

**PAAC** PPMD ADULT  
ADVISORY COMMITTEE

**QUARTERLY**  
**SUMMER 2025**



**Las Vegas...**

# **THAT'S HOW WE ROLL!!!**

In June, we gathered at Caesar's Palace Las Vegas for PPMD's 2025 Annual Conference. More than 80 adult individuals living with Duchenne or Becker attended "PAAC TRACK" either in person or virtually. We love getting together to socialize, talk life and grow friendships, but this year, we unleashed PAAC on the whole conference! We had our own resource fair, many sessions and social gatherings, as well as community slides that featured projects and businesses that have been developed by the adult Duchenne and Becker community.

We also presented our low-cost robot arm (beta) that we are developing with Virginia Tech engineers that will attach to a power chair to push elevator/door buttons as well as help with drinking. Read further into this newsletter to learn how we are raising our voice to become the world changers that we want to see. Join us!  
#GOPAAC





# PAAC SESSIONS FOR EVERYONE

This year, we held the following workshops for the teen & adult Duchenne and Becker community:

- Technology hacks
- Hotel and air travel with a wheelchair (tips & tricks)
- Life planning: legal and financial decisions
- Finding and acting on your life's passion
- Mental health and wellness
- Coping with the loss of physical ability
- Relationships and intimacy
- Transition to "adulting"
- Community spotlight: Conrad Reynoldson, WA Attorney

We also featured a PAAC-run resource fair that was open to all conference attendees! Members of the Duchenne and Becker community presented at tables and spoke about:

- Service animals
- Starting a business
- Adaptive driving
- Navigating state benefits
- The PAAC robot arm project partnership with Virginia Tech



# THE VIRGINIA TECH PROJECT

Over the past two college semesters, the PAAC worked with five Virginia Tech mechanical engineering students to develop a low-cost robotic arm as part of a senior capstone project funded by PPMD. Keith Van Houten, father of PAAC member Kyle Van Houten, helped to organize the project.

The PAAC worked with Keith and the engineering students through all steps of the project, holding meetings every two weeks to focus on planning, designing, and trialing the robotic arm design. Once the prototype was developed, the students visited PAAC President Colin Werth's house in Virginia to allow him to test the prototype and give feedback. Based on Colin's feedback, the students made changes that included an easier to use joystick and arm rest padding.

Colin brought the robotic arm on his cross-country road trip to display at PPMD's 2025 Annual Conference in Las Vegas.

The arm was presented during the PAAC resource fair and received funding from PPMD to continue the project for another year. We will improve the usability and functionality of the robotic arm and develop it to be built from a kit. If you have engineering skills and are interested in helping with the project over the next year, please reach out to us!



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



**Upcoming: TWEEN TRIVIA and GAMES**  
**August 21 | 6:30-7:30 PM EST**  
**Register on our Facebook page in August**

## PAAC ADVISOR

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