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JUST LIKE EVERYONE ELSE

Daughter remains healthy despite skin disease

Posted by the Asbury Park Press on 11/4/06

BY **BONNIE DELANEY**
STAFF WRITER

Isabella Hakim has long, wavy brown hair. Lilliana Hakim does not.

Lilliana, who turned 2 Oct. 19, has alopecia areata. Isabella, who celebrated her third birthday in June, does not.

The girls' parents, Donna and Matthew Hakim of Wall, want people to know that despite their obvious differences, both of their daughters are healthy, active toddlers.

The Hakims, with the help of their friend Steven Lance of Howell, organized Let Your Hair Down, a fundraising reception, Oct. 27 at The Renaissance in Ocean Township to raise awareness about alopecia areata and raise money to benefit the National Alopecia Areata Foundation.



(STAFF PHOTO: JERRY WOLKOWITZ)

Lilliana Hakim, 2, who has a disease that causes hair loss; her sister, Isabella, 3; and their parents, Donna and Matt of Wall, are educating the public about the disease, called alopecia areata.

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"Everyone thinks she's (Lilliana's) sick. We get a lot of 'He's such a cute little boy'," Donna Hakim said about people's reaction to Lilli's lack of hair.

At the age of ten months, Lilliana lost 80 percent of her hair in three weeks, she said, and subsequently was diagnosed with alopecia areata — a common, but highly unpredictable autoimmune skin disease that results in the loss of hair on the scalp and elsewhere on the body, her mother said. It affects 1.7 percent of the population overall and more than 5 million people in the United States.

The Hakims decided they wanted to raise awareness about the disease and this summer set up a booth and handed out information about alopecia areata at Toms River Fest, held at the Ritacco Center in Dover Township.

"Then we decided we had to do more. So we put together this fundraiser in two months," Donna Hakim said. About 175 people attended the reception, which the Hakims hope to hold annually.

Matthew Hakim said several of his family members have juvenile diabetes, an autoimmune disease.

"When you have an autoimmune disease in the family, you have a far greater chance of getting an autoimmune disease," he said.

Lance, an advanced clinical hypnotherapist and master hypnotherapist for Integrated Health and Wellness Center in Neptune, was the master of ceremonies for the reception.

"Donna is my best friend, and Matt is my colleague and friend," said Lance, who also is a doctoral candidate in holistic nutrition.

Lance said he believes his friends can help make a difference in the lives of people with alopecia areata by raising awareness and money for research.

Vicki Kalabokes, chief executive officer of the national foundation in San Rafael, Calif., came to the event, as did Maureen McGettigan of Flourtown, Pa., who is on the board of the national foundation.

"I was diagnosed with alopecia at the age of 16. It was devastating to be a teenager and lose your hair," McGettigan said.

Kalabokes said she got involved with the foundation at the request of a friend who has the disease.

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"Then when I saw all the kids who had it, I just never left," she said.

Kalabokes said the foundation offers a summer camp for children with the disease and 60 support groups.

Also attending the event were Tonia and Paul Ramirez of Kinnelon, whose 6-year-old daughter, Susie, was diagnosed with the disease in April 2005, and Maria and Frank Borgese of Brooklyn, N.Y., and their children, Amanda, 3, and Nicholas, 4. Amanda was diagnosed with alopecia areata at the age of 15 months, her mother said.

"It's a social issue. My daughter is 6, and she doesn't want to wear a wig or a hat," said Tonia Ramirez. "She tells her friends that she isn't sick even though her friends' parents often tell their children that Susie is a sick girl with cancer."

"It is shocking to learn that your child has it when no one in the family does," Maria Borgese added.

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