

ZOGENIX

High Seizure Frequency in Children with Dravet Syndrome Negatively Impacts Quality of Life, New International Caregiver Survey Finds

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(GLOBE NEWSWIRE via COMTEX) --Global survey of 584 caregivers of children, young adults and adults with Dravet illustrates the detrimental effect of debilitating, frequent seizures on quality of life and co-morbidities

Results suggest a need for more effective antiepileptic treatments

EMERYVILLE, Calif. and BREST, France, Oct. 19, 2017 (GLOBE NEWSWIRE) -- The Dravet Syndrome European Federation and Zogenix, Inc. (NASDAQ:ZGNX), a pharmaceutical company developing therapies for the treatment of rare central nervous system (CNS) disorders, announced today the publication of the initial results from a landmark survey into the clinical, social and economic consequences of Dravet syndrome on children, young adults and their families in Developmental Medicine & Child Neurology [doi:10.1111/dmcn.13591].

This study was led by Lieven Lagae, M.D., Ph.D., Professor at the University of Leuven, Belgium, Head of the Pediatric Neurology Department and Director of the Childhood Epilepsy Program at the University of Leuven Hospitals, in cooperation with the Dravet Syndrome European Federation, a federation of European Dravet syndrome patient organizations aiming to improve the quality of life of patients and caregivers. Zogenix provided financial support for the study.

Dravet syndrome is a rare form of intractable (treatment-resistant) epilepsy that begins in infancy and is associated with potentially life-threatening, frequent and severe seizures, developmental delay, cognitive impairment and an elevated risk of sudden unexplained death in epilepsy (SUDEP).¹ The wide scope of comorbidities associated with this condition, combined with it being a rare disease, can be expected to result in a high impact on caregivers, affecting all aspects of their lives.²

"Children and Adults with Dravet syndrome face a diminished quality of life due to the debilitating number of seizures they experience, as well as the associated developmental issues. The prognosis for these children is poor as current treatment options are limited and often fail to provide adequate seizure control," said Isabella Brambilla, chairman of the Dravet Syndrome European Federation. "These results from the DISCUSS survey allow us to gain a deeper understanding of seizure burden for patients with Dravet syndrome and the disease's impact on quality of life for patients and their families."

Survey findings reveal that, despite broadly following current treatment guidelines, less than 10 percent of patients with Dravet syndrome were seizure free in the previous three months. Additionally, half of the patients required at least one emergency admission and 46 percent at least one ambulance call in the previous 12 months.

With regards to associated comorbidities, nearly all (99.6 percent) patients aged 5 years or older experienced at least one or more motor, speech, learning, or behavioral impairment. Of that group, 74 percent experienced motor impairment, 80 percent experienced speech impairment, 98 percent experienced learning difficulties, 42 percent were diagnosed with autism, 24 percent were diagnosed with ADHD, and 51 percent experienced other behavioral difficulties. On average, patients aged 5 years or older had four of the six surveyed impairments or comorbidities. Of interest, 13 percent of all patients older than 5 years of age were reported as not speaking at all.

Results from the survey also suggest that physician awareness of Dravet syndrome has markedly improved over time. Doctors immediately recognized Dravet syndrome in 45 percent of preschool children versus only 12 percent of adult patients. Overall, there were no clear differences in disease characteristics for patients when looking at the length of time to diagnosis, but early diagnosis is associated with earlier access to appropriate drug therapy and earlier access to specialized rehabilitation programs.

"As a physician who has worked with children and young adults with Dravet syndrome for many years, I have witnessed first-hand the negative effect this condition has on quality of life for both patients and their loved ones," said Lieven Lagae, M.D., Ph.D., Professor at the University of Leuven, Belgium, Head of the Pediatric Neurology Department and Director of the Childhood Epilepsy Program at the University of Leuven Hospitals and lead author of the article. "Currently, there are no available therapies that are able to provide lasting control over seizures for the vast majority of patients. The Dravet syndrome community desperately needs new treatment options that provide durable seizure control."

About the Survey

The Dravet syndrome caregiver survey (DISCUSS), was the largest survey ever conducted with caregivers of children with Dravet syndrome. DISCUSS was an online international cross-sectional study that sought to determine the social and financial impact of Dravet syndrome on patient and their caregivers and explore healthcare resource utilization associated with its current management. The survey was available in 12 languages (English, Spanish, Portuguese, French, Dutch, German, Italian, Polish, Croatian, and Romanian, Latin American Spanish and Brazilian Portuguese) and completed by 584 caregivers, of which over 92 percent lived in Europe.

Participants were recruited through email invitations to approximately 1,000 members of European patient advocacy groups associated with the Dravet Syndrome European Federation (DSEF) as well as through related internet based sources (Facebook and Twitter).

About the Dravet Syndrome European Federation

Dravet Syndrome European Federation (DSEF) is a federation of 15 European Dravet syndrome patient organizations aiming to improve the quality of life of patients and caregivers, promote research and knowledge exchange around Dravet syndrome, raise funds for medical and social research and raise disease awareness. www.dravet.eu

Aggregated DISCUSS survey results are available to the Dravet community for research purposes. Patient organizations, researchers, physicians, and industry can request access to the data via the DSEF. The DSEF board and their data management committee will consider any request for access where the proposed use of the data is of benefit to the Dravet community.

About Zogenix

Zogenix (Nasdaq:ZGNX) is focused on developing therapies for patients with rare central nervous system (CNS) conditions that have limited or no treatment options but face a critical need. For more information, visit www.zogenix.com.

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