



# Dravet Syndrome Foundation

2023 Annual Report

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## A Message from our Executive Director, Mary Anne Meskis

Dear Friends,

It is with immense gratitude and pride that I share our 2023 annual report, which serves as a testament to DSF's growth and, more importantly, celebrates the achievements of our incredible community throughout the last year.

From our humble beginnings, our focus has remained steadfast – advancing our collective understanding of Dravet syndrome, providing support and advocacy, securing new treatments, and tirelessly working towards finding a cure. Our commitment to transparency, inclusion, impact, and collaboration has guided every aspect of our organization, shaping our values and actions.

In December 2023, I had the honor of receiving the *Extraordinary Contributions to the Field of Epilepsy Award* from the American Epilepsy Society. This recognition is not only a personal accolade but a testament to the collective effort of our entire community. I humbly acknowledge that our progress is a result of the collaborative spirit that binds us together, and we would not be where we are today without your unwavering support. So, to our dedicated supporters, patient families, researchers, clinicians, staff, volunteers, and pharmaceutical and biotech partners – thank you. Your contributions have been instrumental in advancing the field of Dravet syndrome and improving the quality of life for patients and their families. Your support fuels our critical efforts, and we are immensely grateful for the strength of our community.

As we approach the new year, DSF is poised for further growth. We are excited about the possibilities that lie ahead and are committed to continuing our efforts to make a lasting impact. I am genuinely looking forward to the next phase of our journey together and the opportunities it presents for us to make a meaningful difference in the lives of all of those affected by Dravet syndrome.

With gratitude,

*Mary Anne*

Mary Anne Meskis  
Executive Director

# Staff, Board, and Advisory Members



## Staff



Mary Anne Meskis, Executive Director  
Veronica Hood, PhD, Scientific Director  
Jamie Cohen, CPA, Finance & Program Director  
Cheyenne Wolf, Development Coordinator  
Shannon Cloud, Patient Advocacy Director  
Misty Ried, Campaign Director  
Meredith Bankston, Event Coordinator  
Karen Masters-Foster, Administrative Assistant  
Rich Maxey, Family & Caregiver Engagement Coordinator  
Erin Reoyo, Family Network Liaison  
Austin Watson, Family Network Coordinator



## Board



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Ross Nicholas, Vice-President  
Clare Carey, Secretary  
Josh Goldman, Treasurer  
Nathan Batt, Board Member  
Gail Farfel, PhD, Board Member  
Ashley Kerns, Board Member  
Bill Kirshner, MD, Board Member  
Joseph Sullivan, MD, Board Member



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Danielle Andrade, MD, MSc, FRCPC, *University of Toronto*  
Sookyong Koh, MD, PhD, *University of Nebraska*  
Kelly Knupp, MD, MSCS, *Children's Hospital Colorado*  
M. Scott Perry, MD, *Cook Children's Medical Center*  
Ingrid Scheffer, AO, MB, BS, PhD, FRACP, FAHMS, FAA, *University of Melbourne*  
Joseph Sullivan, MD, *University of California, San Francisco*  
Elaine Wirrell, MD, *Mayo Clinic*



## Scientific Advisory Board

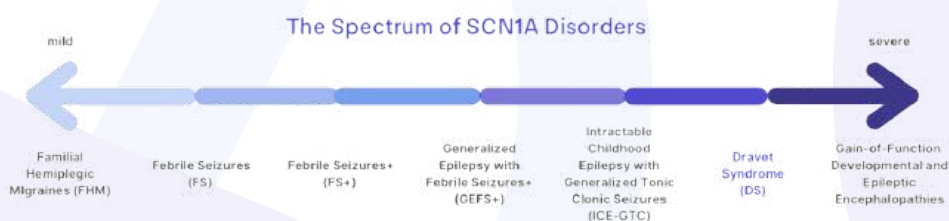


Lori Isom, PhD, Board Co-Chair, *University of Michigan Medical Center*  
Jack Parent, MD, Board Co-Chair, *University of Michigan Medical Center*  
Scott Baraban, PhD, *University of California San Francisco*  
Gaia Colasante, PhD, *IRCCS Ospedale San Raffaele*  
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Ethan Goldberg, MD, PhD, *Children's Hospital of Philadelphia*  
Jennifer Kearney, PhD, *Northwestern University*  
Heather C. Mefford, MD, PhD, *St. Jude's Research Hospital*  
Miriam Meisler, PhD, *University of Michigan Medical Center*  
Sarah Weckhuysen, MD, PhD, *University of Antwerp in Belgium*

