Monica Coenraads

MOTHER OF INVENTION
The birth of a first child is always a momentous event, as it was for Monica Coenraads when her daughter Chelsea arrived in October 1996. By Chelsea’s first birthday, however, it was clear she was not developing normally. Six months later, Chelsea was diagnosed with Rett syndrome. But there was no definitive test for Rett syndrome, no known cause, and no treatments. Coenraads dedicated herself to seek out and work with scientists willing to study the disease. A cofounder of the Rett Syndrome Research Foundation (RSRF) and its current director of research, Coenraads has helped provide more than $11 million in research grants.

We can be nimble in ways that large federal agencies aren’t, funding risky projects that the government isn’t willing to take on. We have an esteemed scientific advisory board, chaired by Adrian Bird of the University of Edinburgh, and many ad hoc advisors who ensure that we fund high-impact projects directly relevant to Rett syndrome.

RSRF funding has played a part in nearly every breakthrough that’s happened in the field since the MECP2 gene mutations were discovered. For instance, we funded the development of an animal model of Rett that has proved crucial. Currently, we’re funding collaborative work between HHMI investigators Huda Zoghbi and Nathaniel Heintz, targeting genes whose expression is up- or down-regulated because of MECP2 dysfunction.

My style is very hands-on. I comb through scientific journals and press releases on a daily basis and regularly recognize work that could be synergistic with Rett syndrome. When I contact these scientists and engage them in discussion, they are intrigued by the scientific challenge of Rett.

In working with these researchers, I have definitely developed personal relationships. I think the fact that I’m a mother with a child with Rett personalizes it. Recently, we’ve created opportunities for researchers to meet our children, which I think helps them understand the urgency of the disease. It’s true that science takes time and that good science takes even more time, but as a mother of a child with this syndrome, I know that we don’t have time. And I think they get that.

During the last 7 years I’ve witnessed Rett syndrome rise from obscurity to become a high-profile disorder with links to autism, schizophrenia, and a host of other neurological diseases. It is my hope that Rett syndrome will prove to be the first treatable childhood neurological disorder.

Interview by Alicia Aust. Monica Coenraads, her husband, Pieter, daughter Chelsea, and sons Alex, age 8, and Tyler, age 6, live in Trumbull, Connecticut.