

ALL ABOUT BECKER EDITION



Those of us living with Becker muscular dystrophy (Becker) have often felt that progress in understanding and addressing our condition lags behind the progress we've seen in Duchenne. However, thanks to advances in research, education, and the efforts of organizations like Parent Project Muscular Dystrophy (PPMD), we are seeing developments in research and clinical trials, with a renewed focus on improving the lives of individuals with Becker.

To those unfamiliar, Becker can present as an invisible disease. However, nothing could be further from the truth. While those living with Becker may have limited symptoms early on, the disease is progressive and occurs with more than physical symptoms. From troubles with stairs, walking long distances, getting up from a seated position, and standing for a long period of time, there can also be anxiety and fear of falling, which impacts your daily life.

Becker progresses differently for all living with the disease. Coping with the unknown of the future and the increased need for adaptive equipment and assistive mobility devices can be challenging. However with increased awareness and community peer support, self-acceptance & advocacy has become easier each day.

Being involved in this community and preparing for the future is key. By establishing and maintaining a care team and community support, the better quality of life you will have. It's important that you do everything you can to live your life to the fullest, and don't be afraid of living productively with Becker muscular dystrophy.

Sincerely,
PAAC Adults living with Becker

BECKER FACTS

Becker impacts everyday life just like Duchenne

There are many challenges individuals living with Becker face everyday. The future is uncertain, as it is with all types of muscular dystrophy. Here are a few things that go through our minds, and what we want society to know:

- Fear of falling = All the time
- Using stairs = Nearly impossible
- Getting up from any chair = Struggle
- Getting off the toilet = Struggle
- Getting out of bed = Struggle
- Opening doors = Nearly impossible
- Bending down and getting back up = Struggle
- Getting up from the floor = Struggle
- Planning ahead every day = Anxiety

“At my age (15), no one can tell that I’m living with Becker, but I can feel it!” -Max

“Just because I can walk on Monday, doesn’t mean I can walk on Tuesday.” -Carter

“Living a full life with a little bit of ups and downs along the road!!” -Mike



MEMBER SPOTLIGHT

NEVIN STEINER



Living Life With Becker

How has being a member of the PAAC helped you become an advocate for Becker?

I joined the PAAC in January of 2023. I was already advocating for muscular dystrophy at that time, but the PAAC took my voice to the next level. I felt more empowered to use my voice to advocate for change. The PAAC opened me to more doors of advocacy. I don't do this just for me, but to improve the lives of all living with muscular dystrophy, and for my family as well.

What would you say to Duchenne/Becker individuals that are thinking about joining the PAAC in 2024?

Individuals who are thinking about joining the PAAC, jump right in to improving your life and the lives of everyone in the community. The reward of knowing you are making a difference and changing people's lives, will never grow old!

To help the community shine a light on living with Becker, what is one thing you would tell the world, if you had everyone's attention?

Fact: Becker impacts everyday life just like Duchenne does. We all face daily challenges, and we are in this together. Becker isn't an after thought anymore. The more people that join in the fight to end Becker and Duchenne, the sooner it can become a reality.

In regards to care - To clinicians, we are the Becker/Duchenne community, we are the experts: ask us what we need! You have the resources to guide us as we live our best lives.

Tell us a little bit about how you were diagnosed with Becker:

I was diagnosed with Becker muscular dystrophy at the age of six, and that is early, especially for the late 80's. My parents were aggressive in seeking doctors that could explain why I walked late and had trouble with stamina at a young age walking more than five minutes.



ABOUT PPMD

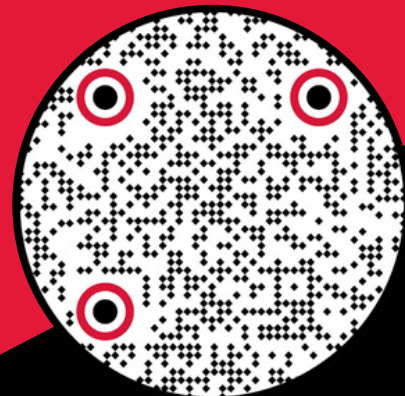
Parent Project Muscular Dystrophy (PPMD) fights every single battle necessary to end Duchenne. We demand optimal care standards and ensure every family has access to expert healthcare providers, cutting edge treatments, and a community of support. We invest deeply in treatments for this generation of patients and in research that will benefit future generations. Our advocacy efforts have secured hundreds of millions of dollars in funding and won seven FDA approvals. Everything we do—and everything we have done since our founding in 1994—helps those with Duchenne live longer, stronger lives.

Parent Project Muscular Dystrophy JOIN THE FIGHT. END DUCHENNE.

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



PAAC ADVISOR

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