THALASSEMIA PROFILE

Chanapa Tantibanchachai

My name is Chanapa Tantibanchachai. I'm 28 years old and I live in Baltimore, Maryland, where I work as a press officer for the Food and Drug Administration. I grew up in a small town in Arizona, where my parents still live. When I was 8 months old, my parents learned I had thalassemia. Thalassemia is an inherited (i.e., passed from parents to children through genes) blood disorder caused when the body doesn't make enough of a protein called hemoglobin, an important part of red blood cells. As a baby, I started losing hair, became fussy about feeding, and my skin became unusually pale. Nobody else in my family had thalassemia, and my parents were unaware that they carried one of the genes that causes thalassemia, making them thalassemia carriers. The diagnosis came as a shock to everyone.

Learning to Manage Thalassemia

Thalassemia results in serious anemia, which is treated by frequent blood transfusions. A potentially life-threatening side effect of frequent transfusions is a build-up of excess iron in the body. For the first 16 years of my life, I took a medicine called Desferal®, which had to be administered through a needle in my arm, stomach, or leg for 12 hours each night, 5 nights a week. Desferal® was used to remove the excess iron building up in my body. This medicine was pushed through a small pump that had to remain strapped to my body. It was emotionally difficult at times, because the treatment kept me from doing much physical activity or attending social outings between 6 p.m. and 6 a.m, causing me to miss many childhood activities. Eventually, I switched to a newer medicine called Exjade®, which I dissolved in juice and swallowed. This greatly improved my quality of life, because I no longer needed to insert a needle and remain connected to a pump nearly every night! Eventually, another medicine became available—Jadenu®—which could simply be taken in tablet form, enabling me to manage my iron overload by simply taking a few pills every day. I no longer had to plan my life around my iron overload treatments.

As a family, we overcame many challenges as a result of my thalassemia diagnosis. My parents came over from Thailand and settled in a small town in Arizona. We faced many barriers, due to the fact that English was not their first language, including difficulty accessing specialized health care. Not only did my parents have to learn English quickly, they also had to learn complex medical and insurance terms—something even native English speakers have a hard time with—in order to support me in obtaining care.

> *"I recall at age 15 having to write an appeal letter asking my insurance company to cover my Exjade® treatments. Fortunately, I was successful in ultimately getting coverage for my treatments. This experience taught me to speak up and assert myself to get the care that I needed to manage my chronic illness."*

Cooley's Anemia FOUNDATION
Leading the Fight Against Thalassemia

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Transitioning to Adult Care

The time during adolescence and early adulthood is an important phase of life for all people with thalassemia in which we must transition, or make the switch from pediatric (the care of infants and children) to adult thalassemia care, and take a more active role in our treatment. This transition was a lot more difficult than I had anticipated. For example, I went to college 4.5 hours away from home and didn't have a car, so in order to get to the hospital for my transfusions, I had to take two buses and a light rail each way. This travel time, as well as the time spent in the hospital, would take an entire day. In order to get the care I needed, I was oftentimes forced to rearrange my coursework, some exams, and eventually, internships and work. There were also many times when my health insurance provider wouldn't give prior approval for my blood transfusions, so I'd end up sitting in a corner of the hospital, setting up calls between my doctor, the insurance company, and the hospital so I could receive my blood transfusion already scheduled for that day.

With the many demands of college, such as attending classes, study groups, and extracurricular activities, I found it hard to make the time to take my medicine. I'll admit that I skipped some of my Exjade® treatments. Although it was much easier to take Exjade® by mouth than to receive Desferal® through a pump, I still found some aspects of taking it difficult: it needed to be taken on an empty stomach, it needed time to dissolve into my juice, and I disliked the grainy texture of my juice after the medicine had dissolved My ferritin level (a measure for excess iron in the organs) greatly increased during this time.

> *"It eventually occurred to me that no one was going to take care of me but me, and that without my health, I would never be able to pursue my dreams."*

It was this realization that gave me the kick I needed to consistently stay on track with my medicine and follow my treatment plan as my doctor prescribed.

I am organized by nature, so it wasn't hard for me to track everything connected to my adult care. I learned to ask for names and employee ID numbers when speaking to insurance representatives and hospital administrators, I double-checked which lab tests were ordered at my appointments, and I kept a paper trail of everything. However, I did find it frustrating that I had to keep asserting myself to get the care and the medicine I needed. Last year, for example, my specialty pharmacy failed to confirm the dosage of my new medicine before the holidays, so they were unable to send me my refill before I left for winter break. After a series of missteps that caused me to miss my refill, resulting in my leaving town without my medicine, I brought the issue to the highest level of customer service at the pharmacy. Because I was so organized and able to provide them with the exact dates and details of previous phone conversations, the pharmacy was able to express ship my medicine to me.

Now that all my specialists are located in one city, it is much easier for me to coordinate my care. I also enjoy interacting with my medical team. Sometimes I email my hematologist (blood disorders specialist) directly, and I have even spoken with the blood bank director.

Chanapa's Perspective and Tips for Others

I offer the following tips for others:

- With all the medical advances available today, thalassemia is no longer a life-threatening disease, just a high-maintenance one. Having thalassemia makes some things harder, but it isn't something that has to limit you in life.
- You are your own best champion! Learn the language of medicine, insurance, pharmacies, hospitals, and thalassemia so that you can be knowledgeable and empowered as you manage issues that arise.
- Be assertive and persistent! Don't be shy about calling out issues when you see them, because overcoming challenges at the root level may end up saving you time over the long run. Your efforts might even help others avoid similar issues by removing common roadblocks.
- Notice how some of the things you perceived as limitations may have made you stronger over time. All the activities I missed out on growing up due to thalassemia, and even the hassles I go through today in connection with my health insurance, have ultimately made me a stronger, more resilient, and more thoughtful person. Managing thalassemia may feel impossible sometimes, but the struggles you go through truly do build character.

CDC thanks Chanapa for sharing her personal story.

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