

PAAC PPMD ADULT
ADVISORY COMMITTEE

QUARTERLY
SPRING 2026



Take Charge Of Your Path...

TELL ELECTED OFFICIALS ABOUT DUCHENNE AND BECKER

Each year, the Duchenne and Becker muscular dystrophy community comes together in Washington, DC with a shared mission: to ensure that the voices of individuals living with Duchenne and Becker and their families are heard where policy decisions are made. This year, PPMD's Advocacy Conference once again demonstrated the extraordinary power of community advocacy in early March.

Families, adults living with Duchenne and Becker, clinicians, researchers, and partners from across the country gathered to share their stories, educate policymakers, and champion the federal investments that are driving real progress for our community.

You can help shape your own future by visiting www.parentprojectmd.org/advocacy. Let your members of Congress know your story and ask them for their support. The website gives you step by step instructions on how to raise your voice.



SPRING STUFF FROM OUR MEMBERS:

Devin Argall

Hello everyone! Here is a fun thing that I do in my free time: Snack Checks on TikTok. I review snacks that get sent to me from Amazon. When I get the snacks I try them and rate them then post to TikTok. I also share a positive quote in these videos such as: "Focus on the good things in life!"

I publish these videos to show people that I don't let Duchenne stop me from having fun. I also like to help others who may be having a hard time by making them smile.

I've met many Duchenne families on TikTok. If you'd like to check out my channel you can search: snackcheckwithdevin. I hope to see you and review YOUR favorite snack!



Adam Malone

I am a travel agent with a specialty in helping those with disabilities travel. I work for the company Adventures by Jamie. The most rewarding part of being a travel agent is knowing that I made a trip possible for my clients and helped create memories for them.

I am also the host of The Handicapable Podcast; focused on raising awareness about and advocating for the disability community. Our slogan is "changing the world, one story at a time." It is my goal in life to help others in the disability community, and what better way than raising awareness through this awesome show? I want for everyone to have a voice.

Visit www.hcmedia.org to learn more.



WE ARE LAUNCHING A LIVESTREAM!

KEEP YOUR EYES AND EARS OUT...

One thing that we are very excited about is called PAAC COMMUNITY CHATS. This is our new livestream on YouTube and other social media platforms! Open to everyone!

Each month, 4-5 PAAC members will go live to speak with the Duchenne and Becker community about issues such as traveling, DIY life hacks, mental health, staying social, finding your life passion, and more.

We would love to know what YOU would like us to talk about. During our sessions, we will take questions about life and keep a loose, conversational tone going so others may learn about how we see, hear and interact with the world around us and how each of us is active in society.

To find out more about PAAC COMMUNITY CHATS as well as times and dates of our streams, please email pmoeschen@parentprojectmd.org or check in with the QR code on page four.





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.



PAAC ADVISOR

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