Vertex stands with the sickle cell disease and beta thalassemia communities and continue to work closely with them to best learn about the disease experiences and needs of the community

The below collection of photos and quotes intend to demonstrate some of our most important learnings from our partners in the sickle cell disease and beta thalassemia communities:

Sickle Cell Disease

Sickle cell disease (SCD) is a serious, life-threatening, and progressive inherited genetic disease, with a global incidence of approximately 300,000 infants with SCD born each year. There are approximately 100,000 people in the U.S. thought to have SCD. SCD can cause severe pain, organ damage and shortened life span due to the misshapen or "sickled" blood cells.

Mapillar Dahn, mother to three daughters living with sickle cell disease

"We know that not everyone is worried about blood. We worry about the temperature, we worry about being taken seriously, not being stigmatized. And for caregivers, we worry about not being fired from jobs. I've been fired from a few jobs because my kids were in the hospital and I chose to be there with them. That is a story of so many parents. This is our normal."

"When you're forced to visit the hospital a lot like many families who are impacted by this disease, parking might be one dollar – but that dollar isn't just a dollar. That dollar becomes: Do I use this dollar to get a bagel for my child to eat, or do I use it to park?"

Kevin Wake, living with sickle cell disease

"For me, it is almost like bone crushing pain and it just hurts when somebody even touches you when you're in pain. Just the simple touch on the skin intensifies that pain even more."

"Sickle cell is a disease that needs to continue to be talked about and understood, and there needs to be more formalized education around SCD with training for doctors and health care providers. I'm thankful that I've lived long enough to start seeing more research in the sickle cell space. I never thought that I would see this much interest in research and education taking place in the SCD arena."

For more information, visit vrtx.com/our-science/

Beta Thalassemia

Beta thalassemia is a serious, life-threatening inherited genetic disease that is thought to affect around 288,000 people worldwide and an estimated 1 in 100,000 individuals in the general population in the U.S. Transfusion-dependent beta thalassemia (TDT) is the most severe form of beta thalassemia and requires frequent, lifelong blood transfusions.

Tracy Antonelli, living with transfusion-dependent thalassemia, and mother to three daughters living with transfusion-dependent beta thalassemia

"Sometimes I think those emotional impacts are the hardest parts, but I definitely think that it's the time that it takes to manage it and to treat it and time away just from your normal life."

"When people think of blood transfusions, they often think of surgeries or someone in an accident, or sometimes as an adjunct therapy to chemo or something like that. But a lot of people don't know that there are patients who need regular blood transfusions just to live."

Pranav, living with transfusion-dependent beta thalassemia

"I was diagnosed by age one, and that caused my parents to look to immigrate to the U.S. When we got to the U.S., I was misdiagnosed and they said I didn't need transfusions. We had moved across the world to not get any treatment at all? At age eight, I remember very vividly going to the pediatrician who said 'You have transfusion-dependent thalassemia, you have an enlarged spleen, you don't get to go home. You go directly to the hospital. You get a splenectomy, and now you start monthly transfusions.' Almost overnight, the entire universe changed for me."

Yasmeen, living with beta thalassemia

"I am a teacher - I can't miss school. When I do, sometimes there is no subsitute available. My students end up suffering when I have to take days off for treatments, and I feel doctors don't understand that."

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