Duchenne Advocates Russell, Werth Use Platform to Amplify Patient Impact

Duchenne Advocates Russell, Werth Use Platform to Amplify Patient Impact

By Alexander Diegel

Duchenne Regulatory Science Consortium (D-RSC) members Ryan Russell and Colin Werth are two busy guys. In addition to their roles with D-RSC, both are part of the Adult Advisory Committee with Parent Project Muscular Dystrophy (PPMD), where Colin also serves as President of the Committee, while Ryan also works with Patients Rising Now as a Senator, is Founder of Life on Positivity, and Ambassador of the Jett Foundation. They both lead busy careers, Colin in IT, Ryan as a Life Coach with a PhD in Psychology, and just for good measure, Ryan recently decided to take up skiing and eagerly awaits the lift to the top of the mountain this winter.

But perhaps the most important roles they fulfill are those as advocates and mentors for fellow people living with Duchenne Muscular Dystrophy (DMD). Duchenne results in a number of ailments such as difficulty running or jumping, muscle pain and stiffness, an altered gait followed by a non-ambulatory lifestyle and a shortened life expectancy. Needless to say, receiving a Duchenne diagnosis is not easy for anyone — Ryan didn't believe he had it until he saw video of himself and his slowed movement in relation to other kids, then lived in hopes that someday it would just go away.

Now, he uses his voice as a resource for the younger generation and parents in the Duchenne community, so they don't have to live with a feeling of exclusion and lack of resources like he did growing up in a small town. In 2020, after he got his PhD and became a Life Coach, Russell started reaching out and looking for other organizations that dealt with Muscular Dystrophy. He soon found an opportunity where his story could not only be heard, but would make a difference.

“There aren’t very many of us over 40, so mostly I try to mentor the younger generation,” he explained. “The best thing that happened to me in Advocacy wasn’t talking to the Senators or a member of Congress. There were two mothers at an event, whose children were recently diagnosed with Duchenne. When they heard that I was 40 years old, they broke down in tears. They had no idea that their child could live that long, or that they could do all the things that I can, like skiing and kayaking. The things I do speak volumes, more than what I say. The biggest thing I think they see is, “ok that’s possible.” I try to help them see that their dreams still can come true.”

Like Ryan, Colin works with the younger generation. He also ensures that the pharmaceutical industry is having the voice of people living with Duchenne heard as a Patient Advocate. Colin’s role as an advocate has been highly impactful — in the past few years, he has participated in numerous patient listening sessions and played an active role in sharing the perspective for those living with Duchenne in front of drug developers, researchers and regulators.

“I try to get the pharmaceutical industry to be more interactive with the community and realize the importance of hearing the voice of patient advocates,” Werth explained. “It’s very important for pharma to receive feedback, to ensure they’re designing the best possible clinical trials and to get better treatments approved. Because if they’re not listening and getting feedback, they’re not going to get drugs that succeed.”

As if their respective advocacy and committee work wasn’t enough, both Ryan and Colin made the decision this year to join C-Path’s D-RSC program as advisors. D-RSC supports collaborative research through shared data access and advances development of drug development tools in order to provide better medicines and treatments for this fatal disease.

A major hurdle when it comes to improving treatments for DMD is the complexity of the disease itself, including the wide variety of genetic mutations. This complexity means that developing effective treatments can be difficult, as researchers must consider multiple factors, such as the specific type of mutation, disease stage and age of individuals living with DMD.

To combat these challenges, the consortium created an integrated database of patient-level clinical data from DMD studies, which is partially available for analysis by the Duchenne community as permitted by the owners of each dataset.

Since joining D-RSC, Werth has seen first-hand the impact of this group’s work. “The more data we have, the better the predictions will be,” he explained. “We’re working to get better data from medical records, comb through patient data, getting into electronic records management, working with that. The continued involvement of D-RSC is great, and we’re getting more of the data that is needed.”

“Somewhere in the future, hopefully there’s not a DMD community. Until that time, I hope that D-RSC becomes more well known, and that everybody knows what kind of work we’re doing,” Russell added. “I see

a bright future ahead, and I see things being more accessible with the help of D-RSC. If there's somebody out there that's reading this, and they don't know how to contribute or what they can do, there's always something for someone to do. You can make a difference."

Want to make a difference today? Contact a member of C-Path's D-RSC team today to get started.