

PAAC PPMD ADULT
ADVISORY COMMITTEE

QUARTERLY
SUMMER 2024



FOCUS ON...

PAAC AND THE COMMUNITY

We continue to hear from families all over the country who live with Duchenne and Becker or are carriers of the condition. One of the things that we are frequently asked is: "How am I supposed to plan for my future, when I don't know what's going to happen to me, or how hard this is going to get?"

We hear you and we've been there. While we don't have any magic, what we do have is community, connection, and culture. Through our experiences, we can offer support and advice to help guide you in accessing the care and resources needed to live your best life.

As you get older, it's important to start planning for your life and future as you would like it to be. Set goals, dream big and connect with people who know about your condition. Life will not be "traditional" but so what? You have stuff to accomplish. Get started!



CONFERENCE 2024 RECAP OF OUR TRACK

OUR OWN “CLUB HOUSE”

Held in Orlando in June, PPMDs’s 30th Annual Conference saw the PAAC take a larger role in planning, implementing, and presenting a well-rounded program aimed at providing our community a deep bag of tricks to live your best life.

For the first time, the Teen/Adult track was held in one space the entire time and we were able to establish a “club house” atmosphere where people could come and go as they pleased, make new friends, strengthen old friendships, swap stories, knowledge, information, or simply talk life. We had live music and comedy at our welcome social and sessions focusing on life with muscular dystrophy.

CONFERENCE SESSIONS:

In order to raise our voice in the strongest way, we developed sessions that focused on topics that are important to the community.

Session I - Socializing and Conversation Skills

Session II - Living with Becker

Session III - Ryan Russell Talks Marriage

Session IV - Asking for Help/Caregiving

Session V - Intimacy and Sex

Session VI - Jenn Bauer Carrier Conversation

Session VII - Mental Health - Buddy Cassidy

Session VIII - With Duchenne, You Can! - Dain Wiseman

Session IX - Finding Your Passion

Session X - Adventures in Duchenne - Jacob Gapko

What do you want to see next year? Email and let us know!



SPOTLIGHT ON POWER SOCCER

What is power soccer?

The sport is played in on a standard-sized basketball court. Each team is allowed four players on the court at one time, including the goalkeeper. A match consists of two 20-minute periods.

The U.S. Power Soccer National Team has competed independently since 2007, and officially joined U.S. Soccer's Extended National Team program in 2022. Power Soccer is the first competitive team sport developed specifically for powerchair users. According to powersoccerusa.org, there are currently more than 250 teams worldwide. We recently spoke with PAAC members Jack, Kyle, and Austin about their love for the sport. To learn more, and find a team to join, please visit www.powersoccerusa.org

How did you find out about power soccer?

Kyle: I had heard about power soccer from other Duchenne guys and it sounded very cool. Also, our local rehabilitation hospital was offering a clinic to try it out.

What made you want to play?

Austin: I wanted to play power soccer because I have always been competitive and sports are a good way to be competitive and compete at the same level as other athletes. Powersoccer was what made that possible.

Do you use a special wheelchair for this?

Jack: We use a special chair just for power soccer. The chair is called a Strike Force chair which is rear wheel drive. This enables a player it to have extremely fast turning ability.

What advice would you give someone that is thinking about playing but is not sure?

Kyle: If you are a sports minded or like sports then this is for you. I recommend that everyone give it a try. It's a great opportunity to play in a competitive atmosphere.

Austin: I think it's important for those who are considering playing that no matter how severe your disability is it is possible to play Powersoccer. I've played against players with vents, that have to fully lay flat or even lay on their stomach.





Parent Project Muscular Dystrophy 30

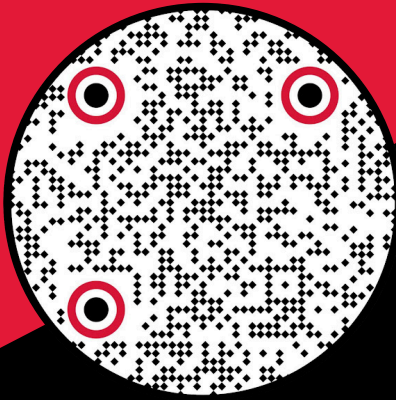
ABOUT PPMD

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



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