# About Dravet Syndrome & Dravet Syndrome Foundation

## Dravet Syndrome

Dravet syndrome is a **rare, challenging, and incurable** condition. It begins in infancy and has significant long-term impacts on patients and their families. Dravet syndrome has an estimated **incidence rate of 1:15,700**, with the majority of patients carrying a mutation in the sodium channel **gene SCN1A**.



Currently, patients with Dravet syndrome face a **15-20% mortality rate** due to Sudden Unexpected Death in Epilepsy (SUDEP), prolonged seizures, and seizure-related accidents.

***Make no mistake, this diagnosis is challenging for many patients and families. But Dravet Syndrome Foundation is here to make this journey easier in any way that we can.***



Seizures associated with Dravet syndrome typically first appear within the first year of a child's life, are often prolonged, and do not respond well to existing medications. Dravet syndrome encompasses more than just challenging seizures; it often involves co-occurring conditions, such as developmental delays, beginning in the second year of life. Treatment options are limited, and the constant care required for someone suffering from Dravet syndrome can severely impact the quality of life for patients and their families.

***For more information on Dravet syndrome, visit [dravetfoundation.org](http://dravetfoundation.org)***





# Dravet Syndrome Foundation

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

When a group of parents started Dravet Syndrome Foundation (DSF) in **2009**, there were no treatments specifically for Dravet syndrome. These passionate caregivers set their sights high, with the goals of **advancing our collective understanding of Dravet syndrome, providing support and advocacy, securing new treatments, and tirelessly working towards finding a cure.**

The mission of DSF has grown, but continues to have patients and their families at the heart of all we do.



As a convener for all affected by and invested in Dravet syndrome, DSF engages and educates all community stakeholders - patient families, clinicians, researchers, and industry partners. We want and need everyone to believe in and fight for better treatments and a better future for patients with Dravet syndrome.



DSF's steadfast commitment to advancing Dravet syndrome research and our community's engagement throughout the clinical trial and drug development process has helped enable three new treatments for the disease, with several additional clinical trials already underway or soon starting.



Looking back on 2023, this has been another year to celebrate. Our Day of Dravet workshops brought together **510 individuals**; we hosted 12 Steps Toward a Cure events that **raised over \$153,000** and five galas that **raised \$1.3 million**; distributed **140 Newly Diagnosed Kits**; and were awarded the highest rating possible from Charity Navigator.



In 2023, we achieved the milestone of **awarding \$2.475M in grant funding**, bringing our **total awarded since 2009 to more than \$9.1 million**, making us the largest non-governmental funder of Dravet syndrome research worldwide.

DSF-funded science has made a significant impact on research. Over 80% of DSF grants result in scientific publication upon completion, and **DSF-funded researchers have secured over \$30 million** in subsequent NIH-funding focused on Dravet syndrome or related topics. NIH funding for all projects related to Dravet syndrome has also greatly increased, **from less than \$3 million in 2009 to now over \$10 million each year since 2018.**

***The driving factor of DSF's success so far is our growing community. The more people we can educate, the more patients we can support, and the more research we can fund - the closer we are to finding a cure.***

## Impact & Growth

Significant achievements and breakthroughs marked 2023 for our organization. By the year's end, we reached a remarkable milestone, having awarded over

# \$9.1 million

in research grant funding. This accomplishment solidifies our position globally as the **largest non-governmental funder of Dravet syndrome research**.

In November, we hosted our **14th annual DSF Research Roundtable**. This event is a crucial forum for collaboration and knowledge exchange, bringing together researchers, clinicians, and other community stakeholders. The number of attendees and the breadth of expertise represented at the annual Research Roundtable has grown considerably over the years. Our 2023 event had over 180 attendees and some of the scientists in the audience who first came to the Roundtable as junior researchers now attend with members of their own independent laboratories focused on Dravet research. The insights gained from these gatherings contribute immensely to advancing our understanding of Dravet syndrome.



