PAAC PPMD ADULT ADVISORY COMMITTEE

QUARTERLY

SUMMER 2023

FOCUS ON...

PPMD'S ANNUAL CONFERENCE

In June, the Duchenne and Becker community traveled to Dallas Texas for PPMD's 29th Annual Conference. This was the largest conference in the history of PPMD, with over 1,000 people partcipating in talks focused on research, care, and life with Duchenne and Becker. The PAAC presented sessions on mental health, asking for help, as well as social connections, intimacy, and romance. We also had a PAAC table at the vendor fair, with our own PhD Ryan Russell speaking and signing his novel "RECTIFY."

PAAC MEMBERS REACT TO THE CONFERENCE:

"This was my first time attending. It was awesome to meet so many people who understand DMD." - Thomas Canter

"It was cool to hang out late night with all of my friends." -Ravi Lipman

"The conference is a time to see lifelong friends, and make new friendships as well." -Mike Voto

PAAC Happenings...

An Interview With...

From being a PAAC member since 2015. What has inspired you to continue your role?

I'm proud of what the PAAC has accomplished for the Duchenne and Becker community and PPMD. Together we've helped PPMD connect with teens and adults in ways they never could before. What's inspired me to continue is knowing I can make a difference fighting Duchenne and Becker.

What do you see the PAAC doing in ten years' time? Are we still a thing?

I think the PAAC will be doing much more at this time. We have a ton of stuff we want to do with pharma companies, doctors, and other advocacy organizations that are just getting started. We'll be more involved in advocacy and probably have a few bills passed that will help all adults with disabilities. The teen and adult track of PPMD's conference will be much bigger and help people with DMD. There's so much more we'll be doing in terms of college, creating a career, dating, handling benefits, money, independence, and managing your healthcare.

Can you give us a few examples of how the PAAC has changed over the years?

As PPMD has evolved over the years so have we. When we first started there were no approved treatments and now there are 5 with more on the way. Adults were dealing with just going to college but now we're thinking about careers and marriage. At first we did much more advocating on Capitol Hill and in the government outside of the advocacy conference because we had more people located around DC like Ben Cumbo, Buddy Cassidy, and Mario Damiani. Now we're a nationwide group with people around the country so we're focusing on other areas. We're focused throughout the year on conference and have a much bigger role organizing the teen and adult track. It's an exciting time for our community with so much being done and gene therapy becoming a reality and we can't wait to see how we continue to grow.

Many younger readers may be interested in joining the PAAC when they turn 18. What advice would you give them about joining us? Is it worth it?

The PAAC is the perfect place to get involved in the DMD community and make friends with others fighting DMD. It's absolutely worth it because you'll be doing meaningful work to help PPMD. If you think you have something to contribute, definitely apply in the fall.

What does the PAAC offer to the entire Duchenne and Becker community?

The PAAC offers a way for adults with Duchenne and Becker to help the community. There's so much we each want to do to help the community, but can't do by ourselves. By uniting together and with PPMD, we're able to do so much more than we could've done individually. We're each always constantly coming up with new projects to pursue and unite to accomplish them. If it can help someone with Duchenne or Becker live their life easier, we'll work to get it done.

PAAC MEMBER CONNECTION TO COMPANIES

All Wheels Up

Someday soon, you may be able to remain in your wheelchair on an airplane!

All Wheels Up (AWU) is the first not-for-profit organization in the world to fund research and development for a “wheelchair spot” on commercial aircraft. We work with airline carriers and aircraft manufacturers to make airplanes wheelchair accessible for the millions of people who depend on them for mobility and safe seating.

Michele Erwin started All Wheels Up in 2011 when she was traveling to Disney World with her son Greyson who has SMA and saw how difficult it was to travel as a wheelchair user.

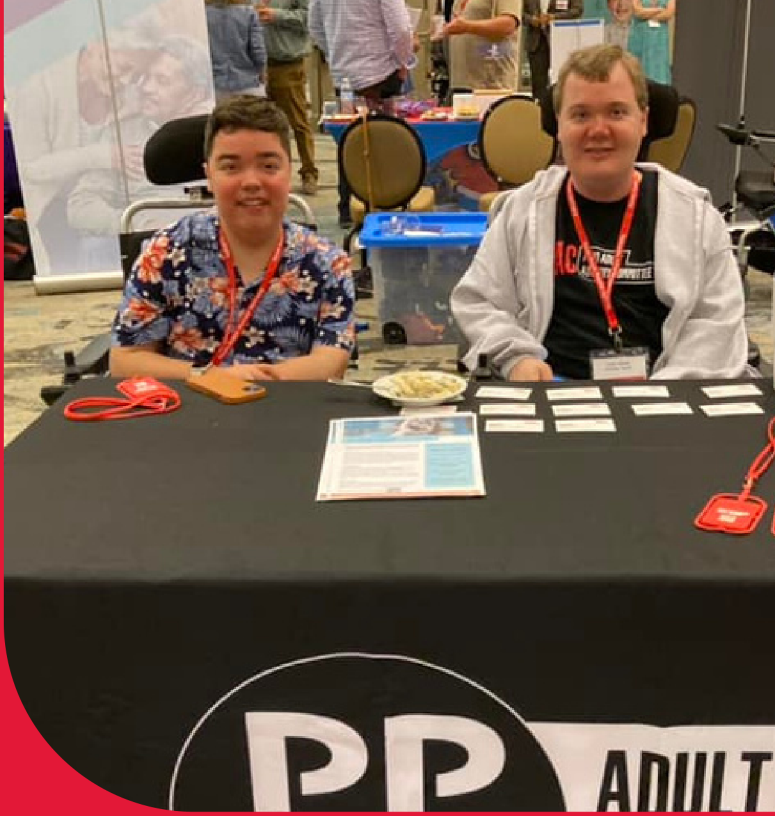
All Wheels Up started the conversation of a wheelchair spot on planes. We could not be more proud of the progress made since 2011. From the very first animation (2014), First proof of concept (2016), and first federal funding for a wheelchair spot on planes (2018), our work has gained so much exciting momentum. The work of All Wheels Up also led to a feasibility study in 2021 that proved there were no design and engineering challenges so formidable that they call into question the technical feasibility of an in-cabin wheelchair securement system and the value of exploring the concept further.

Alan has been working as All Wheels Up Vice President since 2014 and some of his responsibilities include:

- Serving on the Advocacy, Wheelchair Advisory, Communications, and Development Committees
- Lobbying Congress
- Presenting about our work and flying with a wheelchair on webinars hosted by disability nonprofits and pharma companies

HOW CAN OTHERS BE INVOLVED?

Disabled Individuals can get more involved by following us on social media, spreading the word about our work to their friends and family, hosting fundraisers to support our research, working group, community programs, and advocacy, or donating to us. We post about everything happening in accessible air travel and how people can help. We want everyone in the disability community to know about all the progress. Visit and learn at www.allwheelsup.org



ABOUT PPMD

Parent Project Muscular Dystrophy 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 Duchenne patients and in research that will benefit future generations. Our advocacy efforts have secured hundreds of millions of dollars in funding and won five 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

The 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 Parent Project Muscular Dystrophy (PPMD).

Check us out and GET INVOLVED at:
www.parentprojectmd.org/paac

PAAC ADVISOR

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