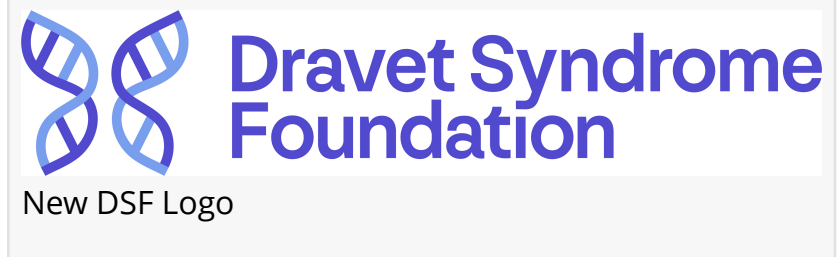


Dravet Syndrome Foundation Releases Voice of the Patient Report

The Dravet Syndrome Foundation released its Dravet Syndrome Voice of the Patient report, summarizing outcomes from a February 2022 EL-PFDD meeting.



CHERRY HILL, NJ, UNITED STATES, July 13, 2022 /EINPresswire.com/ -- Today,

the Dravet Syndrome Foundation (DSF), the largest non-governmental funder of Dravet syndrome-specific research, released its "Dravet Syndrome Voice of the Patient" report, summarizing outcomes from a February 2022 Externally Led Patient Focused Drug Development (EL-PFDD) meeting. For the first time ever, parent caregivers and family members were able to

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*Veronica Hood, PhD, DSF
Scientific Director*

share the lived experience of patients living with Dravet syndrome, a rare form of intractable epilepsy that begins in infancy and proceeds with accumulating morbidity that significantly impacts individuals throughout their lifetime. Dravet syndrome has an estimated incidence rate of 1:15,700, with the majority of patients carrying a mutation in the sodium channel gene SCN1A.

Parent caregivers and family members shared riveting stories of symptom burdens, challenges of managing the disease, associated health comorbidities, and treatment

needs and expectations with U.S Food and Drug Administration (FDA) regulators, drug developers, researchers, and clinicians. The meeting was recorded and is available for viewing on our website at www.Dravet-EL-PFDD.org.

The "Dravet Syndrome Voice of the Patient" report is a comprehensive document created from the feedback gathered at the Dravet syndrome EL-PFDD meeting. It includes shared testimony and data from attendees who participated via webcast, as well as submitted comments before and after the meeting. The report also includes the results of a survey that was promoted concurrently with the EL-PFDD meeting process detailing the preferences of 114 caregivers regarding disease modifying therapies for Dravet syndrome

Veronica Hood, PhD, DSF Scientific Director stated, “DSF is proud to have led this effort to ensure

that the patient voice can be actively incorporated into the drug development and approval process. The Voice of the Patient report enables any of the stakeholders involved in this process to easily identify the top needs of patients and families and to better understand the priorities of this population in regards to treatment options.”

DSF thanks their staff who developed the meeting content and agenda, with assistance from consulting partners James Valentine, Esq. and Larry Bauer, RN, MA, from Hyman, Phelps & McNamara, P.C. They also acknowledge the industry partners who helped support the cost of the meeting: Encoded Therapeutics, Stoke Therapeutics, Zogenix (now a part of UCB), Eisai, Biocodex, Jazz Pharmaceuticals, and Takeda.

The "Dravet Syndrome Voice of the Patient" report will inform the plans and programs of the Dravet Syndrome Foundation as well as sponsors developing new treatment therapies. The report has been submitted to FDA and will serve as a lasting resource for regulators, life science companies, researchers, the patient community, and the public. To read the report and learn more, visit www.Dravet-EL-PFDD.org.

About Dravet Syndrome Foundation

Dravet Syndrome Foundation (DSF) is a 501c(3) nonprofit organization whose mission is to aggressively raise funds for Dravet syndrome and related epilepsies; to support and fund research; increase awareness; and to provide support to affected individuals and families. Since its inception in 2009, DSF has awarded over \$5.6M in research grant awards and over \$196K in patient assistance. For more information, visit dravetfoundation.org.

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