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Becker muscular dystrophy is a serious health condition.

Becker muscular dystrophy is a genetic disorder, predominantly affecting males, that can impact your everyday life by limiting your ability to walk or climb stairs as well as cause muscle fatigue and pain. Disease progression can occur at any age, and once decline begins muscle damage is irreversible. Some studies show what this might look like over time:

- In one study, almost half of those living with Becker lost the ability to run in their early 30's¹
- In another study, some people living with Becker started using a wheelchair, either part-time or full-time, in their mid 30's²
- Several studies suggest that about 30-40% of individuals living with Becker were unable to walk at all in their 40's and 50's^{1,3}

Help the Becker community and spread the word about the seriousness of the disease!

¹Bello L, et al. Sci Rep. 2016;6:32439. ²Nakamura A, et al. Ann Clin Transl Neurol. 2023;10(12):2360-2372. ³Clemens PR, et al. Muscle Nerve. 2020;62(3):369-376.

The Second Annual Becker Education and Engagement Day is Coming Up!

This September, there will be a **Becker Education and Engagement Day (BEED)** in six different locations across the United States on September 28th, and two locations in Europe on September 14th. ***It's not too late to register for this year's BEED event.***

September 28th US locations: Sacramento, CA; Orlando, FL; St. Louis, MO; Pittsburgh, PA; Dallas, TX; and Seattle, WA. [Register here!](#)

Topics for this year include: Building and Coordinating Care; Cardiac Care; Exercise and Physical Therapy; Becker Clinical Trials and Research; Mental Wellness; Everyday Strategies for Living with Becker; and Planning for the Future



Becker Education and Engagement Day is Going Global!

Edgewise is proud to sponsor Treat-NMD in bringing the **Becker Education and Engagement Day** to Europe on September 14th in two locations: Amsterdam, The Netherlands and Milan, Italy.

Contact Treat-NMD for more information.

Clinical Trials Update

BECKER GRAND CANYON

Edgewise is continuing to broaden recruitment for its **GRAND CANYON (NCT05291091)** trial across the United States, Europe, Israel, New Zealand, and Australia. **GRAND CANYON** is a pivotal clinical trial designed to evaluate the safety and efficacy of sevasemten in adults with Becker. Males with a genetic diagnosis of Becker, between the ages of 18 and 50 who are ambulatory and can meet certain functional criteria are eligible. To learn more about **GRAND CANYON**, contact studies@edgewisetx.com.

DUCHENNE LYNX FOX

LYNX (NCT05540860) and **FOX (NCT06100887)** are Phase 2 trials for Duchenne muscular dystrophy. **LYNX** is assessing the effect of different dose levels of sevasemten in children aged 4-9 living with Duchenne. **FOX** is assessing the effect of sevasemten in children and adolescents aged 6-17 living with Duchenne who have previously been treated with gene therapy. To learn more about our Duchenne trials contact studies@edgewisetx.com

Edgewise Initiatives and Community Engagement

The Edgewise Team has been busy this summer engaging with community members, partnering with advocacy groups and individuals on impactful events.

SUMMER CAMP: This summer, Edgewise hosted the “Banana Olympics” and “Shark Tank” at summer camps with MDA and Jett Foundation in Colorado! Organizations like MDA and Jett Foundation allow those living with neuromuscular diseases to attend a free camp program with lots of fun activities, with everything accessible and tailored to those with different abilities.



PPMD WEBINAR: On August 7th, Edgewise partnered with PPMD to host a webinar on disease process in Duchenne and Becker, Exercise in Becker, and Clinical Trial Updates. Find the webinar [here!](#)

EDUCATIONAL VIDEO: With input from members of Edgewise’s Becker and Duchenne Patient Councils, we developed a **short animated video** to provide education about injury caused by muscle contraction and the disease process in Becker and Duchenne. (See Edgewise’s full YouTube Channel here: [Edgewise Therapeutics - YouTube](#))



TRIAL ARTICLE: On August 26th, [Edgewise published an article](#) on Clinical Trial education in the August issue of MDA Quest Magazine.

