle of the night, phone calls – we've had calls from Australia at 3 o'clock in the morning.

"A lot of SJS patients are children, and a lot of them have gotten it from over-the-counter children's ibuprofen. Doctors give it out like water."

McCawley said it's a huge problem because many doctors and nurses don't know about SJS, and 80 percent of SJS patients are misdiagnosed with chickenpox, including Julie. She said there is no mandatory reporting system to the Food and Drug Administration (FDA), which means there are no accurate statistics on how many people have it, and no warning signs on medication labels to help prevent it.

"In 2006, I went to an FDA hearing and testified on behalf of the children's ibuprofen products trying to get them to change the labeling," McCawley said. "I got nowhere."

Julie McCawley, who will attend Metropolitan State College of Denver this fall and wants to become an elementary school music teacher, started the SJS Kids Foundation and designed its website to help children understand the disease.

"It explains what SJS is in terms a child can understand, because I know growing up it was really hard for me to understand it, and it was hard for me to explain it to other people," said Julie, who has had 14 surgeries on her eyes alone, and who must wear specially-made scleral lenses that cost \$7,000 a pair. "I just think that everyone needs to know about it. If you don't know the warning signs, you need to learn them because it can happen to anyone at anytime."

The McCawleys are asking anyone who would like to participate in the walk to bring a \$10 donation for SJS research. For more information, please call the SJS Foundation at 303-635-1241 or visit their website at sjsupport.org.

"It's a very scary situation," Jean McCawley said. "They say it's one in a million, but we know it's not. They like to say it's rare. I'd love it to be as rare as that, but how rare is rare when it happens to your child?"

"We just hope everybody will come out and walk, and find out about Stevens-Johnson syndrome before it finds someone you love."