

WELCOME NEW MEMBERS!

THE PAAC IS GROWING!



- NEW PAAC 25' -

As we begin 2025, we welcome new members that have joined our PPMD Adult Advisory Committee to bring our total membership to 60! By spreading the word through our Certified Duchenne Care Centers, social media, and advocating to raise our voice in the rare disease community, we continue to represent the expert patient voice. We continue to work to improve adult care as well as advocate for better policies that support adults living with Duchenne and Becker. Meet some of our new members and learn how they are changing the world.

NEW MEMBER THOUGHTS:

“Living with Duchenne is hard, but having a great family and community is very helpful.”

- Garrett

“I think the thing I want people to know is that they should not feel bad for people like us, or see us any different. I may not be able to run for very long, or do things that ‘normal’ people do, but I am still worthy of having a normal life. For me, my life always has some level of doubt.” - Seth

“I have Duchenne....and a fullfilling life!”

- Brayden

“The one thing I would say is that the disability isn't what makes life hard. What makes it hard is the systematic barriers and the societal attitudes. I don't want to be pitied, felt sorry for, or infantilized. I just want to be treated like everyone else. I don't want to have to constantly fight for the basics.” - Cody

“I am just as capable as ‘normal’ people are.” - Seph

“Duchenne doesn't define who I am and I don't let it get in my way of achieving my goals or dreams.”

- Joel



THE HANDICAPABLE PODCAST

MEET NEW PAAC MEMBER ADAM MALONE

We recently spoke with Adam about starting a business in the land of podcasting. He and his team are on a mission to share the story of adults living with all kinds of disabilities, not just muscular dystrophy. His interview style episodes are available every Friday anywhere that you listen to podcasts. Let's learn more:

Adam, what motivated you to start this podcast?

First off, thank you for speaking with me. I started the podcast to provide awareness about the disability community on topics that aren't discussed enough. I want to be able to show all the good parts of our community and be an advocate for the vulnerable.

Describe what you mean by the word vulnerable:

Simply helping more disabled adults find a voice and a platform from which to share it on.

What kinds of topics do you cover?

We cover everything on the show regarding life with a disability: relationships, travel, careers, day-to-day life, and everything in between.

What are the lessons that you hope the audience will learn from your episodes?

I'm hoping our listeners learn there is more to our community than just disabled individuals, I want people to see how awesome our community is. We have had some pretty big stars come on the show and we are gaining listeners and sponsors every week. I also want everyone to know that our show invites all disabled adults to share your story for a future episode. If you want to get involved you can email us at productions@hcpod.com.

We thank Adam and his team, and we wish him luck as he unites the adult disabled community!



Parent Project Muscular Dystrophy

JOIN THE FIGHT.
END DUCHENNE.



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.

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.

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



PAAC ADVISOR

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