



PAAC PPMD ADULT
ADVISORY COMMITTEE

QUARTERLY

WINTER 2025-2026

MEET THE 2026 PAAC OFFICERS

As we welcome 2026, we are excited to announce that the PPMD Adult Advisory Committee (PAAC) has grown to 70 members strong!

We work together to elevate the lives of individuals living with Duchenne and Becker through mentorship, outreach and education.

PAAC officer elections were recently held and we invite you to get to know our 2026 officers:

- President - Adith Thummalapalli
- Vice President - Ravi Lipman
- Secretary - Adam Wechsler (interim)
- Historian - Tyus Hill
- Officer at Large - Adam Wechsler
- Becker Officer (New Position) - Nevin Steiner

Please visit the PPMD PAAC page to learn more about the officers, the group, and connect with us. We are always open to speaking with families and individuals living with duchenne and becker to offer expert advice, tips, and share our lived experiences.

You can also connect with us on various social media platforms where you can ask us anything!



MARCH ADVOCACY: WE NEED YOU!

NATIONAL WORK:

Want to be part of history? Want to contribute to future progress in understanding, diagnosing, and treating Duchenne and Becker?

Register for PPMD's 2026 Advocacy Conference, March 8-10!!

In 2026, PPMD marks 25 years on Capitol Hill, turning lived experience into action and ensuring Duchenne and Becker muscular dystrophy are not just mentioned, but prioritized throughout the halls of Congress. Your voice has and will continue to drive progress forward.

The 2026 PPMD Advocacy Conference will take place March 8-10, 2026. Join us in Washington, DC by scanning the QR code below to register and get more information. #GOPAAC!!



To date, Duchenne Advocacy has resulted in...

- Over \$850 million in funding for Duchenne related programs at the National Institutes of Health, Centers for Disease Control, and Department of Defense.
- Duchenne being added to the Federal Recommended Uniform Screening Panel (RUSP) for newborns.
- An ever-growing Duchenne drug development pipeline with over 40 companies developing drugs for Duchenne.
- A standard of care established and updated for all those diagnosed with Duchenne, which has markedly improved the quality of life and extended lifespan.



PAAC MEMBER SPOTLIGHT

MARTIN HODAPP

Martin loves history and wanted to see the ruins around Mount Vesuvius near Naples, Italy. In the fall of 2025, Martin and his family traveled to Europe to fulfill this dream!

While seeing Lichtenstein, Switzerland, Austria, Germany and Italy, Martin kept a journal. Below is an excerpt. The link at the end takes you to Martin's blog where you can learn more about traveling internationally as a wheelchair user.

"Our first day in Rome started with a bizarre accident that we remember as the "Fall of Rome". We were being picked up by a pretty big wheelchair van for a guided tour of the Colosseum. The driver had just loaded my wheelchair in the back of the van and my parents were taking their seats in the front of the van. Suddenly, my dad's seat fell sideways out of the open door of the van, and my dad hit the pavement pretty hard. Fortunately, my dad, as a young man, had practiced the martial art of Judo and some of the reflexes are still there, so he executed a passable Yoko Ukemi to break the fall, which limited the damage to his right forearm. It turns out the van driver had forgotten to tell us that the seat was not attached. After that painful start, we had a very nice tour of the old Forum Romanum, with its temples and the Senate building, and then the Colosseum. Despite some ancient Roman pavement, both are adequately accessible, provided you have a guide to show you where the elevators are."



"The next day we decided to walk from the hotel to the Vatican. Since my dad's arm was still swollen and hurting, my mom did most of the wheelchair pushing. The sidewalks in Rome were so bad that we walked most of the way to the Vatican in the street, so cars and bicycles had to go around us. No problem, this is Italy after all. The Vatican is very crowded with tourists, and St. Peter's Square in front of the Basilica was being prepared for a major event, so that we had to ask a police officer again how to best access St. Peter. He was very helpful and within a few minutes, we were in via an elevator reserved for wheelchair visitors. St. Peter, being the largest Roman Catholic church, is really gigantic and elaborately decorated. Numerous volunteers are trying to control the crowds of tourists, and were very helpful for us."

Check out all of Martin's blog [HERE](#).

You can also email Martin at:
martinhodapp@gmail.com



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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