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### Maturing into My Disease

Angela Rodgers  
*New York Medical College*

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## Maturing Into My Disease

Angela Rodgers

I stared at myself in the mirror. Big brown eyes, caramel skin, smooth shiny head. “You are beautiful.” I spoke these words to my reflection as confidently as I had practiced with my psychiatrist the day before. Today was the day. I walked past my wig, headscarves, hats, and for the first time in three years left the comfort of my home without anything on my head. My feet quickly made their way to the medical school for the first day of small group summer classes. With my heart pounding, I took a deep breath and hesitantly opened the classroom door. My courageous self waltzed into the room with a smile and greeted my classmates as I had envisioned myself doing on countless occasions. To my surprise, warm hugs and encouraging words such as “You look great!” “Nice hair-do!” and “Beautiful” welcomed me. Unveiling my disease to my classmates was supposed to end my journey. Little did I know, it was only the beginning.

I was diagnosed with mild alopecia areata (an autoimmune hair loss condition) when I was four years old. My mom found a nickel-sized bald spot one day and took me to see my pediatrician who referred us to a dermatologist. Because there is no cure or FDA-approved therapy for alopecia areata, my dermatologist successfully treated me at that time with an experimental but dangerous medication regimen. The hair loss returned in elementary school and again in high school, finally progressing to alopecia universalis (an advanced form of alopecia areata involving complete loss of all body hair) in college.

During college, I felt like I was all alone living with my condition—alopecia areata and me. I didn’t know anyone else who had alopecia areata and I was too ashamed to tell anyone besides my immediate family about the disease—even my roommate. I hid my alopecia areata like a deep dark secret. The academic quarter that I lost all of my head hair marked the most terrible period of my life. By day I attended college lectures, worked as a student advisor, and volunteered at a local hospital, while each night I would watch helplessly as my long dark curly hair disappeared down the bathtub drain. I remember silently crying myself to sleep so I wouldn’t disturb my roommate and desperately wishing that this hair loss nightmare would soon end. In the mornings, when I was fixing the sparse strands of what was left of my once voluminous hair, I tried to suppress the complete and utter loss of control I had of my hair follicles and focused on the day’s tasks. At that time in my life my dermatological disease was not my priority. It was an embarrassment. A source of anxiety. My burden to bear. Something to be hidden from the world and tamed in secret.

Through the years I had many good and bad interactions with medical professionals and interestingly enough it had nothing to do with medication. It was all about how they interacted with me. Some of the physicians who treated me seemed to put themselves in my shoes. They could envision themselves

as a teenage girl living in a world fixated on beauty defined as a woman’s hair—a victim of losing her own hair, her beauty, and secretly her worth. Other physicians appeared to completely disregard my feelings about how the disease affected my self-perception, my interactions with others, and my life. As a patient, I was completely vulnerable. I learned from these physicians what kind of doctor I wanted to be vulnerable with.

After I had spent a few years wearing wigs in order to attempt to re-create a physical appearance that resembled the pre-hair loss Angela, my mother discovered an organization called the National Alopecia Areata Foundation (NAAF). She said this organization was sponsoring a conference close to our southern Californian home and I should check it out. I was surprised that I had never heard about NAAF from any dermatologist who treated me. This organization had been founded 30 years ago according to their website. I can’t even begin to describe the emotions that filled me when I entered the conference hotel in Los Angeles in June of 2011. My 24-year-old eyes were met with a sight I had never seen in my two decades of living with alopecia areata—a sea of incredibly beautiful bald heads of every age, gender, and ethnicity. Some were completely bald and shiny. Some were shaven. Some had small patches of hair. I quickly raced to my hotel room and shut the door just in time to privately celebrate with tears of joy the moment I realized I was not alone.

As a patient, I could see that medical providers struggled to understand my autoimmune disease medically and many didn’t investigate its psychosocial impact. I also was unsure of how to express to my doctor that I did not know how to deal with my alopecia areata in a healthy way. During the conference, I not only learned about the current research updates regarding alopecia areata, but I also learned about the existence and purpose of support groups for people with chronic disease. Most importantly, I learned how to advocate for myself. Meeting others like myself encouraged me to embrace the unpredictable course of my condition by being confident in who I was as a person despite my hair loss.

I started medical school in the summer of 2011 and, with the goal of being completely independent of wigs, I began regularly meeting with a psychiatrist on campus to prepare my mind for the transition. I knew that my self-confidence and perception of my physical appearance were severely damaged from the way I handled my hair loss during my college years, so I recognized that an important aspect of progressing from wig to no wig would require professional support. Finally in the summer of 2012, I attended class for the first time without my wig. The response from my classmates was overwhelmingly positive, but most importantly the positive way I felt about myself was unforgettable.

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One of the most worrisome aspects of alopecia areata is that it is unpredictable. One can lose his or her hair over weeks to months and then without notice grow it back and then lose it again. The vicious cycle has deeply wounded so many Alopecians I know, including myself. I definitely do not have everything figured out. However, peace centers me despite my lack of control over my hair because despite what the media tell me, I am not just my hair. This is true in all of medicine as our patients are more than their disease. Now, I can control the meaningfulness of my support group and my advocacy work at NAAF. I have finally matured into my disease.