



PAAC QUARTERLY



About Us

PPMD's Adult Advisory Committee (PAAC) amplifies the teen and adult voices of Duchenne, Becker, and carriers as an extension of Parent Project Muscular Dystrophy (PPMD). The PAAC takes a holistic approach to advocacy by 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.

Meet the PAAC

- | | |
|---------------------|-------------------|
| Adith Thummalapalli | Jack Ridolphi |
| Thomas Canter | Charlie Riesebeck |
| Anthony Castle | Ryan Russell |
| Alan Chaulet | Nevin Steiner |
| Sean Crosby | Steve Teal |
| Mallory Dupree | Kyle Van Houten |
| Taylor Ferrell | Mike Voto |
| Jake Fritz | Adam Wechsler |
| Michael Gaglianone | Colin Werth |
| Keenan Gluck | Jake Wesley |
| Jacob Hill | Dain Wiseman |
| Jenn Bauer | James Wood |
| DJ Kimball | Chris Younkin |
| Austin Leclair | Suhail Zuveri |
| Ravi Lipman | |
| William Ma | |
| Patrik Nabelek | |
| Dhruv Prasad | |
| Ethan Pyles | |
| Cal Quitzau | |
| Jordan Reidenberg | |
| Colin Rensch | |

What's Going On?

Our 36 members are located throughout the United States and are working on a number of projects:

- Sharing life hacks, tips & tricks in all areas: clothing, self care, travel, and more in the new PPMD Knight Hacks hub. You can VISIT the hub and share hacks that work for you.



ONE DAY YOU'LL
LOOK BACK
AND THANK
YOURSELF FOR
NOT GIVING UP.

PAAC PROJECTS

- ❑ We network with other Duchenne non-profits, as well as CureSMA and hold online socials together.
- ❑ We follow bills in Congress that affect our lives.
- ❑ We mentor younger individuals on topics such as school, relationships, privacy and boundaries as well as social isolation, life after high school and adulting with Duchenne/Becker.
- ❑ We work with industry to make sure the patient voice is heard when designing clinical trials
- ❑ We are open to talk about mental health and how sometimes it's ok to not be ok.
- ❑ We are working to make air travel easier for wheelchair users.
- ❑ We play fantasy sports.
- ❑ We are here just to let you all know that NO ONE is alone living with Duchenne or Becker

MEMBER SPOTLIGHT

ATLANTA BRAVES FAN

MUSICIAN



GET IN TOUCH

PAAC PRESIDENT: Steven Teal

Steven grew up in the small town of Thomaston, Georgia. He was diagnosed with Becker muscular dystrophy when he was 10 years old. After high school, Steven attended Georgia Southern University where he received a B.S. in Sport Management with a business minor. He then went on to attain a M.A. in Communication from Liberty University. Currently, Steven resides in Statesboro, Georgia with his wife Aly and their three children.

Steven is a writer for The House That Hank Built, which is a site that is 100% dedicated to The Atlanta Braves. In addition, he helps to produce two podcasts: "Beaneater Buzz" (about MLB) and "Teal Death Do Us Part", which he co-hosts with his wife Aly, focusing on their interabled relationship, marriage through triumph and challenges.

In his spare time, Steven watches sports, plays bass guitar, collects vinyl records and attends concerts with friends. Metal is his favorite genre of music, but he listens to anything!

Steven also mixes front of house sound and music for his church each week as well as editing other media elements needed from time to time.

Steven is proud to be a member of the PAAC, as he wants to ensure that future generations have access to the care that they need when it comes to Becker and Duchenne muscular dystrophy. He welcomes your comments, messages and correspondence.

Please get in touch if there is anything the PAAC can help you with, or simply to say hello.

Email: steventeal09@gmail.com

Connecting you with hope, help, and hype!

The PAAC is open to new members each fall, however if you missed the deadline, or are under the age of 18, you can still be involved with us.

We offer bi-weekly socials on Zoom as well as a Discord game server. In addition to social media and the PAAC CHATS app, PAAC members are happy to connect with you about Duchenne or Becker to talk with you about life, school, the future, friendships, relationships, social skills, getting organized, arranging privacy for yourself, educating others, navigating difficult situations, and anything else you can think of. No one is alone.

Be sure to check us out:

parentprojectmd.org/paac

Connect with us on Instagram, Facebook, and Discord. We also hold biweekly socials every other Sunday night at 8PM EST. Hosted by PAAC member Colin Werth. To join the social, email Colin for the link: cjrailstar@gmail.com

Fun Fact: Guillaume Duchenne was a French doctor and the first medical professional to use a biopsy to study muscle tissue. He lived from 1806-1875, and is credited with giving DMD its name.

Bonus Fun Fact: Peter Becker was a German neurologist who lived from 1908-2000. In 1955 he published an article leading to Becker muscular dystrophy being named for him.

Contacts

PAAC ADVISORS

Patrick Moeschen

pmoeschen@parentprojectmd.org

Jamie Jones

jamie@parentprojectmd.org



Parent Project Muscular Dystrophy
JOIN THE FIGHT.
END DUCHENNE.