

# Annual Report

# 2013

**DRAVET  
SYNDROME  
FOUNDATION**



Raising Hope & Changing Lives through Research!

## **DSF Board of Directors**

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Jennifer Tischer—*Board Member*

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Christina Montanari—*Development Director*



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Annapurna Poduri, MD—*Boston Children's Hospital*



## Our Year in Review

Dear Friend,

DSF was established in 2009, by a small group of parents anxious to see research happening that would directly impact their own children's futures. The original goal was to raise the funds for a \$100,000 research grant. In the four years since our inception, we have awarded over \$1.6M in research grants and over \$65,000 in patient assistance grants.

### Some of the high points for 2013 include:

- \$695,000 Awarded in Research Grants
- 5,000 *Consider Dravet* brochures distributed to neurologists and other medical professionals
- 46 Families served by our Patient Assistance Grant Program
- Our 4th Annual Research Roundtable was held in Washington, DC

While the founders of DSF may have had a vision, it is the families and supporters who have joined us in this fight that have helped us make a genuine impact. We have each and every one of you to thank for our success! It is with great pride that I share with you our 2013 Annual Report.

With Sincere Gratitude,

*Mary Anne Meskis*

*Executive Director*

## DSF Research Roundtable

This Annual Event brings together researchers from around the globe who have a keen interest in syndrome-specific epilepsy research with a target of Dravet syndrome. The 2013 event was held in Washington , DC.

*The past year saw outstanding success in efforts to advance Dravet syndrome research. This was particularly evident at the 4<sup>th</sup> Annual DSF Research Roundtable, which was a very exciting event that brought together some of the world's foremost epilepsy researchers to hear the latest cutting edge research into Dravet Syndrome. Talks ranged from descriptions of the use of new fish and mouse models of Dravet and related disorders to identify new therapies and disease mechanisms, to the use of two of the most well-studied mouse models of the disorder (from Japan and Seattle) to uncover new insights into brain and autonomic nervous system dysfunction. Over the past year, the number of experimental model systems to study Dravet syndrome has increased dramatically.*

*These now include zebrafish, fruitfly (Drosophila), at least two new mouse models, human induced pluripotent stem cell models from 3 groups, and a rabbit model that is being generated. These advances raise exciting prospects for rapidly translating therapies that work in multiple model systems to the clinic to treat patients. Lastly, the upcoming 4<sup>th</sup> Gordon Research Conference on Epilepsy, the premiere epilepsy basic science meeting, will feature at least four talks related to Dravet syndrome and will include ten speakers, moderators or meeting co-chairs who work on Dravet syndrome or related epilepsies. Given the progress made over the past year, the prospects are excellent for an accelerating pace of research discoveries to help solve Dravet syndrome.*

*Jack Parent, MD*

Scientific Advisory Board Chair



## DSF Patient Assistance Grant Program

Raising a family member with any disability is draining both emotionally and financially. DSF recognizes the impact a diagnosis of Dravet syndrome or a related epilepsy has on a family, and thereby established the Patient Assistance Grant Program. Families in need may apply for items that would not otherwise be covered by insurance. To date the program has awarded over \$60,000 in durable medical goods including, but not limited to: adaptive strollers, cooling vests, iPads, seizure alarms, monitors, and much more.



### ***From the Barnette Family—recipients of a Patient Assistance Grant***

*Dravet Syndrome Foundation's grant has helped change our lives. Our daughter Claire is 9, and because she struggles with the heat, poor balance, and the constant desire to run away from me, she and I had always seemed to watch things from the safety of our car. This year we were both on the sidelines cheering him on! In the past Claire could only stay at the zoo for an hour at the most. With her stroller, she was able to stay for over 3 hours and enjoy a day at the zoo with her friends! The cooling vest allows her to enjoy the playground on days she would've typically had to stay inside. I just can't say enough about the DSF grant and how these items have impacted our lives. Claire is even going to get to participate in the special needs baseball league in our area this fall with the help of her "super vest" and stroller. Thank you DSF for making some very big dreams come true for a very special girl. It has truly been an answer to prayer. Now Claire can take her God-given smile, light, and joy into even more places. Watch out world—Claire is on the move!*

