



To learn more about Edgewise, go to [www.edgewisetx.com](http://www.edgewisetx.com) or follow us on [LinkedIn](#), [X](#) (formerly Twitter), [Facebook](#), [Instagram](#) and [Threads](#)

## Clinical Trials Update

### BECKER: GRAND CANYON CANYON MESA

#### Evaluating sevasseten in Becker muscular dystrophy

Enrollment for the **GRAND CANYON (NCT05291091)** study will be wrapping up at the end of this year, so the time to join this study is now! **The GRAND CANYON** study has 26 sites across the United States, and is also recruiting in the United Kingdom, the Netherlands, Denmark, Belgium, France, Spain, Germany, Italy, Israel, New Zealand, and Australia.

We expect to share new data regarding the **CANYON (NCT05291091)** study in December 2024.

Our open-label extension study, **MESA (NCT06066580)**, is available to all eligible trial participants who completed a sevasseten trial in Becker. Open-label extension studies allow us to continue to evaluate long term effects of sevasseten while ensuring ongoing access to the study drug for those who already completed a sevasseten trial in Becker. Currently 99% of those who complete our trials have chosen to enroll in MESA.

For more information about these studies, including enrollment opportunities for **GRAND CANYON**, you can email [studies@edgewisetx.com](mailto:studies@edgewisetx.com).

### DUCHENNE: LYNX FOX

#### LYNX and FOX for Duchenne muscular dystrophy

**LYNX (NCT05540860)** and **FOX (NCT06100887)** continue to advance in identifying the dose range and design to support a Phase 3 trial for those living with Duchenne.

## What is the North Star Ambulatory Assessment?

The North Star Ambulatory Assessment is a standardized tool used regularly in Duchenne and increasingly in Becker as well. It is a standardized set of activities meant to assess functional level that can help with monitoring disease progression. Edgewise's trials in Becker and Duchenne use the NSAA as an important clinical trial endpoint.

Lately, we have been working to educate the community about what the NSAA entails and why it's important.

[Click here](#) to view our short, animated video explaining the North Star Ambulatory Assessment.

[Click here](#) to view our recent webinar hosted by the Muscular Dystrophy Association and led by Joanne Donovan, MD, PhD, Edgewise's Chief Medical Officer, and Tina Duong, MPT, PhD, of Stanford University.



# Edgewise Initiatives and Community Engagement

**BECKER EDUCATION AND ENGAGEMENT DAYS:** Edgewise was proud to participate in the US and EU Becker Education and Engagement Days in September.

In the US, over 330 individuals attended across 6 locations (Seattle, Sacramento, Dallas, St. Louis, Pittsburgh, and Orlando). If you missed the event, video recordings of each of the agenda topics (genetics, cardiac considerations, exercise and physical therapy, mental wellness, living with Becker, and Becker research) have been uploaded to the [BEED website](#). Additionally, all event sponsors contributed resources to a post-event newsletter that can be downloaded [here](#).

In the EU, over 100 members of the Becker community gathered in Milan and Amsterdam for a first of its kind event hosted by TREAT-NMD. Clinicians from across the UK and EU gave presentations about living with and managing Becker and patient advocacy groups helped to chair the sessions. For many individuals living with Becker, it was the first time they had met someone else living with the disease and were able to share their stories amongst others in the community.



**WORLD MUSCLE SOCIETY CONFERENCE:** Edgewise recently attended the World Muscle Society (WMS) conference in Prague and presented several posters to healthcare provider audiences, including [Clinical Trial Readiness in a Rare and Underserved Disease: Learnings from Community Engagement and the Lived Experience in Becker Muscular Dystrophy](#).



**MICHAEL'S STORY:** Edgewise continues our commitment to disease awareness through patient stories. Check out our [YouTube channel](#) to learn more about people like Michael, who lives with Becker and uses his talents to bring people together in the community.



## Meet Our Chief Scientific Officer

**Alan Russell** serves as Co-Founder, Chief Scientific Officer, and a member of the Edgewise Board of Directors. Alan's expertise is in muscle biology and he has dedicated his 20+ year career to advancing new treatments for serious muscle diseases. He received his BPharm and PhD from the University of Bath in the UK and completed his Postdoctoral training at the Stanford University School of Medicine. Alan lives in Boulder, Colorado with his wife, Jina, their two teenagers, Alastair and Nuri, and their bernadoodle, Rosie. He is a man of many hobbies, including roasting his own coffee. Over the summer, Alan enjoyed volunteering his time with kids living with Duchenne at the Jett Foundation's summer camp in Colorado where he got to be a judge during the "Shark Tank" activity. We had the pleasure of sitting down with Alan and asking him a few questions:



### Q What is your favorite thing about working at Edgewise Therapeutics?

**A** *I consider myself "the luckiest duck." I get to have my own lab, do the biology I love, with a team full of wonderful scientists alongside me. And we get to apply science in a way that makes a difference and helps those who need it.*

### Q What made you want to become a scientist?

**A** *My dad was a pharmacist, and I grew up in the back of a pharmacy and getting to do experiments with him, so I didn't know much else. I love the creativity of biology, and how complicated and random it can be so you're always surprised. Some science can be very formulaic, but I consider myself to be a chaos agent and applied biology is a perfect fit for that.*

### Q What is one thing you would like to share with the Becker and Duchenne communities?

**A** *I have so much admiration for the Becker and Duchenne communities. Even with all the challenges they face, it is a wonderfully unified group of people who are driven to improve their lives and the lives of those around them. As a scientist, there is still so much more for us to do.*

### Q What is something about you that sometimes surprises people?

**A** *I am sometimes referred to as the "Reluctant Beekeeper." When my family moved into our current home, we inherited a bee colony from the previous owner. I wasn't too keen on it at first, but my wife thought it would be good for the garden, so now I tend to the bees and have a basement full of honey!*