## Charity Ratings

For seven years now, we are proud to have earned Candid's **Platinum Seal of Transparency on Guidestar** for our demonstrated commitment to financial and organizational transparency.

For the first time this year, we have also received a **Four-Star rating from Charity Navigator**, the highest possible rating they issue. Dravet Syndrome Foundation received a **perfect score for Leadership & Adaptability and Accounting & Finance**, ensuring that when donors give to us, their funds are used as effectively and efficiently as possible.





***Dravet Syndrome Foundation offers educational webinars to learn more about Genetics and Gene Therapies.***

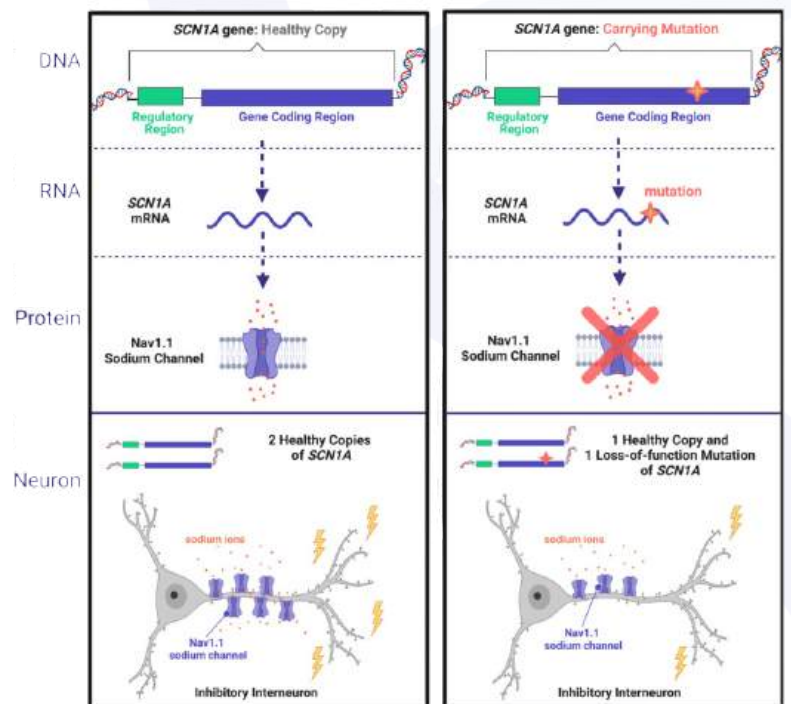


Our understanding of the SCN1A gene and the mutations underlying Dravet syndrome has expanded significantly. This deeper comprehension has not only refined diagnostics but has also shed light on the impact of these mutations on brain development. This, in turn, opens new avenues for exploring genetic-based therapies, offering promising possibilities for the future.

Furthermore, DSF is actively investing in efforts to enhance our understanding of the progression of symptoms in Dravet syndrome.

This investment is intended to provide a more detailed characterization of the clinical picture, ultimately leading to earlier diagnosis, improved outcomes, and better treatment strategies. The strides made in 2023 reflect our unwavering commitment to advancing research and knowledge, ultimately bringing us closer to transformative therapies and improved outcomes for those affected by Dravet syndrome.

A particularly exciting development is our proximity to therapies that have the potential to be truly disease-modifying. These therapies aim to address the symptoms and target the root cause of Dravet syndrome, offering hope for a transformative impact on the patient experience. DSF is actively engaged in closing the final gaps in the development and accessibility of essential research tools, such as animal and cell models. An illustrative example of our commitment is the initiation of the development of commercially available iPSC (induced pluripotent stem cell) lines. These lines will be invaluable for academia and industry, facilitating the exploration of potential new treatments for Dravet syndrome.



*Image created with Biorender.com*



# New 5-Year Strategic Plan

## Looking Ahead to the Next 5 Years

So much has changed since DSF was formed in 2009 and since the adoption of our most recent 5-Year Strategic Plan in 2018. The purpose of that plan was to articulate the long-range direction and priorities for the organization, and it was inspired by the state of the Dravet syndrome landscape at the time. **What were the treatment options? What were researchers looking at? What did our community need? What gaps could we fill?**

To answer these questions, we listened to a broad range of input from key stakeholders regarding community priorities, emerging needs, and organizational strengths and vulnerabilities. The strategies from those discussions informed our efforts and investments throughout 2022.