## DSF Research Grant Program

The primary mission of DSF is to fund research to find better treatments and eventually a cure for Dravet syndrome and related conditions. Each year, the application process is opened for researchers who have valuable projects, but need the funding to make them happen. Each application is reviewed thoroughly by the Scientific Advisory Board and voted on by the Board of Directors. To date, DSF has awarded \$1.6 million dollars in research grants.

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*I had planned on practicing pediatric epilepsy, and toward the end of my clinical training, I realized that not only were there many unanswered questions that needed to be studied, but also that I would be in a unique position as a clinician-scientist to know what questions to bring to the lab. I developed a clinical epilepsy genetics program to consult on patients with known genetic epilepsies like DS, as well as patients with suspected but as yet uncharacterized genetic epilepsies. We now have a way to do clinical genetic epilepsy testing, but just a few years ago, all we could offer was research testing and analysis of samples in the lab. For a junior researcher, this was a daunting challenge. The costs of sequencing were still high, and doing this work required not just a question and an approach but a team to enroll patients into research studies, obtain clinical information for phenotyping, handle samples, analyze genetic data and do follow-up benchwork. At this critical juncture, DSF presented us with a generous grant that allowed us to get this project off the ground.*

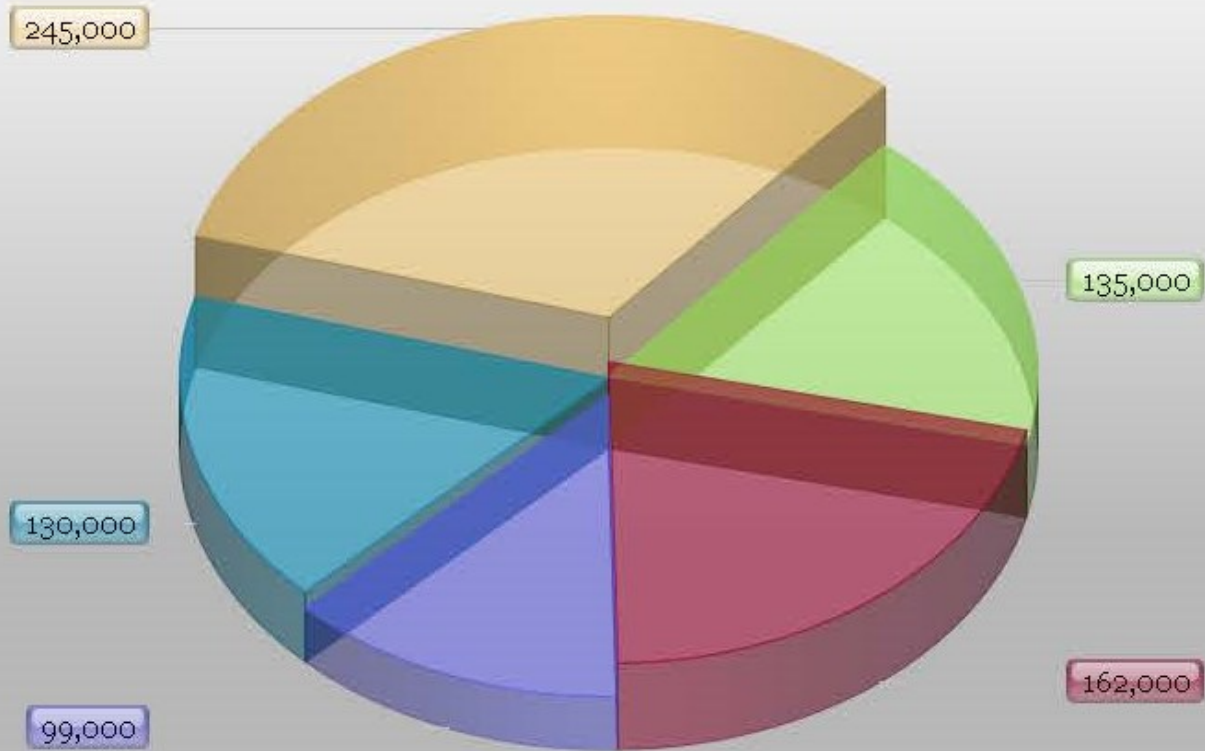
*We are now trying—fervently, but responsibly—to move our genetic epilepsy discoveries back toward rational treatment based on the biology of each epilepsy (“precision medicine”). The funding my group has received from DSF really facilitated our setting up a program to be able to embrace this new era with the right team of people in place. DSF’s scientific advisory board has also placed me, as a junior faculty member, in contact with leaders in the field with whom collaborations are now on-going and planned. This has been another invaluable aspect of having received funding from DSF for which I am truly grateful.*

