

WELCOME NEW MEMBERS!

THE BIGGEST PAAC CLASS EVER!



Congratulations to our 17 new PPMD Adult Advisory Committee (PAAC) members joining us in January of 2024. With the addition of these fine individuals from all over the country, the PAAC has reached 50 members for the first time in its 10-year history. 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. Read on to meet our new members and visit us online to see how we are changing the face of Duchenne and Becker muscular dystrophy.

MEET OUR NEW MEMBERS:

Does anyone live near you?

Our new members are happy to speak with anyone living with Duchenne or Becker, as well as female carriers. See below to find out where we are:

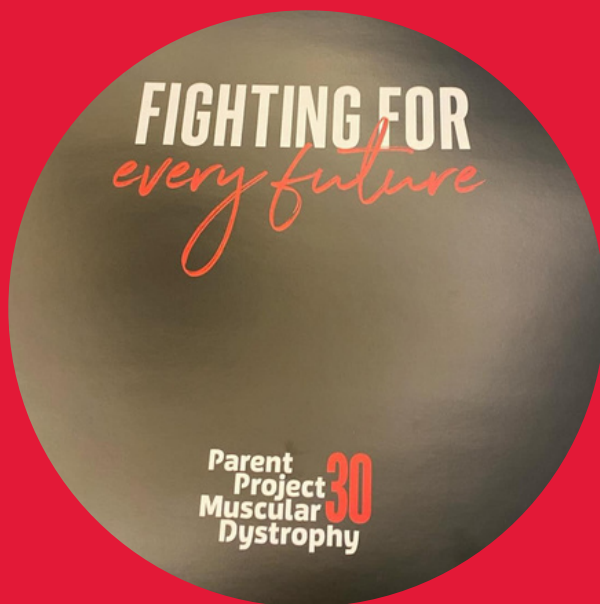
Burr Ridge, IL
Edgewood, KY
Grand Rapids, MI
Eau Claire, WI
Dallas, TX
Downingtown, PA
Oakton, VA
Orangeburg, NY
Wendell, NC
Hamilton, VA
Lacey, WA
Penfield, NY
Norwalk, CA
Firestone, CO
Odenton, MD
Missoula, MT

The class of 2024 ranges in age from 18-46. We have all kinds of varied job skills ranging from engineering, to computer software, to forestry and conservation. We have also been brought together by pledging our voices to work with the community to help better understand how to live your best life. We work, play, travel, date, and socialize. We have many things to share with you, but let's start with why we decided to join the PAAC:

"I want to become an activist that brings out the issues that the government and community hide from the public, like the shortage of personal care assistants."
-Josh S.

"I joined the PAAC to help gather the Becker community." - Reece L.

"I would love to help the community express their feelings through writing."
- Jon P.



MEET OUR NEW MEMBERS CONTINUED:

MEET GUI

Gui lives with Duchenne muscular dystrophy with his parents and younger sister in São Paulo, Brazil. Every year, he comes to the US for medical appointments in a Duchenne clinic and, since then, has started to have contact with Duchenne associations in the US and in Brazil. Gui has joined the PAAC with the goal of making new friends with muscular dystrophy, sharing experiences, and helping younger people with Duchenne with the daily challenges and living life to its fullest. He is also working to create a group in Brazil similar to the PAAC and on other advocacy projects for Duchenne in Brazil. Gui has traveled to more than 10 countries with his family, he likes to try new food and places, and is really into playing video games.

“I have learned a lot from having Duchenne. I have learned to be resilient and open to changes. As with many disabilities, Duchenne brings challenges every day, however, it has helped me to build my character and become who I am today!” - Gui P.

“Disability is part of nature and I like to think of it in that way as well, where I am beautiful just as nature intended for me to be and I do things differently and that is absolutely wonderful.” - Cory S.

“Despite our disability, our lives are not without value and purpose.” - Elliott J.

“My main goal in life is to be a successful person which I define as being able to get most things I want with minimal difficulty.” - William J.





Parent
Project
Muscular
Dystrophy **30**

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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