***Since initially drafting our 5-year strategic plan in 2018, DSF has awarded an additional \$5.5 million in research grants, \$925,000 of which was invested into research on genetic or other disease modifying approaches to treating Dravet syndrome.***

That plan also **led to us unveiling a new brand identity** last June to reflect the organization's history and its strategy for the future. This included launching our new website, which features more ADA accessibility, website translation capabilities, updated physician and comprehensive care center directories, caregiver and HCP resource pages, an educational video directory, and a consolidated news page.

DSF has continued to support the development of clinical treatments to reduce seizures in Dravet syndrome by working with pharmaceutical and biotechnology companies to bring their treatments to the market. Since the inception of the Strategic Plan in 2018, three medications have received FDA approval for the treatment of Dravet syndrome.

Our **new 5-year strategic plan** is now completed and will guide us through 2028 and beyond. Early in 2023, we again looked to our community for input and used their feedback to guide our strategies for the coming years. This inclusive approach allowed us to define four core pillars, each brimming with multiple objectives strategically structured to guide our endeavors over the next half-decade:

 **improve access & quality of care**

**support & empower constituents** 

 **accelerate research**

**build & strengthen organization** 

At the pinnacle of our high-level goals is a commitment to bolstering research funding and support. Having already **disbursed over \$9.1 million, DSF proudly stands as the largest non-governmental funder of Dravet syndrome research worldwide.** Recognizing that there is more work ahead, our strategic plan aims to further elevate our impact in the realm of research.



Additionally, we are poised to support and empower our constituents through various initiatives, including launching our new **Legislative Advocacy program.** This innovative program positions DSF to collaborate with other rare disease advocacy groups, amplifying our collective voice to bring the needs of the Dravet syndrome community to the forefront of local, state, and federal government officials.

Education and engagement remain pivotal elements of our strategic plan. By uniting all stakeholders, we aim to better address the unique challenges families living with Dravet syndrome face. From addressing issues such as delayed diagnosis and limited access to services to alleviating the high treatment costs, our comprehensive approach ensures that patient families have the tools and information necessary to provide the best possible care for their loved ones. Through this strategic plan, we look forward to advancing our mission, breaking new ground, and impacting the lives of those affected by Dravet syndrome.



**For our full strategic plan, scan the QR code below or visit [www.dravetfoundation.org/about-dsf/dsf-strategic-plan/](http://www.dravetfoundation.org/about-dsf/dsf-strategic-plan/)**

**DRAVET SYNDROME FOUNDATION**

**5 YEAR STRATEGIC PLAN 2023 - 2028**



SCAN CODE



# Improving Access & Quality of Care

## Comprehensive Care Center Meeting

Individuals with Dravet syndrome have complex, lifelong, unique neurological and medical needs. Often, local care teams are not familiar with the syndrome or how to treat it. This leads to many families having to travel far from home to access the care their loved one requires.

This is why we are passionate about identifying and featuring Comprehensive Care Centers on our website. For a healthcare facility to be recognized as a DSF Comprehensive Care Center, the center is required to embrace a multidisciplinary approach to Dravet syndrome treatment and offer a wealth of expertise and resources dedicated to the condition.

In the year 2023, **DSF proudly added three new Comprehensive Care Centers** to our listing, bringing the **total to 24 centers** strategically located across the United States. This expansion reinforces our ongoing commitment to help patient families access specialized care while navigating the complexities of Dravet syndrome.

A visit to a Comprehensive Care Center proves invaluable for patients and their families, fostering connections with seasoned experts, while also helping to create a vital connection between the Comprehensive Care Center and their local care team.

This year, DSF also had the opportunity to convene a virtual meeting with representatives from our Comprehensive Care Centers to facilitate open communication, discuss outstanding needs for the patient community, ensure centers are aware of currently available resources from DSF, and share unique approaches that centers are taking to support families.





## Prioritizing the Patient Voice

We consider ourselves a convener for the Dravet syndrome community, uniting patient families, clinicians, researchers, and key partners in the pharmaceutical and biotechnology sectors.

Within the biopharma community, our goal is to establish and maintain meaningful partnerships by actively championing the patient voice and experience. By establishing patient advisory boards with biopharma partners who are advancing therapeutics for Dravet syndrome, we can ensure that the unmet needs within our community are not merely heard but earnestly addressed in the development of groundbreaking therapies.

