

# Dravet Syndrome Foundation Partners with Mason's Movement Foundation

*This new partnership is aimed at providing additional support to bereaved families within the Dravet syndrome community.*

CHERRY HILL, NJ, 08034, August 23, 2024 /EINPresswire.com/ -- Dravet Syndrome Foundation (DSF) is pleased to announce its new partnership with the Mason's Movement Foundation, aimed at providing additional support to bereaved families within our community.

The Good Mourning Project, led by Mason's Movement, is dedicated to offering resources, support, and remembrance items to newly bereaved parents and siblings. They provide a selection of carefully vetted books on grief for all ages, along with remembrance items for every family member. This partnership ensures that grieving families within the Dravet syndrome community who are located in the United States will have access to the support and resources they need during a challenging time.

Said Amanda and Matt Langford, founders of Mason's Movement, "As Mason's parents, we know the sacred dance between pain and peace. Gratefulness and despair. Our vision for Mason's Movement is to hold space for those who have lost a child or sibling, and offer light in a time of darkness. When we lost Mason, we made it through with the support of family, friends, and complete strangers who understood the depths of our loss. We are grateful for the opportunity to help others, the same way we were once guided in our grief journey."

Dravet syndrome is an intractable developmental and epileptic encephalopathy that begins in infancy and proceeds with accumulating morbidity that significantly impacts individuals throughout their lifetime. Dravet syndrome is a rare disease, with an estimated incidence rate of



DSF Logo

## Dravet Syndrome Foundation



Mason's Movement logo



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*Amanda & Matt Langford*

1:15,700, with the majority of patients carrying a mutation in the sodium channel gene SCN1A. Patients face a 15-20% mortality rate due to SUDEP (Sudden Unexpected Death in Epilepsy), prolonged seizures, seizure-related accidents such as drowning, and infections.

Mary Anne Meskis, Executive Director of DSF, expressed, “We deeply appreciate the Mason’s Movement Foundation for offering this invaluable support to our families who

have lost a loved one. Their support offers significant comfort during a time when families are struggling to find their footing.”

About DSF: 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 \$9.1M in research grant awards and over \$240K in patient assistance. For more information on Dravet syndrome or DSF, visit [dravetfoundation.org](https://dravetfoundation.org).

About Mason’s Movement Foundation: Mason's Movement Foundation is a 501(c)3 non-profit, established in 2020 in loving memory of Mason Langford. The foundation supports families locally, nationally, and internationally through research funding, grief support to families, and aid to those in need. They live to let Mason shine, and his legacy lives on through helping others. Learn more at [masonsmovement.org](https://masonsmovement.org).

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