BECKER RESOURCES: Another way Edgewise is supporting disease awareness is by continuing to create informative materials for the Becker community. Explore beckermusculardystrophy.com for a valuable resource for people living with Becker.

BRYAN’S STORY: Edgewise also continues our commitment to disease awareness through patient stories. Check out our YouTube channel to learn more about people like Bryan, who lives with Becker muscular dystrophy and has always been drawn to exploring nature and the great outdoors.



Exercise and Muscular Dystrophy:

A Conversation with Claudia Senesac, PT, PhD, PCS, Clinical Professor | Imaging NMD; University of Florida

Exercise and physical therapy are regularly topics of interest in Becker and Duchenne muscular dystrophy. We had a conversation with Claudia Senesac, who will also be speaking at the BEED event in Orlando, Florida.



Q What advice would you give to someone living with muscular dystrophy who is interested in participating in some form of exercise?

A *First, I would say that exercise is a good thing and can be modified for anyone's ability level. Exercise makes people feel good and has been shown to improve many aspects of the body and mind. When someone with muscular dystrophy is interested in beginning an exercise program, we recommend they consult with their physician first. Their physician might suggest having some tests done to determine what would be best for the person's heart related to exercise intensity and to rule out any contraindications.*

Second, determining what a person's goals are for exercise can be extremely helpful. Working towards meeting goals makes exercise more meaningful and more likely to improve overall health. Third, consult a physical therapist that has experience working with individuals with muscular dystrophy so that a plan of care can be specific, based on an evaluation of strengths, challenges, and goals.

Q What are some ways to know if an exercise is helpful or harmful to someone living with muscular dystrophy?

A *Exercise should be enjoyable and fun. However, everyone responds to exercise in different ways. Finding the right exercises for a person with muscular dystrophy may take trial and error. This is another reason to consult a physical therapist who can design a program that fits individual needs.*

Some things you might experience if your exercise is HELPFUL.

1. Improved circulation, a pinkish color to the skin that people get when they are moving around
2. Feeling more relaxed all over
3. Feeling more flexible or mobile
4. Decreased pain – if you had painful areas
5. A change in the way you are breathing- deeper breathing, able to exhale more completely
6. Sleeping better
7. More alert
8. Happy, feeling of accomplishment
9. Talking/engaging more
10. Increased appetite
11. Exercise can help to lower blood pressure if your regular BP is high

Some things you might experience if your exercise is possibly HARMFUL.

1. Increased fatigue
2. Increased muscle, joint, or back pain
3. Muscle soreness that lasts greater than 24 hours
4. Dark or red urine
5. Difficulty sleeping
6. Shortness of breath that continues longer than a couple of minutes after ending the exercise
7. Tachycardia-rapid heartbeat that does not resolve a few minutes after exercise is over

Most of these are signs you may have overdone your exercise(s) or you need to reassess the exercises you are doing and modify them. A therapist can assist in modifying the exercise regime to better fit your needs.

A Conversation with Claudia Senesac continued

Q How can individuals living with muscular dystrophy ensure that their local physical therapist is aware of important factors for someone living with muscular

A *This is a great question. It is perfectly ok for the individual to ask when making the appointment for therapy if any of the therapists have experience or expertise in treating people with muscular dystrophy. Finding the right therapist for a person can be challenging but not impossible. Since we are dealing with a rare disorder and a condition that is constantly changing in the amount of the information we know about it, finding a therapist that is willing to collaborate with others and seek out resources to learn more should be a top priority.*

There are some articles that are now published talking about appropriate exercise in these populations listed below and there are resources through recorded events and on websites like the Becker Education and Engagement Day starting with Muscle Health, Physical Health, and Exercise at, <https://www.youtube.com/@BeckerEducationEngagementDay/videos> and the Website: www.imagingNMD.org under resources/exercises.

References (note that references are continually being updated as the research landscape evolves):

Garber CE, et al. Med Sci Sports Exerc. 2011;43(7):1334-59.

American College of Sports Medicine. ACSM's Guidelines for Exercise Testing and Prescription, 11th edition. Philadelphia: Wolters Kluwer, 2022.

Birnkranz DJ, et al. Lancet Neurol. 2018;17(3):251-267