*Annapurna Poduri, MD*  
*Boston Children’s Hospital*



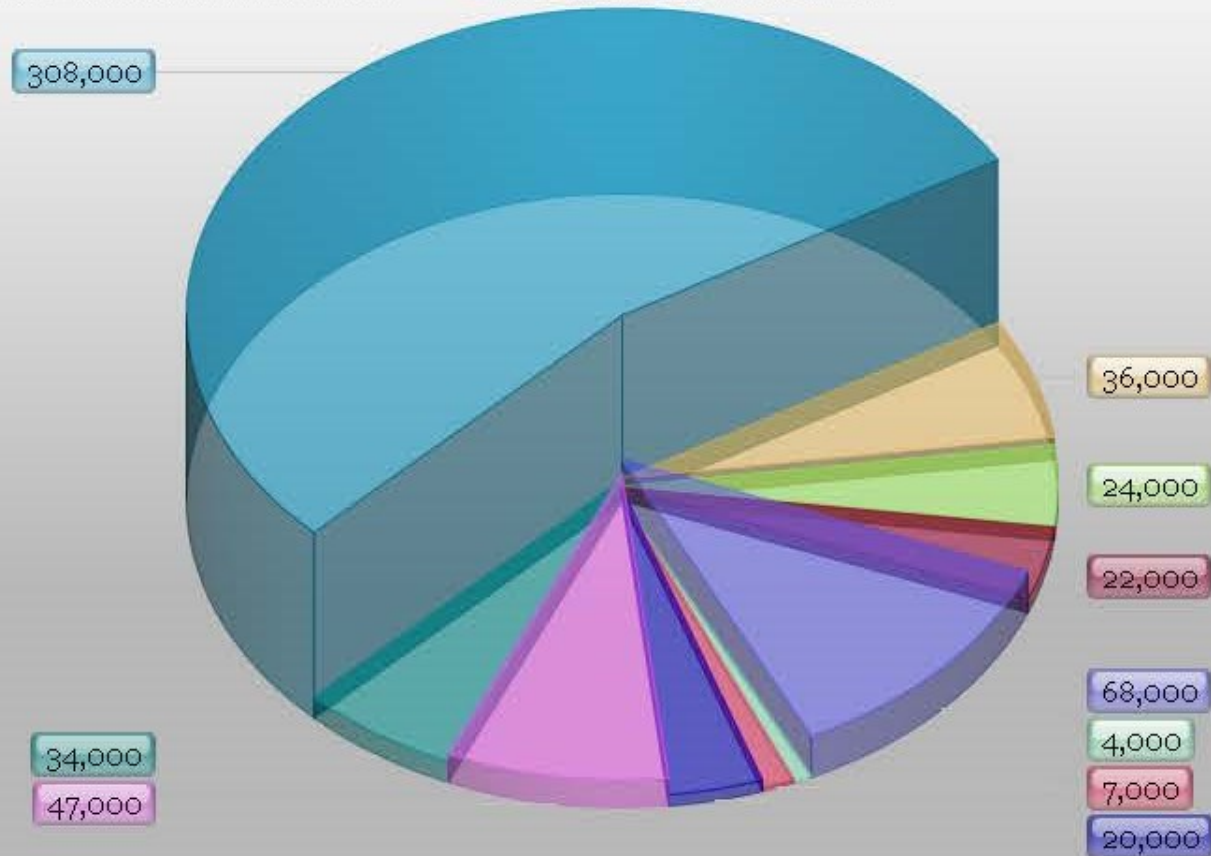
## 2013 Income

■ Restricted Funds   ■ Unrestricted Funds   ■ Special Events - Ciara's Butterfly Bash   ■ Special Events - Steps Towards a Cure  
■ Special Events - Other Events



## 2013 Expenses

Research   Programs   Operations   Fundraising   Staffing   Advertising   Travel & Meetings  
Events, Other   Events, Ciara's Butterfly Bash   Events, Steps Towards a Cure





**Due to space limitations, donors at the \$250 and up level are listed here, but we are thankful for all gifts received!**

***\$30,000 and above***

Tim and Ashley Wood  
The Matthew R. Stone Trust DTD

***\$10,000- \$29,999***

Transgenomic, Inc.  
Paula Silverman  
Fidelity Charitable Gift Fund  
Joseph & Catherine Johnson  
Family Foundation

***\$5,000 - \$9,999***

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Bradley & Haley Barrett  
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Acacia Petroleum LP  
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SAP Matching Gift Program  
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***\$2,000 - \$4,999***

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WM Fares Family Foundation  
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United Rentals  
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St. Francis Veterinary Hospital, Inc  
Paul & Stephanie Stellato  
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The Longhorn Truck & Car Plaza  
The Plourde Family Charitable  
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W. R. Berkley Corporation  
Dan Walsh  
Timothy & Kara West  
Patricia Ann White  
Worthington Industries

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Joseph & Erin Jackson  
