

NEWS

May recognized as Dandy-Walker Syndrome awareness month

By **BECKY CRUM**
Herald Reporter

Gov. Dave Freudenthal signed a proclamation on March 8 declaring the month of May as Dandy-Walker Syndrome and Hydrocephalus Awareness Month.

Evanston resident Lisa Van Langen said she started doing research on the disease when her now seven-month-old daughter Ruby was born on Sept. 11, 2009 with Dandy-Walker Syndrome.

Van Langen said when they went to find out her baby's gender, the doctors told her the baby had hydrocephalus. She said after undergoing more tests in Salt Lake City, they were told their baby had Dandy-Walker Syndrome.

Said she wanted to understand what doctors were talking about when she went to appointments.

"I did a lot of reading and research about the brain. I tried to learn as much as I could online and elsewhere about resources and information on the disease," Van Langen said.

Van Langen said the more she researched, the more interested she became about how she could help Ruby. She said DWS is a genetic mutation that doesn't run in the family. She said even though it is common, the cause is unknown. Patients with Dandy-Walker Syndrome have developmental delays,



larger head circumference or signs and symptoms of hydrocephalus.

"I saw that the Dandy-Walker Alliance was doing a 50-state initiative, so I got involved," she said.

The Dandy-Walker Alliance is a non-profit organization for people who have been affected by Dandy-Walker Syndrome. They support research for DWS and are working toward getting all 50 states to proclaim May as Dandy-Walker and Hydrocephalus Awareness Month.

"We are doing a bake sale at the Bear River Festival on May 22. All the money that we raise will go to the Dandy-Walker Alliance," Van Langen said.

Van Langen said there is another condition called Aicardi Syndrome that the doctors thought Ruby had at first. She said some children in the community have been diagnosed with Aicardi Syndrome and hydrocephalus, meaning excess water on the brain.

"With hydrocephalus, it usually requires having a shunt put in the brain. It is a little tube that is put in the brain to drain excess fluid to the tummy," Van Langen said. "Hydrocephalus isn't that rare. You don't hear about it very often, but it is fairly common. Dandy-Walker Syndrome affects the cerebellum. In Ruby's case, she has hardly any cerebellum."

Lisa van Langen with her son, Dallin (2) and daughter, Ruby (7 months). Ruby was born with Dandy Walker Syndrome, a congenital brain malformation involving fluid-filled spaces around the cerebellum.

HERALD PHOTO/Becky Crum

Dandy-Walker Syndrome is determined by how well the child develops.

"Some children can have Dandy-Walker and be completely functional as they go into adulthood and not have many problems at all. Other kids with the disease can be completely debilitated by it," Van Langen said.

Van Langen said Ruby meets with an occupational therapist from LUCDA two times a month. She said the therapist comes into the home and analyzes Ruby's development. She said the therapist makes sure Ruby is on track and gives suggestions on how they can

strengthen her muscles.

"I think eventually, probably sooner than later, she will start working with a physical therapist on a regular schedule," Van Langen said.

Van Langen said that every three months, they take Ruby to Salt Lake City for appointments at Primary Children's Hospital for neurology, neuro surgery and genetics.

Van Langen said they are grateful to the Dandy-Walker Alliance for all they do. She said she corresponds regularly with them through e-mail.

Van Langen said the last she heard was that about ten states had signed proclamations declaring the month of May as Dandy-Walker Syndrome and Hydrocephalus Awareness Month. She said the disease affects about one in 5,000 live births and it is estimated that between 10,000-40,000 people in the United States have Dandy-Walker Syndrome.



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