

# One Family's Journey Through Chronic Illness and Clinical Trials

The Havert family is taking on a major health diagnosis and taking care of each other along the way.



PHOTO: FRED GREAVES PHOTOGRAPHY

**A**aron Havert, 40, and daughter Eleanii, 9, both have Hemophilia A, a genetic bleeding disorder caused by a lack of blood clotting factor VIII. The main symptoms of Hemophilia A include prolonged bleeding and bruising. Aaron's case is considered severe while Eleanii's case is considered mild. There's no cure for Hemophilia A, but gene therapy may help reduce the severity of the disorder.

Aaron, who was diagnosed when he was 10 months old, needs to prevent a spontaneous bleed from occurring. He treats his Hemophilia A with factor infusions administered directly

into a vein at home every two to three days. Eleanii receives factor treatment on demand, meaning she's treated when she has a bleed.

## Caregiving and advocacy

Melanie Havert, Eleanii's mother, is a caregiver to both her daughter and to Aaron. The family lives in Northern California with their older daughter Charlii, age 11, and three pets.

Melanie, 36, started her caregiver journey in 2004 when she first met Aaron. He taught her at his kitchen table how to infuse him with life-saving intravenous injections.

"According to both Aaron and Eleanii, I am the best at giving infusions," she says.

"Without the factor being administered into their veins, Aaron would die, and Eleanii would have a very painful life and could even lose her life in the case of something like a minor head injury."

Melanie's caregiver role also includes giving Eleanii subcutaneous injections into her thighs; ordering medication and supplies; and attending appointments, conferences, and support groups. She's often a resource for other new caregivers.

When she realized how little information was available about female Hemophiliacs like her daughter, she committed to connecting with female symptomatic carriers of the disorder.

Melanie is also a project manager at Rare Patient Voice, a market research recruitment firm providing patients and caregivers with opportunities to share their opinions and experiences with researchers.

"I love helping others learn how to advocate for themselves and their families," she says. "We need to learn how to stand up for ourselves and voice our needs and desires when it comes to our health, our struggles, our wins, and our needs."

## Clinical trials

Aaron has participated in five clinical trials over the past 30 years, including four for different anti-hemophilic factors

(AHF) and one for a first in-human gene therapy trial.

He participates to help improve treatment for Hemophilia. The condition can be difficult, causing physical limitations, chronic pain, and very expensive medical costs. His monthly medication costs \$20,000.

"There has been such a dramatic change in the medical treatment of my condition over the past 35 years, that the quality of life — and the longevity of life — for Hemophiliacs has so greatly improved," he says. "It is a testament to how important clinical trials and medical research are."

## A better future

When considering participating in clinical trials, Melanie advises patients and their families to understand the risks, ask questions, and speak with others who've participated to gain a better understanding of the process.

She also advises preparing the family for all possible outcomes and discussing it as a unit. A clinical trial has the potential to affect the entire family. When Aaron wants to participate in a clinical trial, he and Melanie have a long discussion of the possible risks. If he decides to participate, he writes a personal letter to each of their daughters explaining exactly why he decided to participate and what he hopes will come out of it.

"Participating in a clinical trial is a big deal," says Aaron. "It is an act of love and hope for a better future. Without those willing to participate in clinical trials, medicine and the medical field would not be where they are today." □

**Kristen Castillo**

Article published in December Clinical Trials Supplement; view full issue [here](#).