

Public Comment of Sarah Mancoll, M.Sc., Public Policy Professional and Mother to Three Children, Ages 4.5, 2.5, and 5 months, in Response to a Call for Public Comments Issued by the Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC) on October 2, 2017

WRITTEN COMMENT

Since the late summer of 2012, I have not been able to receive treatment for an autoimmune disorder that adversely affects my quality of life. The autoimmune disorder, alopecia areata, is a disease that attacks hair follicles, causing hair to fall out in patches. I chose to stop treatment in 2012—treatment which I had been regularly receiving since the fall of 2003—after consulting with my obstetrician and my dermatologist (and later, my child’s pediatrician) about the possible negative effects of treatment on a developing baby during gestation, and/or while receiving breast milk. As my doctors explained, we simply don’t know enough about how treatment for alopecia areata *might* affect a developing baby—we don’t have enough research to confidently say, “Yes, you can continue with treatment, full stop,” or “Yes, you can continue with treatment, after the first trimester.” To play it safe, my doctors told me, it would be best to end treatment before conception and to begin treatment again only after weaning.¹

Between the time that I stopped receiving treatment and the time that I returned to work after my first maternity leave—a period of 12 months—I went from having an almost full head of hair to having full-blown alopecia universalis, the complete loss of hair on the scalp and body. For more than four years now, this has been the state of things.

There is no known cure for autoimmune-related alopecia, and there is no clear understanding of why some people develop the disease and others do not.² Research suggests that genes and environment both play a role.³ Oddly, autoimmune-related alopecia can come and go over the course of a lifetime. Some people lose hair and then regrow it, some people lose hair that never returns, and some people go through a seemingly endless cycle of losing and re-growing hair.

Fortunately, there are some known methods for treating—although not curing—autoimmune-related alopecia. Many of these treatments are thought to suppress, alter, or “trick” the immune response.⁴ One of the most common treatments—the treatment that I received from 2003 through 2012 and that worked for me—is the injection of corticosteroids at the affected site (intralesional corticosteroids), which act to suppress the immune response locally. Injections are typically given every month or so by a dermatologist. The injections are quite painful, and for even relatively small bald patches (e.g., the size of a quarter), you might need ten or more needle insertions. If you have several bald patches, you might need several dozen needle insertions in one sitting. The injection of corticosteroids also causes atrophy of the skin, which can appear as “dents” on the head, especially when bald patches are located near the hairline.⁵ In a nutshell, this and other forms of treatment are unpleasant, but I chose to pursue treatment because I badly wanted to keep my hair.

Although autoimmune-related alopecia only affects hair follicles and has no adverse effects on other parts of the body, the disease can still exact a big toll. It should not be discounted as *just* a cosmetic

¹ <https://jamanetwork.com/journals/jamadermatology/fullarticle/1735120>

² <https://www.niams.nih.gov/health-topics/alopecia-areata#tab-overview>

³ According to comments provided by Frederick W. Miller, M.D., Ph.D., Senior Investigator, Clinical Research Branch / Environmental Autoimmunity Group, National Institute of Environmental Health Sciences, during a congressional briefing held on October 12, 2017 entitled “Individually Rare, Collectively Common: How Environmental Health Science Helps Us Understand and Prevent Autoimmune Disease.”

⁴ <https://www.aad.org/public/diseases/hair-and-scalp-problems/alopecia-areata#treatment>

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3002419/>

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concern. Alopecia in its various forms can be devastating emotionally and psychologically and is associated with depression and anxiety; it's not "*just hair.*"^{6 7}

I speak from experience. From 2003, when I was first diagnosed, to 2012, when I received my last injection of corticosteroids, I lived with constant worry that more and more hair would fall out and that I would no longer be able to hide my alopecia areata. Every few years, I would go through a period of great hair loss, when clumps and clumps of hair would come out in my hairbrush, in the shower, and in my hands. In 2013, when I finally lost the last bit of remaining hair, I struggled to present myself in public and sometimes avoided social gatherings altogether. Itchy wigs were uncomfortable to wear in hot and humid D.C., and I wasn't comfortable wearing my baldness out in public. As a result, I chose to wear head wraps. Unfortunately, head wraps come with complications, too: Head wraps can be uncomfortable in hot and humid weather, they can cause headaches, and they can lead to awkward social interactions. (For example, strangers come up and ask me if I have cancer, and old acquaintances will sometimes not recognize me unless I reintroduce myself.) Since I no longer have eyebrows or eyelashes, my eyes sting with dust when I walk outside and I hide whenever someone's taking a picture. To be honest, I still don't recognize myself in the mirror—even today, more than four years after I lost the last of my hair.

My husband and I have considered having a fourth child. Since I'm now 36, we would need to do that sooner rather than later. I hesitate not only because I worry about the effect of a fourth child on our careers (and sanity); I hesitate because I hate being bald. I'm afraid that the longer I forgo treatment, the more likely I am to never regrow hair. (Follicles die if they are fallow for too long.⁸)

When I went to my very first obstetrics appointment back in 2012, I came home with a list of medications that I was allowed to take while pregnant. It was not an especially long list. I joked with my family that the only drugs I could take were acetaminophen and antacids. For every condition that couldn't be addressed with acetaminophen or antacids, I was out of luck. Several months later, when I forgot to take that list of medications on vacation with me and came down with a cold, I sweated bullets trying to recall whether medicated cough drops had been on the list.

The reality for many pregnant and/or lactating women is that our treatment options are limited as compared to the general population—either because treatments have been shown to be unsafe, or because there simply isn't enough research to make an educated decision. For many women—especially women of my generation who waited until their 30s to start families and so try to have their children in rapid succession—having children can mean several years in a row of limited treatment options. For me, with alopecia universalis, it's a pain. For other women with more serious conditions, it can be much more than a pain.

In closing, I want to thank the Task Force on Research Specific to Pregnant Women and Lactating Women for exploring how pregnant and lactating women might better benefit from knowledge produced by research. Equity in research and healthcare matters. Just as we demand today that research reflects and benefits people of different genders, ethnicities, and life stages, we must also make sure that pregnant and lactating women are both represented in and benefit from research.

⁶ <https://www.yalemedicine.org/stories/alopecia-doctors-reverse-hair-loss/>

⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1261195/>

⁸ <https://www.yalemedicine.org/stories/a-mom-struggles-with-hair-loss/>