

FOCUS ON...

PPMD'S 2025 ADVOCACY CONFERENCE



PPMD ADVOCACY IN WASHINGTON D.C.

THE BACKSTORY:

PPMD's advocacy efforts focus on advancing care and treatments for Duchenne and Becker by leveraging federal resources, building partnerships, and creating regulatory procedures and infrastructure.

Few rare disease health organizations have come so far and so fast in the realm of Congressional advocacy as PPMD. Since our advocacy efforts began in 2000, our community has helped to leverage over \$800 million in federal funding for muscular dystrophy research, with over \$600 million specifically for Duchenne and Becker.

MARCH 2025

Earlier this spring, we had 14 members of the PAAC, along with almost 200 people, visit the offices of our elected members of Congress.

This year, the PAAC took an important step as we encouraged all individuals living with Duchenne and Becker to lead the meetings by speaking from the heart about what it's like to live with a chronic illness and educate our elected officials about our lives.

We ask that Congress continue to support funding for research and treatments for Duchenne and Becker. We need EVERYONE to help raise their voices as one. YOU can be involved from home by visiting parentprojectmd.org and click on **ADVOCACY**.



PAAC MEMBER SPOTLIGHT

JONAH AND ELI PEREZ

Brother helping brother

We recently had a talk with twin brothers Eli and Jonah, who both live with Duchenne. As siblings, they have grown up sharing more than blood and DNA. Here are a few highlights of our conversation:

OK, let's get the boring stuff out there first. Who is older and who is better looking?

Jonah: I am...by one minute.

Eli: I am better looking.

Jonah: I am better looking.

Have there been any challenges to being a twin?

Jonah: Being a twin is great, but the hardest thing is the label: 'Oh, those guys are the twins in the wheelchairs.' Because we went to different colleges, I got to shake that and just be an individual.

Eli: I have the opposite opinion. I love being a twin and I have never had a moment like that, but I'm better looking.

Who has the faster power chair?

Eli: It depends on who charged or who gets off the line quicker!!!



What are some positives to both of you growing up while living with Duchenne?

Jonah: Being a twin kind of feels like playing catch with one another. Our parents kept us busy by having us play together. This helped us with isolation issues.

Eli: Something else that has been great is that if one of us has an issue with Duchenne, the other one knows exactly what we are living through. We also get along in general in terms of music, sports and activities. We are really close and always have been, so we can discuss all kinds of things. We can and do lean on each other for support.

Any pro tips for families reading this that have multiple diagnoses in the house?

Eli: It's no different than any family with multiple kids: everyone needs space. Treat everyone normal and give your kids responsibility. We had chores as kids and we still have tasks around the house that we can do now.

Jonah: We were told 'no', given rules to follow, and learned that we are not special because we live with Duchenne. Our parents treated us the same as everyone else. They still do.

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



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