Tyrosinemia Society, Inc. Partners with PatientsLikeMe to the Tyrosinemia Community

Alabama, Huntsville, Feb 26, 2021 (Issuewire.com) - The Tyrosinemia Society has joined forces with PatientsLikeMe (PLM), the world's largest integrated community, health management, and real-world data platform. In celebration of Rare Disease Day on February 28, we are announcing this collaboration which will allow the Tyrosinemia Society and its members to make their voices heard, learn from their peers living with Tyrosinemia, and provide an opportunity for the Tyrosinemia community to share their lived experience through contributing patient-generated data. Ultimately, we will use these patient-generated data contributions to increase researchers' knowledge of the condition through a natural history study.

The Tyrosinemia Society's mission has always been to educate and inspire individuals to improve their health outcomes and advocate for adults and children with Tyrosinemia and related disorders. This partnership is a giant leap forward in our ability to accomplish that mission and continue to serve families affected by Tyrosinemia. The Tyrosinemia Society has earned a global reputation for transforming health care outcomes for those affected by Tyrosinemia and related disorders through advocacy, education, and research, and now we will have a strong partner to assist us in fulfilling all of our mission. "We are extremely pleased to be working with PLM at this pivotal moment in history," said Elizabeth Barnby, DNP, ACNP-BC, FNP-BC, CRNP, President of the Tyrosinemia Society.

“This partnership is exciting in many ways, but the most exciting thing for us is that we get to continue our mission of elevating the patient voice to the level of data while bringing focus to a little-known and little-studied condition,” continued Dr. Kate Burke, Senior Medical Advisor for PatientsLikeMe. “As we involve more and more individuals in research and empower them to share their stories, we can help researchers discover new treatments and cure faster. We hope to start similar partnerships with other rare disease communities in the future and accelerate timelines for the development of new therapies while building a strong community of peer support.”

By jointly developing an online community to support Tyrosinemia patients and caregivers, the Tyrosinemia Society and PLM will be able to help guide patients through their care journey in part by providing co-developed condition-specific educational content focused on the standard of care for Tyrosinemia and the development of current and new therapeutics. This platform, hosted by PLM, will provide additional resources and opportunities for the families we serve to participate in research. This will be the first time a pediatric rare disease community has partnered with PLM, and this collaboration will lay a foundation for other rare disease communities to follow.

About the Tyrosinemia Society

The Tyrosinemia Society is committed to excellence in education, scholarship, clinical practice, and service to families affected by Tyrosinemia. To read more about the organization, visit the website at www.tyrosinemia.org or contact them via phone, email, Twitter, or Facebook.

About PatientsLikeMe

PatientsLikeMe is the world's largest integrated community, health management, and real-world data platform. On PatientsLikeMe, members can put their disease experiences in context and find answers to their questions. They can easily connect directly with members who have the same conditions, are experiencing the same symptoms, or have used similar treatments. Data generated by members themselves are systemically collected and quantified while also providing an environment for peer support and learning. The site enables members to monitor symptoms of their condition(s), share their disease experiences and treatment outcomes, and learn how to improve their care through peer-to-peer interactions. These data capture the complex temporality and competing influences of different lifestyle choices, socio-demographics, conditions, and treatments on a person's health. Everything members share empowers the community with personal agency, establishing PatientsLikeMe as a clinically robust resource with demonstrated impact, including more than 100 studies in peer-reviewed medical and scientific journals. To learn more about PatientsLikeMe, visit www.patientslikeme.com.

FOR MORE INFORMATION AND/OR AN INTERVIEW, PLEASE CONTACT:

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