

NIDDK study participant celebrates decades-long partnership

By Krysten Carrera

Sitting across from her 11-year-old daughter and husband, Radhika Sawh feels lucky. Diagnosed with the chronic disease thalassemia major at birth, she was not expecting to survive past early adulthood.

“I recently turned forty, and I never thought I’d live this long,” Sawh said, looking bright-eyed and vibrant. “I also didn’t think I’d be able to have a child naturally – but here she is!”

Sawh has participated in NIH clinical trials on thalassemia since 1980, and since then, the prognosis has improved greatly for people with her condition. Thalassemia is an inherited blood disease marked by the defective production of hemoglobin, the oxygen-carrying protein in red blood cells.

Much of the success in improving outcomes is due to improved methods for managing iron overload, some developed by or with support from the NIH. Iron overload is a common side effect of the disease, resulting from the constant need for blood transfusions. Iron overload can be fatal and often carries reproductive and other consequences.

“I feel fortunate to have contributed to the body of knowledge around thalassemia since I was five years old,” she said. “My parents understood the challenges I faced and trusted NIH doctors to do their best to treat me.”



Sawh and her daughter embrace.

Credit: Krysten Carrera



Radhika Sawh stands in the NIH Clinical Center during her annual visit.

Credit: Krysten Carrera

Healthcare providers at the NIH Clinical Center were able to control her iron overload with Desferal, a medication that was new at the time. She now returns annually for continued surveillance.

“My visits tell me that my treatments are still working, and also let me contribute long-term data to their ongoing study of people with thalassemia. I’ve been coming to the NIH longer than many people have worked here – more than 36 years!” she said.

This year, she marks 20 years as a patient of NIDDK Director Dr. Griffin P. Rodgers. Though his role has changed over the years – now

he directs an institute, in addition to performing research – their relationship hasn't.

“Dr. Rodgers is like a family member,” she said. “I see him as a trusted advisor and confidante, and I have faith that he'll advise me on what's best for my health.”

“It's been my privilege to treat Radhika, whose contributions to the research community have been invaluable in helping us better understand thalassemia,” Rodgers said. “I've enjoyed meeting her husband and watching their daughter grow up over the years.”

Sawh's experience as a patient has inspired her to reach out to others with blood diseases. She currently volunteers with the New York Blood Center, sharing her story and encouraging people to donate blood. Through the NIH, she also worked with a grantee who in the 1990s developed a machine to measure iron levels in the liver and spleen without having to do a biopsy – a major development at the time.

In addition to taking daily medications, Sawh must get blood transfusions every two weeks. Fitting the transfusions into her schedule can be challenging, and she often experiences low energy before and after – but otherwise Sawh feels that she lives a normal life.

Sawh encourages people with chronic illness to consider taking an active role in research. “Volunteering for clinical studies not only can improve your own situation, but it also benefits others,” said Sawh. “It really is a valuable, respectable thing to do.”

People interested in participating in NIH-funded clinical trials should visit www.clinicaltrials.gov.

Editor's note: This article was featured in the [Winter 2015 NIDDK Director's Update](#).