BECKER EDUCATION & ENGAGEMENT **DAY**

SATURDAY · SEPTEMBER 27TH · 2025

The Becker Education and Engagement Day 2025 was a huge success!

The event gathered over 415 people across the country at locations in California, Washington, Missouri, Pennsylvania, and Florida! The event shared relevant information to the Becker community regarding Becker care considerations, cardiac care, exercise and physical therapy, and practical resources for daily living with Becker.

People from across the country attended BEED, with 37 states represented across locations! This was the largest Becker specific event of its kind!



A huge thanks to all of the attendees, speakers, and community members for making this event possible.

We hope to see you again next year!

If you have not done so already, please complete the <u>post-event survey</u> to help us improve BEED in the future!



Presentations covering content from the event will be shared on the <u>BEED webpage</u> by the end of the month, and you will receive an email once they are available!



Don't forget to participate in Becker Awareness Week, October 5th-11th by sharing your story, and don't forget to use #BeckerAwareness when you post on social platforms!



BEED 2025 Attendees & Speakers



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<u>Connect</u> with the ImagingNMD team for updates in Becker muscular dystrophy care developments, exclusive research insights, and information on our Becker observational study. Join in the effort to build a community where you are the most important team member. Follow us on our <u>social media channels</u> for resources like <u>appropriate exercises</u>, <u>cardiac care</u>, and for updates on our Becker muscular dystrophy natural history study.



Are you living with Becker muscular dystrophy?

If you're interested in learning more about the vamorolone clinical trial for BMD (<u>ClinicalTrials.gov NCT05166109</u>), we'd love to connect with you. For more information, please contact Gabi Niizawa at 412-383-9775 or email: niizawaga@upmc.edu

If you're interested in scheduling a clinical appointment with a neuromuscular specialist in Pittsburgh, Pennsylvania, please contact Rebecca Molczan at 412-692-6748 or email: molcrs@upmc.edu. Lead adult neurologist is Dr. Paula Clemens.



Patients with muscular dystrophy can request clinical appointments with the **UFHealth Pediatric Neuromuscular Clinic** by calling 352-294-5757. Please have referrals faxed to 352-627-4415. For pediatric research inquiries, please email byrneresearchteam@peds.ufl.edu.

Patients with muscular dystrophy can request clinical appointments with the **UFHealth Adult Neuromuscular Clinic** by calling 352-294-5400. Referrals can be faxed to 352-627-9867.



Edgewise is a proud supporter of BEED! At Edgewise we are developing Sevasemten, a daily oral pill designed to prevent the muscle injury caused by muscle contraction that occurs in daily activity in individuals with Becker. Sevasemten is designed to limit muscle damage and aims to prevent the functional decline that accompanies disease progression in Becker. Learn more about how muscles work in individuals living with Becker by watching this video "MuscleTown". To stay connected, subscribe to our Edgewise community newsletter.

Join the movement to connect the Becker community.

For those living with Becker Muscular Dystrophy, a supportive community fosters hope, understanding, knowledge, and connection. Participate in our Power of Community Campaign to support building a bigger and better connected Becker community!

*Sevasemten has not been approved by any regulatory authority and the safety and effectiveness have not been proven

Sponsor Resources

Parent Project Muscular Dystrophy

PPMD fights to accelerate research, raise our voices to impact policy, demand optimal care for every single family, and strive to ensure access to therapies. Register with PPMD to be kept up to date on our efforts in research, advocacy, and care, and receive our monthly newsletter. Join The Duchenne Registry to advance research and treatments for Becker muscular dystrophy.

Save the dates to join PPMD for a two-part webinar series all about Becker muscular dystrophy! We'll get started on <u>Thursday</u>, <u>October 16</u>, at 1:00 <u>PM EST</u> with a discussion on neuromuscular care and genetic considerations. Then, on <u>Wednesday</u>, <u>November 13</u>, at 1:00 <u>PM EST</u>, we'll dive into cardiopulmonary care in Becker. Stay tuned for registration opening soon.



Join MDA to stay connected with a variety of programs, supports, and educational opportunities throughout the year. MDA's mission is to empower the people we serve to live longer, more independent lives.

Check out our Becker specific resources, like our <u>BMD Fact Sheet</u> and our guide for <u>At-Home Physical Therapy Exercises for Becker</u>. To locate an MDA care center near you click here. For additional resources and support, check out MDA.org or call our resource center at 1-833-ASK-MDA1 (1-833-275-6321).

Join the MDA Community! https://www.mda.org/join-mda



Adults living with muscular dystrophy can request clinical appointments with the University of Washington Adult Neuromuscular Clinic by calling 206-598-4295. Referrals can be faxed to 206-598-2813.



Patients with muscular dystrophy and carriers can schedule appointments with the UC Davis Neuromuscular Clinic by calling 916-734-7041 option 4. For research inquiries please contact the <u>Neuromuscular Research lab</u> at 916-734-5057. You can also follow the research lab on social media, check out their <u>Facebook</u> and <u>Instagram</u>.

Want to connect with others living with Becker?

If you are an individual living with Becker (18+) and want to connect with others, join the <u>Becker Discord channel</u> to chat with others living with Becker in a closed online chat platform. The Becker Discord channel was created by individuals in the Becker community as a way to stay connected and chat with one another.



You can download the Discord app on Android and iPhone.

Are You Interested in Building a Becker Community?

We are looking for community members that want to help build out the 2026 Becker Education and Engagement Day and build a Becker community! If you are interested in lending your expertise, skills, and voice to building the future BEED efforts please fill out this short information form. This information will be shared with meeting organizers and sponsors for the purposes of BEED 2026 planning.

VIEW SURVEY

Our BEED 2025 Sponsors

























