

Alopecia's impact goes beyond hair loss

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Those with alopecia areata cope with hair loss, social fallout

By Sandra A. Miller, Globe Correspondent | February 1, 2009

As a young boy, Davio DiSpena took his hair grooming very seriously. Every week, he would have his father, Joseph DiSpena, owner of Continentale Hair Salon in Arlington, give his thick, dark hair a trim - an indulgence that would become a cruel irony.

At age 12, Davio discovered dime-sized bald patches on his head. "I felt really confused at first," said DiSpena, 18, a senior at Bedford High School. "It came up so fast and I had no idea what it was."

But the pediatrician immediately recognized the condition as alopecia areata, an autoimmune disease in which a person's immune system attacks the hair follicles, resulting in hair loss. The condition, which affects approximately 2 percent of the population and often has a genetic component, typically starts with one or more patches on the scalp and can progress to complete scalp hair loss or total body hair loss. It can also simply resolve itself.

"This is a very variable disease that affects every patient in a different way," according to Dr. Lynne Goldberg, associate professor of dermatology and pathology at Boston Medical Center and director of its hair clinic. "One of the scariest things about it is the unpredictability. People can regrow their hair only to have it fall out again."

In DiSpena's case, the bald spots increased in size and number over the next few years. Cortisone injections to the scalp as well as a host of alternative therapies had no lasting effect, and by the time DiSpena was a sophomore in high school, he had a patchy head of hair and almost no eyebrows or eyelashes.

His self-esteem had also taken a beating. That's a typical response, according to Vicki Kalabokes, president and CEO of the National Alopecia Areata Foundation in San Rafael, Calif.

"Anytime you lose part of your body, you go through the five stages of grieving," Kalabokes said. "The same goes for hair. It's so much a part of our cosmetic society."

She also points out that eyelashes, eyebrows, nose, scalp, and body hair are there for warmth and protection. "So you've also lost part of your body with a purpose," Kalabokes said.

Last month, the foundation helped to introduce in the new Congress the Alopecia Areata Medicaid Improvement and Parity Act, a federal bill - whose co-sponsors include Massachusetts representatives James McGovern, John Tierney, and Barney Frank - that would require Medicaid to pay for one wig annually for those with the most serious forms of the disease.

Chrissa Kaselis, 36, of Walpole is one of those people. She started losing her hair at age 23 and now, completely bald, wears a midpriced \$1,300 wig that must be replaced once a year.

Along with 15 members of the Boston Area Alopecia Areata Support Group, which serves all of Massachusetts and meets each month in Wellesley, Kaselis testified in front of the Financial Services Committee on Beacon Hill in November 2007, with the goal of getting insurance companies in Massachusetts to pay for wigs. Though the bill sponsored by state Senator Marian Walsh, a Democrat from West Roxbury, was not passed, it will come up again later this year.

At that same time, DiSpena, consistently losing more hair, was navigating his way through high school.

"It was devastating watching him go through this," Joseph DiSpena said. "But I also tried to keep it in perspective. It's an aesthetic thing. It's not who he really is, and I would always remind him of that."

DiSpena's mother, Susan, took it harder. As a pediatric nurse for Patriot Pediatrics in Bedford and Harvard Vanguard in Burlington, she wanted a medical answer that she couldn't find. "Also, you want to protect your kids," she said. "And I couldn't protect him from how people reacted."

And people did react. Often with worry, like the referee at one of DiSpena's basketball games who approached the family to see if the teenager had a more serious illness such as cancer. Or the high school guidance counselor who responded to some students' concerns that DiSpena could be involved with an LA-based gang that shaves their eyebrows.

DiSpena has also overheard whispers in the school hallways and teasing from the stands at a soccer game, but he now shrugs off those incidents, insisting his condition or people's reactions no longer bother him.

Playing varsity soccer and basketball since freshman year, DiSpena, also an honors student, credits sports with restoring the confidence his hair loss undermined. "Once I was on all of these teams and had a lot of friends, I realized I couldn't let something like this get in the way of everything I had ahead of me. But it was like a brick wall that I had to get around."

A significant turning point occurred two years ago when DiSpena spent an evening at the TD Banknorth Garden meeting Milwaukee Bucks forward Charlie Villanueva, then watching him play in a game against the Celtics.

Villanueva, 24, hairless from alopecia areata since age 12, has served since 2005 as a spokesman for the National Alopecia Areata Foundation. When his NBA team travels for games, Villanueva conducts "meet and greets" with local children and their families affected by the disease, such as the "Charlie's Angels" program held before the Celtics-Bucks game at TD Banknorth Garden on Nov. 7.

"I had nobody to look up to when I was going through this, so I try to give them a role model," said Villanueva, who used basketball as a way to be accepted for his condition. "I wanted to be seen as a good player, not the guy without eyebrows, and that pushed me to my dream."

DiSpena said that talking to Villanueva before the game two years ago was an inspiring experience. His photo with the Bucks player hangs in his bedroom near a quote by Michael Jordan about not letting obstacles stop you.

So far they haven't. Last month he accepted an academic scholarship to Colby-Sawyer College in New London, N.H., where he will continue playing basketball.

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