



## **Kantar Health and the CATS Foundation to present the GM2 disease registry at the 2020 NORD Rare Diseases & Orphan Products Breakthrough Summit**

New York, 27<sup>th</sup> August 2020 - Kantar Health, a leading global healthcare data, analytics and research provider, and the Cure & Action for Tay-Sachs (CATS) Foundation publish the GM2 disease registry (GM2DR) in an effort to increase awareness of and support clinical research on Tay-Sachs and Sandhoff Disease.

Tay-Sachs (TS) and Sandhoff disease (SD) are part of a group of rare autosomal recessive lysosomal storage disorders called GM2 gangliosidoses, which lead to neuronal degeneration and eventual death. Rare diseases are arbitrarily defined as having an incidence such that they cannot be studied effectively on patient groups drawn from one or a few medical centres.

The GM2DR registry, established in 2015 and managed by CATS leveraging the Open App system, includes valuable patient data such as genotype and key disease milestones like seizure activity and feeding intervention. There are currently 85 TS and 29 SD patients included, making it a valuable research platform of real-world data that can provide a deeper understanding of the natural history and the longitudinal progression of these rare diseases. Real world evidence is anticipated to be used for regulatory and health technology assessment evaluations of emerging therapies.

Daniel Lewi, Co-Founder and CEO of the CATS Foundation, commented: “Our disease registry is built on patient and carer data, providing a powerful tool for those seeking a better understanding of Tay-Sachs and Sandhoff disease. Working together with Kantar, we now have an even stronger resource at our fingertips that allows us to gain a deeper understanding of patients and support the clinical development of new compounds which may one day provide a cure for these devastating diseases.”

“The partnership with the CATS Foundation is a great opportunity for us to demonstrate the importance of understanding Tay-Sachs and Sandhoff from the patient and carer perspective, helping life science companies to identify and develop the most meaningful outcomes,” said Michael Fronstin, Global Head of Innovation, Real-World Evidence, Kantar Health.

### **About KANTAR HEALTH:**

Kantar Health, a division of Kantar, provides data, analytics and research to the life sciences industry. As real-world evidence and commercialization partners, Kantar Health enables clients to bring safe and effective treatment to patients around the world. The team has expertise across a myriad of therapy areas, including unique thought leadership in oncology and rare diseases. For more information on how to optimize commercial launch plans, demonstrate real-world effectiveness and safety, and build ongoing value substantiation to unlock your full potential, visit [www.kantar.com/expertise/health](http://www.kantar.com/expertise/health). Kantar helps clients understand people and inspire growth.

### **About THE CURE & ACTION FOR TAY-SACHS (CATS) FOUNDATION**

The Cure & Action for Tay-Sachs (CATS) Foundation is a registered charity based in the UK which supports children and adults affected by Tay-Sachs and Sandhoff disease. We are the founding member of the European Tay-Sachs and Sandhoff Charity Consortium (ETSCC) and have helped drive forward the research and clinical trials for these rare diseases.