



PAAC PPMD ADULT ADVISORY COMMITTEE QUARTERLY

FALL 2026









Welcome New Members!



PAAC GROWS WITH YOU...

In August and September each year, PPMD's Adult Advisory Committee (PAAC) opens applications to anyone interested in joining our work. Anyone living with Duchenne or Becker 18 years or older is welcome to apply.

If you are reading this and the enrollment period has passed, there are still ways to be involved. Please see page four and email us or scan the QR code for more information. We amplify the adult patient voice of this rare, chronic condition and would love for you to raise your voice with us.



In this issue, we welcome Brad, Isaiah, Henry, Suneel, Krishna, Jonathan, Logan, Dom and Andre to the PAAC. Take a look at the next page to get to know our newest members!



NEW MEMBER MICROPHONE...



Why did you join PAAC, and what would you like the world to know about adult life with muscular dystrophy?

"If there was one thing I could tell the world about living with muscular dystrophy, I would say that we are normal people who have nothing to hide or be ashamed of. Many people try to treat us differently either out of empathy or ignorance, but there is nothing wrong with walking up to us and asking us questions or getting to know us just like people do for anyone else. We are regular people who do normal things and we want the same things everyone else does. If you see someone with muscular dystrophy, talk to them like you would with anyone else, not like a foreign entity or a sob story. Overall, I would say that we are humans too and we should be treated as such." - Krishna

"I am interested in the PAAC as it provides a space for me to further my knowledge of how to prepare for more independence as an individual with muscular dystrophy. Additionally I would like to connect and socialize with the community on a more regular basis than solely the PPMD conferences."- Isaiah

"I want to share my story with others, which will help other people living with Duchenne. I would also like to encourage and inspire others." -Suneel

"One thing I would tell the world about living with Duchenne is that you can still achieve your goals, no matter what obstacles you face."- Andre

"Living with Duchenne is hard but it's the cards we were dealt with and we must live to the fullest as much as we can." -Diego

"Have patience." - Henry

"That people with muscular dystrophy can accomplish great things just like people without muscular dystrophy." - Brad

PAAC MEMBER SPOTLIGHT

DEVIN ARGALL: Influencer



Snack videos
TikTok , Facebook, Instagram, &
YouTube: Snackcheckwithdevin

DMD Awareness
Facebook: Devin Strong
Instagram, Tiktok, & YouTube:
DevinStrong327

Hi Devon! What made you want to launch a snack channel and how did you build your following?

I decided to start the media channels Snackcheckwithdevin because I wanted to try some new foods and snacks so I decided to pick up something to try and filmed my honest reaction to what I tried and post it to TikTok just for the heck of it to see what others would think. I post this video and had a lot of great reactions and people liked it wanted to see more so I posted one every week on Tuesdays but the viewers seemed to want more so I started making these videos everyday and I feel like these have helped a lot of people find and try new snacks as well.

What are the best parts of being an influencer?

I'd say the best part is when people recognize me and want to talk to me in person. When they do this I talk to them and hand them out one of my Snackcheckwithdevin stickers.

How do you work talking about life with Duchenne into your content?

I talk about having Duchenne and how it affects my life. I also like to give people advice on how to be positive even if they don't have muscular dystrophy. I like to say quotes at the beginnings of my videos to help people as well. I also spread awareness about dmd by making these videos and I talk about it once in a while.

What are your future goals for your channels in terms of educating others about living with a rare condition?

I hope to reach a ton of people! I want to spread joy and happiness to the viewers so they also realize that life with Duchenne can be a great life!

Parent Project Muscular Dystrophy

JOIN THE FIGHT. END DUCHENNE.



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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