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Robert Wright  
Connellsville Junior High  
School East  
Eric & Jenna Englund  
The Parthum School PTA  
My Tribute Gift Foundation, Inc.  
Travelers Community Connections  
United Way of Central  
New Mexico  
Adventures in Charity, Inc.  
John Barber  
Roy Jr. & Janet Eichhorn  
Russell & Lauren Fuchs  
Steven & Cindy Holder  
ICE Epilepsy  
JW Montgomery  
Oleg Kouskov & Irene Pucciarelli  
Michele Williams  
Tim & Margo Flaherty  
Heather Hatfield & Amy Boyer  
Thomas & Debra Gregory  
Robert & Kathy Dodd  
Shannon & Blaine Cloud  
Marcos & Sarah Daccarett

**\$250-\$499 (continued)**

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Implant Center Prof LLC  
Dale & Michele Asplund  
Jamie Barrett  
Scott & Gayle Baumbach  
Richard & Melissa Birns  
Gretchen Bolton  
Fred Bratman  
Carol J. Bresler  
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Classic Metals, Inc.  
Cohn Reznick Foundation, Inc.  
Consumer Credit Union  
Cornerstone Computer Solutions  
John Crow  
Dalling Construction, Inc.  
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MWI Vet. Supply  
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Greeneville Oil and Petroleum  
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Kathy & Dave Klika  
Knecht's Garage, Inc.  
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Christina Robinson  
Gordon & Susan Roy  
The Rural Gas Company  
John & Jane Schaub  
Steele Street Bank & Trust  
Barbara Brafman and Larry Stein  
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Carolyn Surgent  
Tamarack Municipal Association  
Tiffany Alford Memorial Fund

Max & Dorenda Truesdale  
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