



The Oregonian

Two mothers reach out to others with disorders

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Cindy Hahn and Cyndy Hillier, two Tualatin mothers, met for the first time just weeks ago but for years have had two things in common: a daughter with a rare, debilitating syndrome and a devotion to helping other families.

Hahn's 16-year-old daughter, Alaina, was diagnosed as an infant with Alagille syndrome. The genetic condition affects an estimated 2,000 to 3,000 Americans and can cause serious liver, heart, kidney and a host of other problems, leading to severe itching, malnutrition, stunted growth, even death.

Within a couple of years of her daughter's birth, Hahn had found other families whose children also had the syndrome. She sent out her first newsletter to the group in 1993. The Alagille Syndrome Alliance became a nonprofit corporation in 1997 and has grown with a national board of directors, a scientific advisory board, bi-annual symposiums and various publications.

These days, Hahn, its president, is busy on the latest booklet, "Alagille Syndrome, Tweens to Twenties: A Survival Guide."

She also travels a lot, as chairwoman of the patient advocacy group's committee for the national Cholestatic Liver Disease Consortium and participates in a national coalition of patient advocacy groups for those with a variety of rare diseases.

And she wants to start a young ambassador program for young adults with the rare disease. She's already got one at home.

Hahn is proud of what her daughter has taken on, serving as a mentor to other children with the syndrome and serving as an advocate. The girl won the 2006 essay contest by the American Society for Human Genetics, winning a cash prize and \$2,500 worth of equipment for Tualatin High School's science department. The teenager has expressed an interest in taking a leadership role with the alliance when her mother has grown tired of it.

"She's just a great role model," Hahn said.

Hillier's daughter, Elizabeth, has Klippel-Trenaunay syndrome, a congenital vascular disorder that can cause excessive bleeding, swelling and infections and leading to restricted circulation, impaired organs, lost limbs and many other problems.

She became coordinator of the Oregon K-T Support Group in 2003 when her daughter, Elizabeth, wasn't out of diapers. Hillier reached out to the three dozen or so individuals with the syndrome in Oregon, and then started the K-T Foundation of Oregon. Hillier has organized fundraisers for patient care support and education.

Now that her daughter is almost 6, Hillier sees new challenges to overcome. She wants to start a camp for children in the Northwest with vascular disorders, other kids with port wine stains or wearing compression garments.

She wants to give them a place where they can be surrounded by other children who understand and can ask: "How do you get comfortable?" "What's the silliest question you've ever got?"

Both mothers know what it's like to cry for their daughters, applaud their accomplishments and give their husbands and other children the attention they need. Hahn also has twin 11-year-old sons, and Hillier has a 7-year-old daughter, two grown stepchildren and two grandchildren.

Both mothers deal with the stares, pain, multiple operations and discarded dreams. But they also give their daughters the hope that comes from finding out all they can and reaching out to others.

For information on Alagille syndrome, go to www.alagille.org For information on Klippel-Trenaunay syndrome go to www.k-t.org or contact Cyndy Hillier at goducks00@yahoo.com for K-T activities in Oregon.

-- Maya Blackmun

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