

Issue 4

Living with TM

LGS • DRAVET • TSC

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Pictured here: Bobby, father of Haley, living with Dravet syndrome

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To learn more about the DDF, and how they may assist you, visit www.dannydid.org/



DANNY DID FOUNDATION

The Danny Did Foundation (DDF) was founded by Mariann and Mike Stanton. They lived with their son, Danny, in the north side of Chicago on a street packed with young children, enjoying many kickball games on their front lawn. Danny passed away at age 4 from sudden unexpected death in epilepsy, or SUDEP. His mom and dad started the DDF to help other parents avoid their tragic outcome by way of improved communication.

The DDF wants to make an immediate impact for families, and they have given nearly 2,500 grants to patients and caregivers so they can purchase a seizure alerting device. The peace of mind from knowing you can intervene during a seizure is meaningful.

Collaborations are key to the DDF. They work with and support many other patient advocacy groups, and they are also a founding member of Partners Against Mortality in Epilepsy (PAME), a multi-stakeholder initiative that engages families, doctors, industry and public health officials worldwide.

The DDF believes that communicating with families about the full range of potential risks that accompany epilepsy, including SUDEP, will empower their decision-making. That information-sharing is what families living with epilepsy want and deserve.

Many families ask about the name of the foundation. It comes from the last line of Danny's obituary, "Please go and enjoy your life. **Danny did.**" **The DDF celebrates Danny's spirit in every person they reach.**