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Local business owner raising awareness of alopecia

By Chelsea Garfield Special to the Democrat September 30, 2011



"Chelsea Garfield, one of the owners of Good Friends Group Fitness, has alopecia universalis. September is Alopecia Awareness Month. - Casey Yu/Special to the Democrat

As a small business owner, every day is full, and every month sweeps by in the blink of an eye. This month was no exception; however, I am forcing myself to stop and recognize something publicly that is very dear to me.

Today, I'm discussing a question many people wonder about but never ask -- my baldness. September is Alopecia Awareness Month. Really, for me, every day is Alopecia Awareness Day. When most people see a bald woman, they assume, gasp, cancer (insert look of concern here). I hate seeing those looks; it almost makes me feel like I'm posing as a cancer victim, but really, I'm just a hairless human.

I have alopecia. I tell people I'm like a rare hairless cat, but nicer. When I offer this information, I sometimes see a flicker of recognition. More often, I get a blank stare back because they have never heard of it. That's when I have to do some quick talking to assure them this is a genetic auto-immune disorder, and I'm not contagious.

Alopecia is a general medical term to describe baldness that could have any number of causes. Technically, I have alopecia universalis, a sub form of alopecia areata (AA). Alopecia areata is often triggered by a mental or physical stressor, which confuses an over-active immune system and causes hair follicles to see your hair as foreign and release the hair from its follicle.

Alopecia areata does not stop your hair from growing; it stops the hair follicle from holding onto the hair. I've had many strong conversations with my hair follicles and told them, "It's OK. Hair is our friend," but they never listen.

The areata form of alopecia most commonly shows up as small dime or quarter-sized circular patches of smooth skin. I've had alopecia areata my entire life. I remember as a small child feeling those patches on my scalp, but not thinking much about them as they could be covered by my long hair.

When I was 18, I had a bad fever, and a week later, I started to lose large sections of hair. This is when I first heard the word alopecia. This thing I've had all my life finally had a name.

My dermatologist started me on a harsh but effective treatment of 30 cortisone injections every week. Within a few months, my hair grew back, and I forgot about alopecia.

More than a decade later, I again got a bad flu that came with a fever. One week later, I realized the hair line at the back of my head receded. I went to my dermatologist, figuring it might be that alopecia thing again. The doctor confirmed that it was alopecia, but this time the pattern was "concerning."

Instead of circular patches, the snake-type pattern around the hairline was not a good sign. The thought that I could lose every hair on my head and body never crossed my mind. But this is what she told me. I was likely going to lose all of my hair.

Unfortunately, she was right. The hair loss was aggressive, and while the shots did cause some hair to grow, the hair loss was too swift, and there are only so many shots you can get.

Within two weeks of accepting that the treatments were not working, I lost every hair on my head. Within two more months, I had no eyebrows, no eyelashes, no body hair, nothing. It was very cold that winter.

When AA spreads to the entire body, it's called alopecia universalis. Researchers estimate 2 percent of the population has some form of alopecia areata, but it may be more as it may go undetected or unreported if not very severe.

Of that 2 percent, less than 1 percent turn into alopecia universalis (AU), of that 1 percent most cases are in children. It is rare to have an adult with AU.

It is not easy to live in today's world as a hairless human. Not just bald on your head, but void of facial hair such as eyebrows and eyelashes. It makes a person look different. Worse still, most public images of hairless people are indicative of a severe illness or dying.

As an otherwise healthy child or adult, this is where most of the struggle of alopecia stems from -- self image and a justification of your vitality, health and beauty. I've seen some children who are an inspiration in how well they handle their condition, and I've seen adults who are crippled by their loss.

What I have noticed in living with this disease is that acceptance and education to those around you is hugely influential in how a person copes. A child whose parents and teachers make the effort to educate other children in his or her class goes a long way toward the child's self-acceptance.

Open communication is the best thing you can do for those affected by alopecia. The worst thing you can do is try to cover it up and leave people to wonder, "What's wrong with him/her?"

Everyone handles their alopecia differently, and there is no right or wrong way. Some choose to wear wigs. Others, like me, choose to occasionally wear wigs, but mostly scarves and hats, and still others are just bald. (I'm still working up the nerve to do that).

The message should simply be this: baldness is not bad; it is just different. Bald can even be beautiful. Others with alopecia universalis such as Miss America contestant Kayla Martell or New Zealand model Anna Fitzpatrick display this every day in their quest to promote awareness.

They say one person can't change the world all at once, but you can start within your community. Tallahassee is my community, and I want to educate those within it about alopecia.

What can you do to help? You are already helping by reading this column. In addition, Locks of Love is a nonprofit organization that collects hair donations in order to make wigs for children going through chemotherapy and for those affected by alopecia.

If you are blessed with a long mane of hair, consider donating your hair through your local hair salon. For more information on Locks of Love, go to www.locksoflove.org.

For more information on alopecia, visit the National Alopecia Awareness Foundation at www.naaf.org.

-- Chelsea Garfield is owner of Good Friends Group Fitness.

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