

**PAAC** PPMD ADULT  
ADVISORY COMMITTEE

**QUARTERLY**  
**SPRING 2024**



**FOCUS ON...**

# PPMD'S ADVOCACY IN WASHINGTON, D.C.

In March 2024, more than 100 individuals from around the country gathered in Washington, D.C. for PPMD's annual Advocacy Conference.

Through the efforts of PPMD, you, too, can meet with your members of Congress and/or their staffers to discuss what it's like to live with Duchenne and Becker. Many PAAC members participate, and we would love for you to join us by becoming a PPMD Advocate. More information is below.

Learn how to get involved with Duchenne advocacy! Advocacy takes many forms - from joining us in Washington, D.C., to getting involved from home through virtual advocacy. By signing up to be a PPMD Advocate, you will receive emails throughout the year about how you can take action right from home, as well as hear about opportunities to advocate in person with your elected officials.

Visit [engage.parentprojectmd.org](https://engage.parentprojectmd.org) to learn more.



# PPMD'S 30TH ANNUAL CONFERENCE

## A CELEBRATION

This year's Annual Conference in Orlando celebrates 30 years of progress, community, and resilience. The PAAC is working hard for our community to make this conference one for the books!

Each year, we poll the community to understand the issues that are most important to adults living with Duchenne and Becker. We find that we are not alone in our fears, worries, strengths, problem solving, and our desire to be treated the same as everyone else.

Our Teens & Adults Track agenda appears in full on the next page, but here are some topics we will cover: life after high school, friendships, relationships, sex, asking for help, as well as privacy, and much more. All of our sessions will be streaming live! Visit [www.parentprojectmd.org/conference](http://www.parentprojectmd.org/conference) to register and join us either in-person or virtually. Your voice and expert point of view is needed.

## THE PAAC BOOTH - LIVE!

If you are coming to Orlando in June, the PAAC would love to meet you in-person and help you learn about how to live your best life!

On the evening of Thursday, June 27th, the PAAC will have a booth at the Resource Fair. Stop by to meet and visit with us for free swag, a PAAC video, games, trivia, and more. You can even take a selfie with a PAAC member and spread awareness on social media by posting it with #GOPAAC!



# CONFERENCE PLAN FOR ORLANDO 2024

## PAAC SESSIONS WILL COVER:

Building social skills, life after high school, sex, intimacy and privacy, asking for help, working with caregivers, and much more.

### June 26:

6-9 PM PAAC Social: Live Music and Food!

### June 27:

9 AM Breakfast with the Tweens

2 PM Living with Becker

6 PM PAAC Booth: Ask the Experts!

8 PM Duchenne and Marriage

### June 28:

9:30 AM How Do I Ask For Help?

10 AM Let's Talk About Sex (for ages 18+)

2:30 PM Duchenne Carriers and Females

7 PM PAAC Movie Night (for ages 18+)



### June 29:

9:30 AM Finding Your Life's Passion

10:45 AM What Do I Do After High School?

12 PM Employment and Resource Fair

4 PM Looking at 50 with Duchenne

5 PM Im-PAAC-ting the Future: Main Stage  
PAAC Presentation!





# 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

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