

# Dravet Syndrome Foundation to host first Externally-Led Patient Focused Drug Development meeting for Dravet syndrome

*DSF announced that the U.S. FDA has approved it's externally-led Patient Focused Drug Development meeting on Dravet syndrome to be held on February 3, 2022.*

CHERRY HILL, NJ, UNITED STATES, January 26, 2022 /EINPresswire.com/ -- The [Dravet Syndrome Foundation](https://www.dravet-syndrome.org/) (DSF)

announced that the U.S. Food and Drug Administration (FDA) has approved it's externally-led Patient Focused Drug Development (EL-PFDD) meeting on Dravet syndrome to be held on February 3, 2022 via live-stream. DSF encourages all community stakeholders to register for this meeting at [www.dravet-el-pfdd.org](https://www.dravet-el-pfdd.org).



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We are honored to have the opportunity to communicate with the FDA and other community stakeholders on the impact of Dravet syndrome and our patients' needs through this upcoming meeting.”

*Mary Anne Meskis, Executive Director, DSF*

“We believe that all research should include the patient voice,” said Mary Anne Meskis, Executive Director of DSF. “No treatments should be developed for Dravet syndrome without input from our patient community. As an organization, we are honored to have the opportunity to communicate with the FDA and other community stakeholders on the impact of Dravet syndrome and our patients' needs through this upcoming meeting.”

An EL-PFDD meeting is an opportunity for the patient community to inform the FDA and other key stakeholders about their experiences and how they view the potential benefits and risks of treatments. Caregivers and families

living with Dravet syndrome will have the opportunity to share their insights and experiences on living with this condition and what defines a meaningful treatment via moderated panel discussions, live polling, and audience participation. The discussions will address symptoms and

impact of Dravet syndrome on daily life, current experiences with treatment, and perspectives on and expectations for potential future treatments. The meeting will be moderated by Dr. Veronica Hood, DSF's Scientific Director, and James Valentine, JD, MHS, Senior Associate of Hyman, Phelps & McNamara, PC, who will facilitate panel discussions, polling questions, and comments from the audience. Joseph Sullivan, MD, of UCSF Benioff Children's Hospital, will provide a clinical overview of the disease.

After the meeting, DSF will develop a Voice of the Patient report. This landmark report will document the severe disease burden and unmet medical need in patient families' own voices. It will include written statements and transcripts which are summarized in the report and shared in full in the appendices. Once complete, the report will be submitted to the FDA's Division of Neurology Products, Office of New Drugs, for inclusion in the framework used to evaluate future therapies for Dravet syndrome.

All content for the meeting has been developed by DSF and the Dravet syndrome patient community. Partner organizations include Dravet Syndrome UK, Dravet Syndrome European Federation, Gruppo Famiglie Dravet Italy, Dravet Syndrome Foundation Spain, and Dravet Canada. Fiscal supporters of the meeting include Encoded Therapeutics, Stoke Therapeutics, Zogenix, Eisai, Jazz Pharmaceuticals, and Takeda.

#### About Dravet syndrome

Dravet syndrome is a rare, catastrophic, lifelong form of epilepsy with accumulating morbidity that begins in the first year of life. Patients suffer from frequent and multiple types of seizures, including life-threatening prolonged seizures that can last for hours (status epilepticus), as well as other health issues and developmental delays. Patients with Dravet syndrome face an 18-20% mortality rate due to SUDEP (Sudden Unexpected Death in Epilepsy), status epilepticus, and accidents. Current treatment options are limited and the constant care required for someone suffering from Dravet syndrome severely impacts not only the patient but the quality of life for the entire family.

#### 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 grants. More information is available at [www.dravetfoundation.org](http://www.dravetfoundation.org).

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