



## FOCUS ON... **RAISING ONE VOICE**

Recently, several PAAC members who are living with Becker muscular dystrophy attended the 2nd annual Becker Education and Engagement Day (BEED), which took place in sites across the country: Florida, Pennsylvania, Missouri, Texas, California, and Washington.

This year's BEED event saw more than 300 people gather to discuss topics related to living a full life while managing the condition. Nevin Steiner, Mike Voto, and Charlie Riesebeck spoke onstage in Orlando about the lived patient experience and other speakers covered cardiac care, building your care team, benefits of physical therapy, mental wellness and planning for the future.

If you are reading this and live with Becker, please reach out to the PAAC to connect with people that are raising awareness of living with Becker.



# PROJECTS AND NETWORKING

## PAAC MEMBERS ARE...

Working outside of our network to make a positive difference in the lives of kids and adults living with Duchenne and Becker, as well as female carriers of the condition. In addition to roles in the PAAC, many members have leveraged local and national connections in order to reach a wider community. Here's some things we've been up to (not an exhaustive list):

## SPEAKING & UNIVERSITY ENGAGEMENTS

Keenan G: PPMD End DMD Tour - Denver

Jonah P: PPMD Together - Seattle

Colin W: TREAT-NMD Symposium, Boston

Ravi L & Alan C: World Duchenne Day panel, Jett Foundation

Alan C: All Wheels Up Global Forum, Boston

Nevin S, Charlie R, Mike V: Living with Becker panel, BEED Orlando

Dhruv P: Enhancing Diversity panel, The Ohio State University

Kyle F: Disability Forum panel, Hope College

Ravi L: Patient Advocacy minor, Notre Dame

Adith T: Engineering Ethics course, University of Maryland - College Park

Kyle VH: Robotic Arm engineering project, Virginia Tech

PAAC: Various PPMD panels & events

## PATIENT ADVISORY

PAAC: ACTION network for cardiac treatment in DMD/BMD, various PPMD committees

Mallory D, DJ: DoD CDMRP

Adith T, Colin W: DoD CDMRP, TREAT-NMD, C-Path Institute

Colin R: DMD rep, PPMD Advisory Board

Buddy C: FDA (patient advisor)

## ORGANIZATIONAL PARTNERSHIPS

Jenn B: PAAC - Female Carrier Chapter (Founder, new launch)

Gui P: PAAC - Brazil Chapter (Leader)

Tyus H: Partners Resource Network

Ryan R, DJ: Duchenne Life podcast, Family, Friends and Duchenne

Ravi L: Dyne Rare Disease Day

Colin W, Adith T: PPMDItaly & MDIreland

Keenan G: YAR committee, EveryLife Foundation

Anthony C: Little Hercules Foundation

Nevin S: MDA, The Handicapable Podcast, BEED

Alan C: All Wheels Up (VP), The Handicapable Podcast



# GOING GLOBAL IN 2025

## EXPANDING PAAC FOOTPRINT

In March 2024, PAAC Brazil was founded as part of an international expansion of the PAAC. Inspired by the PAAC in the United States, the Brazilian chapter has quickly grown to 44 members from over five states across the country.

Like the US PAAC, the goal of PAAC Brazil is to provide a supportive space where members can share life experiences, build meaningful relationships, and collaborate on impactful projects. So far, the group has held several online meetings to discuss a range of topics, including adapted sports, disability rights and laws in Brazil, and global developments in treatments for Duchenne and Becker, as well as how to access new medications within the country. Members, aged 18 to 50, come from diverse backgrounds, including journalism, finance, nutrition, programming, and international relations.



One of PAAC Brazil's first major projects was a video for World Duchenne Awareness Day on September 7th, where members shared personal stories, highlighting their abilities and happiness beyond physical challenges. The video aimed to raise awareness and show how individuals with Duchenne and Becker can live happy lives.

The success of PAAC Brazil and PAAC here in the US has sparked the creation of new groups in the Netherlands, England, Italy, and Ireland. Looking ahead, plans for a Global Duchenne Adult Group will further integrate this international community. Together, these efforts will help raise global awareness and strengthen the fight for our cause.

As we look toward 2025, PAAC's reach is truly going global!



PAAC Brazil members during Brazilian Power Soccer Championship



# 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](http://www.parentprojectmd.org/paac)



## PAAC ADVISOR

Patrick Moeschen  
[pmoeschen@parentprojectmd.org](mailto:pmoeschen@parentprojectmd.org)