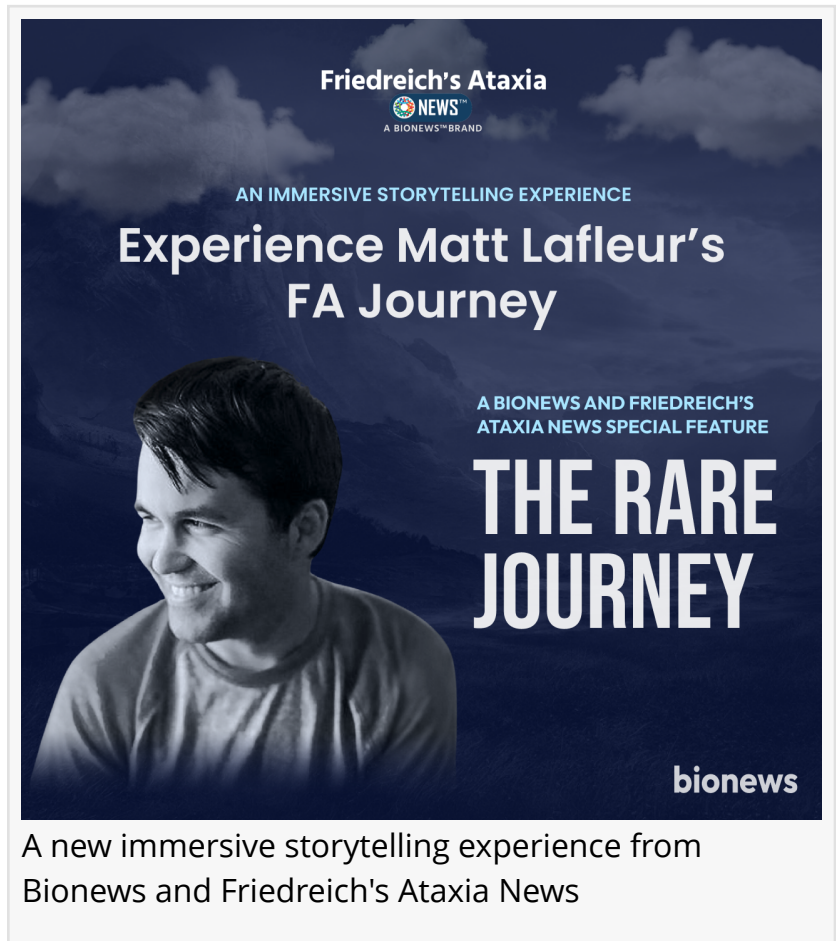


Bionews Launches Immersive Patient Journeys for Rare Disease Community

Empowering Rare Disease Communities Through Immersive Storytelling

PENSACOLA, FLORIDA, UNITED STATES, August 19, 2024 /EINPresswire.com/ -- For millions of people living with rare diseases, every day can bring challenges with isolation and uncertainty. [Bionews](#), a leading digital health solutions company dedicated to empowering the rare disease community, is proud to announce the launch of "[The Rare Journey](#)," a groundbreaking, immersive storytelling experience designed to shed light on these challenges. Featuring Matt Lafleur, who has Friedreich's ataxia, the first "Rare Journey" launched on Aug. 15 on [FriedreichsAtaxiaNews.com](#), a Bionews website. This innovative platform offers a unique perspective on the patient journey.



Friedreich's Ataxia
NEWS
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AN IMMERSIVE STORYTELLING EXPERIENCE

Experience Matt Lafleur's
FA Journey

A BIONEWS AND FRIEDREICH'S
ATAXIA NEWS SPECIAL FEATURE

THE RARE
JOURNEY

bionews

A new immersive storytelling experience from
Bionews and Friedreich's Ataxia News

"The Rare Journey" is a compassionate exploration of the rare disease experience, offering essential support and understanding as well as peer-to-peer connections. This long-form immersive experience takes people through a featured patient's journey, combining animation, video, and interactive content for a deeply personal and empathetic connection.

Drawing on insights from Bionews' 2024 rare disease research, which revealed 87% of our audience values peer-to-peer content the most in their condition management. "The Rare Journey" empowers individuals to:

- Educate themselves, and their families and caregivers, giving them knowledge about their condition and available resources.
- Advocate for their needs, developing the confidence to share their experiences and advocate for change.
- Connect with others, building a sense of community and finding support from those who



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Chris Comish, CEO of Bionews

understand.

- Inspire hope, discovering stories of resilience and perseverance from others in the community.

"This immersive product is a natural extension of what we do at Bionews," said Chris Comish, CEO of Bionews. "We've been bringing storytelling to these communities for years, and we're excited about this new era of immersive experiences that allow us to truly capture the emotional impact of living with a rare disease."

Through these benefits and relatable stories, "The Rare Journey" aims to improve the quality of life for individuals living with rare diseases.

"We are excited to see the launch of 'The Rare Journey,' a powerful tool for the Friedreich's ataxia community and beyond," said Kyle Bryant, rideATAXIA senior director and spokesperson for the Friedreich's Ataxia Research Alliance. "This initiative highlights the importance of the patient voice in raising awareness and understanding of the challenges faced by those living with rare diseases."

Lafleur, a Bionews employee whose story is the first told through this new series, said, "Living with Friedreich's ataxia has been a journey filled with both challenges and triumphs. 'The Rare Journey' captures the essence of that experience in a way that is both powerful and deeply personal. It's a testament to the strength of the rare disease community and the importance of sharing our stories."

"The Rare Journey" is the first of its kind in the rare disease space and represents a significant step forward in patient advocacy and education. By providing a platform for shared experiences, Bionews aims to foster a stronger sense of community among patients and caregivers.

Bionews plans to launch similar immersive journeys across its 50-plus rare disease communities, offering hope and support to an even wider audience.

About Bionews

Bionews is a digital health solutions company dedicated to empowering more than 50 rare disease communities with trusted information, news, and connections. Since 2013, we've been committed to serving patients and elevating their voices. Our motto is "For Rare, By Rare." With more than 50% of our team living with or caring for someone with a rare condition, we understand the unique challenges and needs of these communities. We've built a network of more than 500,000 registered members actively seeking news, clinical information, and sharing

experiences. This creates a safe space for peer support, connection, and learning. Bionews offers a comprehensive platform serving a wide range of rare diseases, from larger condition specific communities including pulmonary fibrosis to smaller communities such as AADC.

About Friedreich's Ataxia Research Alliance

The Friedreich's Ataxia Research Alliance (FARA) is a non-profit organization dedicated to curing Friedreich's ataxia (FA) through research. FARA grants and activities provide support for basic and translational FA research, pharmaceutical/biotech drug development, clinical trials, and scientific conferences. FARA is also dedicated to bringing the patient voice to the drug development process by connecting FA families with the scientific community to create worldwide exchanges of information that drive medical advances. For more information about FARA, visit curefa.org.

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