

INTRODUCING SOME NEW FACES

Last month, the PAAC welcomed 19 new members, bringing the PAAC membership to a total of 73; our largest group ever. Below are a few skills that we have added to our talented team of adults living with Duchenne and Becker.

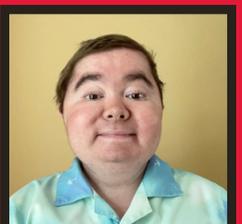
Let's get to work!

The PAAC-ers of '25-'26 include college graduates with degrees in marketing, communication, social science, illustration, engineering, cognitive science, journalism, mathematics, and a member working on a PhD in disability studies!

Our new members speak Spanish, Russian, French and Hindi.

We also have a gentleman who has built an app to help locate accessible spaces, a professional DJ, two guys who have more than 50K followers on their TikTok livestreams, a gentleman who is an appointed Commissioner for the City of Sacramento Disabilities Advisory Commission, many gamers, and more.

Read on to hear their thoughts on life with muscular dystrophy.





TELL THE WORLD ABOUT MD...

When we asked our new members what they wanted the world to know about muscular dystrophy, here is what they had to say:

"It is certainly hard physically, but having Muscular Dystrophy has made me mentally strong".
-Kaden Dickerson

"One thing I would tell the world is that people with Duchenne Muscular Dystrophy should never give up. We should keep doing what we love, stay social, and share our stories. We are not alone — and if others hear what we go through, we can create a more inclusive world where everyone supports each other, no matter their disability. Together, we can build understanding and make things better for everyone". - Aleksai Nechaev

"Your disability doesn't define you, you can still make an impact in this life if you set your mind to it". -Kyle Cox

"I think one often-overlooked facet of Muscular Dystrophy is its social implications. While raising money and hosting clinical trials in order to fund cures to MD is of critical importance, I believe that making Muscular Dystrophy more prominently, publicly acknowledged can go a long way in reshaping patient experiences, particularly in social settings, which are currently inaccessible and hostile to all people with disabilities. Improving social interactions for people with Muscular Dystrophy could jumpstart a crucial process that undoes the disproportionately high instance rates of anxiety and depression among the Muscular Dystrophy community". - Dhruv Mittur

"My life is hard, but that forces me to party harder ;)" - Yuva Gambir



BREAKFALL: A DMD NOVEL

Kevin Counterman is a good friend of the PAAC and his late brother, Michael, was a former PAAC member. He has recently published a new novel, **Breakfall**, centered on his brother's experiences with Duchenne. We are excited to highlight Kevin's book in our latest newsletter. PAAC president Colin Werth caught up with him recently in an exclusive interview.

Colin: Congratulations on publishing your first novel! What has that experience been like for you?

Kevin: It's been exciting. Publishing **Breakfall** has allowed me to connect with so many great people within our community. In sharing our story, we've heard others recount their own, and it's been inspiring. Several parents, grandparents, and siblings have reached out and shared how **Breakfall** has helped them reflect on how Duchenne has shaped their world and the lives of those around them.

C: PAAC member Buddy Cassidy was your editor and wrote the epilogue for **Breakfall**. How did that come about?

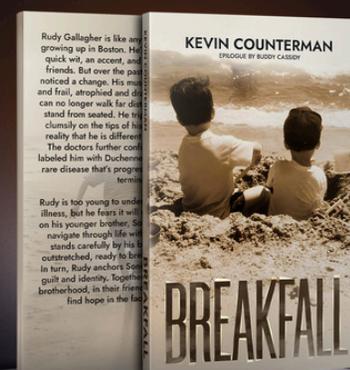
K: It's important to note that while I draw on my own experiences as a sibling, **Breakfall** is not intended to be my story, or my brother's story. As ambitious as it seems, I wanted to share the Duchenne story, with themes we can all relate to. In order to do so, we needed to share the perspective of an individual living with the disease. Buddy Cassidy, who is a PhD candidate in English Literature, lifelong Duchenne advocate, and powerful orator, was the obvious choice. It is an honor to work with Buddy and have his words anchor **Breakfall** with his wonderful epilogue. I tell all readers, if you only read one thing, read Buddy's epilogue. His words are beautiful and insightful, and he captures the Duchenne spirit and themes of **Breakfall** in 10-15 pages. He is a remarkable author, editor, advocate, friend, and person.

C: Your brother was a beloved member of the PAAC and is deeply missed. What about Michael influenced you the most?

K: Michael, like so many young men with Duchenne, was resilient in the face of ongoing adversity. In light of his worsening disease, he made the most of each and every day. He woke up each morning with a vivacious optimism and worked to improve the lives of those in the Duchenne community. He had a simple wisdom about him. He taught me if you have the opportunity to do some good, you should do it. That's what Buddy, Alan Chaulet, and I are trying to do with **Breakfall**. We hope readers can connect with and find strength within our text.

C: The book is great and I encourage everyone to read it, disabled or not. How can we get a copy? Also, can you leave us with any advice about how siblings deal with a diagnosis such as Duchenne/Becker?

K: You can search it up on Amazon, Barnes & Noble and/or order it from your local bookstore. In short, my advice would be that although we try to be strong for our affected sibling, it's okay to share our emotions and have days when we're off or upset. We don't have to be perfect, we just have to be present. I only wish I had realized this when I was young.





ABOUT PPMD

Parent Project Muscular Dystrophy (PPMD) fights every single battle necessary to end Duchenne. We demand optimal care standards and ensure every family has access to expert healthcare providers, cutting edge treatments, and a community of support. We invest deeply in treatments for this generation of patients and in research that will benefit future generations. Our advocacy efforts have secured hundreds of millions of dollars in funding and won eight FDA approvals. Everything we do—and everything we have done since our founding in 1994—helps those with Duchenne live longer, stronger lives.

Check us out and **GET INVOLVED** at
www.parentprojectmd.org/paac

ABOUT THE PAAC

PPMD's Adult Advisory Committee (PAAC) takes a holistic approach to advocacy, addressing: care, community, and quality of life. We work together to elevate the lives of individuals living with Duchenne and Becker through mentorship, outreach, and education. We support the teen and adult voices of Duchenne and Becker as an extension of PPMD.



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