BEYOND A CURE TO AUTISM

BY CRAIG AND MARC KIELBURGER

At three years old, David Patchell-Evans’ daughter seemed to retreat inward before his eyes. Once bubbly and bright, she began struggling with words she previously knew, stopped making eye contact and awoke screaming on many nights. When a doctor diagnosed Kilee with autism, he advised Patchell-Evans to institutionalize her and move on with his life.

Instead, he began a journey to understand and help his daughter.

This was 10 years before the first Autism Awareness Day and many people had still never heard of the condition. At the local library there were only three books that mentioned autism—and none written on the subject—so Patchell-Evans started funding his own research, hunting for a cure.

“I tried for years to find it. When I couldn’t, I felt like a failure,” says the founder and CEO of Goodlife Fitness.

Worse, he says he felt “like I wasn’t a good dad.”

In the 18 years since Kilee was diagnosed, Patchell-Evans’ evolving understanding of her condition has mirrored changes in the way scientists talk about autism. From an incurable disease to a spectrum that will affect 1 in 68 children, we now view autism as a range of conditions that are distinct in every individual.

That switch is part of the larger neurodiversity movement. At the movement’s heart is the idea that just because people’s brains work differently doesn’t mean they don’t work.

But a better understanding of autism was only the first hurdle for Patchell-Evans. Next, he funneled much-needed resources into services and support for families.

“Most parents of children with autism are so emotionally depleted, so exhausted, they don’t have the time, energy or psychological capacity to find the answers they need,” he says. To change that, he worked with the Pacific Family Autism Network and the provincial government in British Columbia to launch the Goodlife Fitness Family Autism Hub.

The hub is a truly Canadian solution focused on building a network of care across the range of the variables involved with the condition, bringing different specialists under one roof.

The hub limits sound and light and serves as an oasis for people with autism and their families—a place where they can visit a doctor, get a haircut, learn new skills in the kitchen or socialize in specially designed playground to increase interactivity. The hub is equipped with the latest communications technology to extend support to the 69,000 people across B.C. who are on the autism spectrum.

Focusing on services and support doesn’t mean we stop searching for ways to help. “But it does mean you stop casting blame for things that can’t be changed,” says Patchell-Evans. “Autism is a way of being in the world—so let’s help people have the best life possible.”

That means looking as much to medical professionals as it does to accommodating teachers, supportive families and innovative designers—all with the needs of people with autism in mind. If we design our buildings, structure our schools and teach our children with empathy, we’ll build a society that recognizes the diversity of experiences and empowers everyone to lead full lives.