THALASSEMIA PROFILE

Yasmeen Anis

I am Yasmeen Anis, age 23, living with a severe form of thalassemia, an inherited blood disorder in which the red blood cells aren't able to get enough oxygen to the tissues and organs in the body. My family learned I had thalassemia when I was 6 months old, and we continue to learn new things as medical research advances. I have been treated with routine blood transfusions every 4–5 weeks since I was first diagnosed as an infant. Without regular transfusions to provide a source of healthy red blood cells, I feel tired and weak – in fact, my survival depends on transfusions. However, these lifesaving red blood cell transfusions contain a lot of iron, which can build up in the organs in my body. If left untreated, this excess iron could lead to complications such as heart failure or liver cirrhosis (a condition in which the liver is scarred and permanently damaged).

As I was growing up, my family preferred to keep many personal things private, so we never told anyone outside of our family about my thalassemia. This made it difficult for me when I had to miss so much school due to my medical appointments. In addition, I wasn't able to tell my friends the real reason I was unable to spend as much time with them as I would have liked.

> *"When I went away to college, I finally began to open up about my experiences living with a blood disorder, and I learned to speak up for myself about the demands that thalassemia care placed on my schedule. I found that people were interested when I shared my story about living with a chronic illness, and I was able to build a strong support system in this way."*

Going away to college proved to be a major challenge though, in part because of the demands of thalassemia. I had been seen by the same doctors at Nemours Children's Hospital my entire life, and I was scared to leave this familiar place that had become my home away from home. The nurses there had become my friends and knew everything about me and my life. When selecting a college, I had many factors to consider–such as whether there was an experienced hematologist (specialist in blood disorders) located nearby and whether or not my health insurance would cover my care if I moved out-of-state for college. In the end, thalassemia proved to be one of the most important factors in my choice of college: I decided to go to Flagler College because it was close enough to home that I could continue receiving my care from the same hospital and staff I had my entire life. I made the 2-hour trip back home once

a month to get my transfusions. Since I didn't have a car until my senior year of college, my dad would make the 2-hour drive to pick me up, then drive another 2 hours to take me to the hospital. When my transfusion was complete, he would make the same 4-hour drive back to school and home. He did that 8-hour trek once a month for 3 years.

When I turned 21, I aged out of my pediatric center and needed to transition and switch to a hematologist who provided thalassemia care for adults. At this point in my life, my main concern in selecting a hematologist was to find a doctor who was near my college. I soon learned that distance to care was perhaps not the single most important factor in choosing a specialist. This experience taught me to also consider the specialist's level of experience in managing thalassemia and their willingness to partner with me in my care and listen to my concerns to best achieve my goals.

Despite the challenges of juggling my college course load, living away from home for the first time, and managing my own health care, college was a place where I thrived and grew. I majored in Elementary Education and Psychology and held leadership positions in a variety of college clubs. I also made the President's List and Dean's List every semester. I graduated from college Summa Cum Laude (with highest honors) and received the Education Department Award and the Presidential Leadership Award for my scholastic achievements.

When the time came for me to start my career–which would require another transition of medical care to a new hematologist in another part of Florida–I was better prepared to overcome the hurdles and equipped with a list of questions to ask potential hematologists. This time, I sought the help of the Cooley's Anemia Foundation, which put me in touch with another thalassemia patient in my local area. Together, they helped me to find a hematologist who was not only skilled in treating my thalassemia, but who was willing to work around my schedule to provide care. Most importantly, my new doctor also understood my goals and set up a treatment plan that would help me to achieve them.

When it came to my career, having thalassemia once again guided my decision-making. I compared the health insurance policies associated with each job offer I received, as well as the distance between each potential job and the new hematologist I had found. In the end, after evaluating multiple job offers, I picked the job that–although it was an hour away from my doctor of choice–offered the best health insurance plan, giving me better access to specialists and the best available care for managing my thalassemia.

> *"Because I had developed the ability to speak up regarding both my healthcare needs and my life goals, I began to experience greater satisfaction in all areas of my life. "*

Today, I have an extremely rewarding career at Moton Elementary School, where I currently teach second grade. I hope that the unique perspective I have developed from coping with a lifelong chronic illness will allow me to better serve my students, who are often struggling with their own challenges.

Tips from Yasmeen

Transitioning to adulthood can be overwhelming for anyone, even people without thalassemia. Having to manage the demands of a chronic illness on top of everything else adds to the challenge at hand. Yasmeen offers the following tips for others who have thalassemia:

- Ask for help when you need it. When I first transitioned to adult health care, I remember thinking that I was 21 years old and, therefore, should be able to handle this on my own. However, thalassemia is not something that should be managed alone. It may take some time for you to find your voice, but there are people who will help you if you can find the courage to ask.
- Make a list of your life goals.
- Share it with your doctor, and ask for their help achieving them. Know that there are hematologists who are willing to treat you as a whole person.
- Know that you are not alone and that you don't have to do it all by yourself. Find your people–people you can talk with about the challenges of having thalassemia, people who are willing to drive you to your doctor's appointments, and people who can support you. Engage these people in your journey, because it will help you feel supported.

CDC thanks Yasmeen for sharing her personal story.

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