Friends of DSF,

We are thankful for our passionate and motivated community who continue to move our mission forward and help us reach our goals. Whether you made a financial contribution, organized a fundraiser, sponsored an event, helped raise awareness or volunteered - you are what has made DSF a success.

We also appreciate the talents and support of our Medical and Scientific Advisory Boards, as well as our esteemed Board of Directors. These leaders oversee and help to chart the future for DSF and assure we reach our goals.

Our total revenue in 2015 was more than $1.1M. We are indebted to each and everyone of you for your hard work and efforts to help us reach our goal of better treatments and a cure for Dravet syndrome.

Sincerely,

Mary Anne
Mary Anne Meskis
Executive Director

Who We Are

The mission of Dravet Syndrome Foundation (DSF) is to aggressively raise research funds for Dravet syndrome and related epilepsies; to increase awareness of these catastrophic conditions; and to provide support to affected individuals and families.

2015 Highlights:

- We awarded two new Research Grant awards, and two Postdoctoral Fellowships, bringing our total awards to over $2.5M since 2009.
- We added our newest board member, Nicole Villas, who was subsequently elected Board President and also serves as our Scientific Director.
- We planned our 2nd Biennial DSF Family & Professional Conference in collaboration with Nicklaus Children’s Hospital to be held in Coral Gables, Florida in June 2016.
- We added two new members to our Scientific Advisory Board and three new members to our Medical Advisory Board.
- We hosted our 6th annual DSF Research Roundtable in Philadelphia, Pennsylvania.
- We were a sponsor of the Epilepsy Genetics in the Era of Precision Medicine conference.
- We continued our partnership with the Rare Epilepsy Network (REN) Registry.
- We awarded over $15,000 in Patient Assistance Grants.
- We sponsored our 2nd Dravet Family Weekend at Camp Courageous for Kids in Scottsville, Kentucky.
- We joined other advocacy groups and families worldwide in celebrating the 2nd Annual International Dravet Awareness Day on June 23rd.
Research Grant Awards

DSF funding is allowing us to advance our research into finding a genetic cause for the ‘unsolved’ patients with Dravet syndrome. The DSF fellowship has been critical in launching this project.

*Alison Muir, PhD*

The fellowship from the Dravet syndrome not only allows me to perform this research project, but also helps boost my career and my goals to becoming an independent investigator.

*Samir Das, PhD*

Patient Assistance Grants

“DSF has helped us attend the 2016 & 2018 DSF Family & Professional Conferences and learn more about Dravet syndrome. As Addison gets older she is now in a different age bracket from the last conference, so being able to attend this year’s conference helped me learn more of what is going on now with her at 5 years of age.

DSF has also helped us by providing Addison with her iPad, and she is now a pro at navigating all the apps. Thank you DSF so much again for everything!!”

*Brenda Tisdale,*

*Mom to Addison*
A LOOK AHEAD

While this was a busy and successful year for DSF, we need to continue working to raise awareness of this catastrophic condition and to fund the important research that will benefit the quality of life of our patient community and their families.

In June 2016, DSF will be hosting our 2nd Biennial Family & Professional Conference in Coral Gables, Florida, in collaboration with Nicklaus Children’s Hospital. We look forward to bringing our professionals and families together to share information, learn about the latest in research and to help us target our research efforts towards the need of our patient community.

It is because of your generosity that we are able to continue to do the work we do. If you are interested in making a financial donation, establishing a planned gift, organizing an event, donating an item or volunteering your time, please contact Mary Anne at maryanne.m@dravetfoundation.org.

THANK YOU!

We couldn’t do this without your generosity and support. Through your financial contributions and your volunteerism we are able to further our mission.


Sign up for a quarterly e-newsletter and emails so you stay informed the latest research, clinical trials, upcoming events, and other news that impacts our community.

http://www.dravetfoundation.org/contact-us/email-signup

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