

Spring 2021

# **New Resources from Ultragenyx Patient Advocacy**

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We're excited to share the **newest resources available on** UltraRareAdvocacy.com! It is our goal to create relevant and useful educational materials for the rare community to support individuals in their journey, no matter what stage. Browse through the Rare Disease Patient Journey here to find additional resources on pursuing a diagnosis, managing day-to-day life, participating in research, becoming a community advocate, and more.

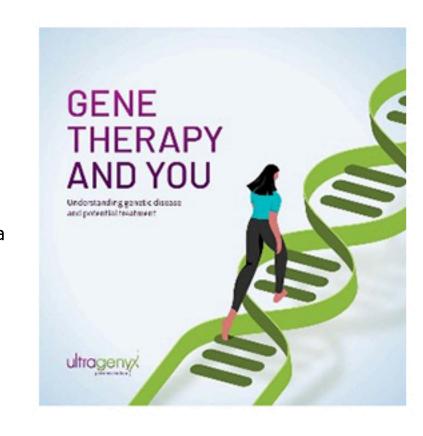
Please connect with us at patientadvocacy@ultragenyx.com or take our User Experience Survey to tell us if there is another educational resource that would be valuable to you.

### **New Educational Resources**

### **Gene Therapy and You**

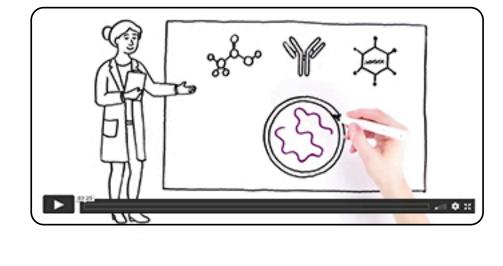
Want to know more about how gene therapy works? Download our gene therapy brochure to learn more about genetic disease and gene therapy as a potential treatment.

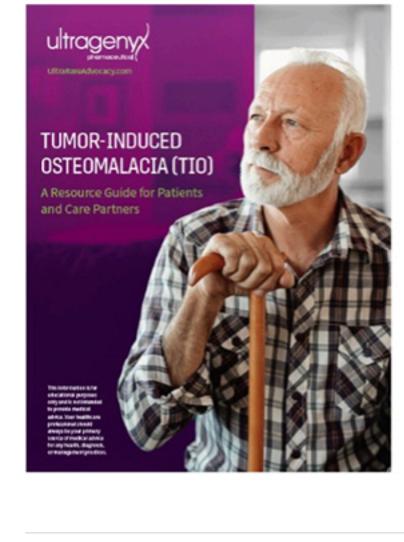
Download the Brochure



What is mRNA Therapy?

At Ultragenyx, we are researching many ways to potentially treat rare diseases. One of those approaches is **mRNA therapy** for glycogen storage disease type III (GSD III). To learn more about how mRNA therapy is designed to work, check out the animation below.





# (TIO) Resource Guide TIO is a rare condition caused by

**Tumor-induced Osteomalacia** 

tumors in the body that cause an overproduction of a certain protein. People with TIO can experience muscle weakness, fatigue, bone pain, and fractures that have a significant impact on daily life. This resource guide discusses symptoms, disease management, and support for people and care partners impacted by TIO.

Find out More

# **Ann: Achieving Balance**

**New Patient Journey** 

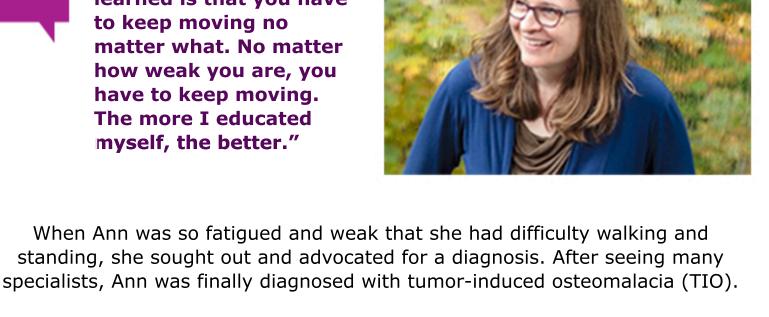


have to keep moving. The more I educated myself, the better."

"I think the lesson I've learned is that you have

matter what. No matter how weak you are, you

to keep moving no



Check out Ann's Story

Thank you for your continued support for rare disease. If you found this E-News Update helpful, feel free to invite your friends and family to join our mailing list.

Thank you!

If you'd like to stay up-to-date with resources, events, patient stories and more, we hope you'll also follow us on Facebook and visit our website! The patient advocacy department within a company serves as the point of connection to individuals and families impacted by rare diseases and works to understand and represent their views within its organization. Ultragenyx is a

biopharmaceutical company committed to bringing to market novel products for the treatment of rare and ultra-rare diseases, with a focus on serious, debilitating genetic conditions. Sincerely, The Ultragenyx Patient Advocacy Team patientadvocacy@ultragenyx.com

Visit our Patient Advocacy Website

To give us feedback on this newsletter or our other advocacy content, fill out our survey.

Patient Advocacy at



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