This collaborative approach serves as a foundation for shared insights, creating a dynamic platform for collective progress. Additionally, it enables us to provide robust support for educational initiatives and resources that prove invaluable to our patient families.

Thanks to the support of these partnerships and the ongoing conversations we have about patient needs, DSF has been able to provide significant support to our patients and their families:

These collaborations played a pivotal role in hosting the **2023 Educational Webinar Series**. We distributed over **140 Newly Diagnosed Kits, 116 VIP Sibling Kits, and 568 Birthday Buddies**, all of which offer crucial information, support, and a sense of community during various stages of the Dravet syndrome journey.

We are immensely proud of these collaborations that enhance the quality of treatment, support, and additional resources that are available to our community.

## Patient Assistance Grant Program

Families caring for a loved one with Dravet syndrome face high care costs. Whether it's for an adaptive stroller, food and tools for the ketogenic diet, communication and educational devices, or other medical or therapeutic equipment, we know that most families in our community need help at some point.

We want families to focus on offering the best quality of care for their loved ones regardless of their financial situations. Since our inception in 2009, we've offered our Patient Assistance Grant Program to help pay for these necessary and valuable items that insurance might not cover.

This program offers grants worldwide to patients with Dravet syndrome. **Each year, the grant cycle runs from January 1-December 1. Families can receive up to \$1,500 a year with a lifetime maximum award of \$5,000.** To date, we have distributed more than

**\$257,971** to **232 families**



# Supporting & Empowering Families

## Newly Diagnosed Kits

Receiving a diagnosis of Dravet syndrome can be overwhelming and may leave a family with many unanswered questions and unsure of where to begin. Much of the general information they come across may be outdated or based on studies done on people diagnosed clinically at an older age. And within the diagnosis of Dravet syndrome, there is a wide range in the variety and severity of symptoms and comorbidities.

For families looking for support after this life-changing diagnosis, we offer them the chance to join our DSF Family Network, which is open to any parent/legal guardian or adult sibling interested in accessing our advocacy services and programs.

To help make the first steps in their journey a little easier, everyone who registers in the DSF Family Network receives a Newly Diagnosed Kit, which includes a printed guide for newly diagnosed families, as well as a medication bag and other materials to assure that families new to this diagnosis have the tools and resources they need for their child's care.

# 140

**newly diagnosed kits**, were sent out from October 2022 to October 2023, telling us that newly diagnosed patients and families continued to need our support.



## Support Groups

Living with a rare disease like Dravet syndrome can make families feel isolated and overwhelmed. Our private moderated support groups, which are tailored to various needs, serve a vital role for parent caregivers and legal guardians by providing support, educational resources, and a sense of community.

Here's a snapshot of our diverse support groups, which altogether support more than 5,000 individuals:



### international caregivers group:

A global network with 3.4K members, fostering a sense of shared experience and support on an international scale.

### five regional U.S. groups:



Tailored to specific geographic areas in the U.S., these groups provide localized support and understanding.



### caregivers of adults:

A specialized group addressing the unique challenges faced by caregivers of adult individuals with Dravet syndrome.

### bereavement:



A compassionate space to find support and discuss the loss of a loved one to Dravet syndrome.



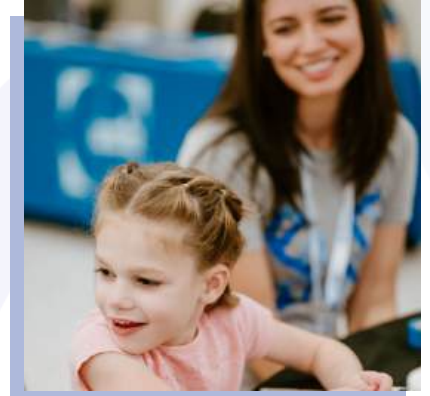
### Spanish-speaking:

This new and growing group offers an inclusive and understanding environment for Spanish-speaking caregivers.

In these groups, parents gain access to essential information, empowering them to make informed decisions about their child's treatment and care. Moreover, the connections formed within these groups create a supportive network, helping families navigate the complex medical journey that Dravet syndrome presents.

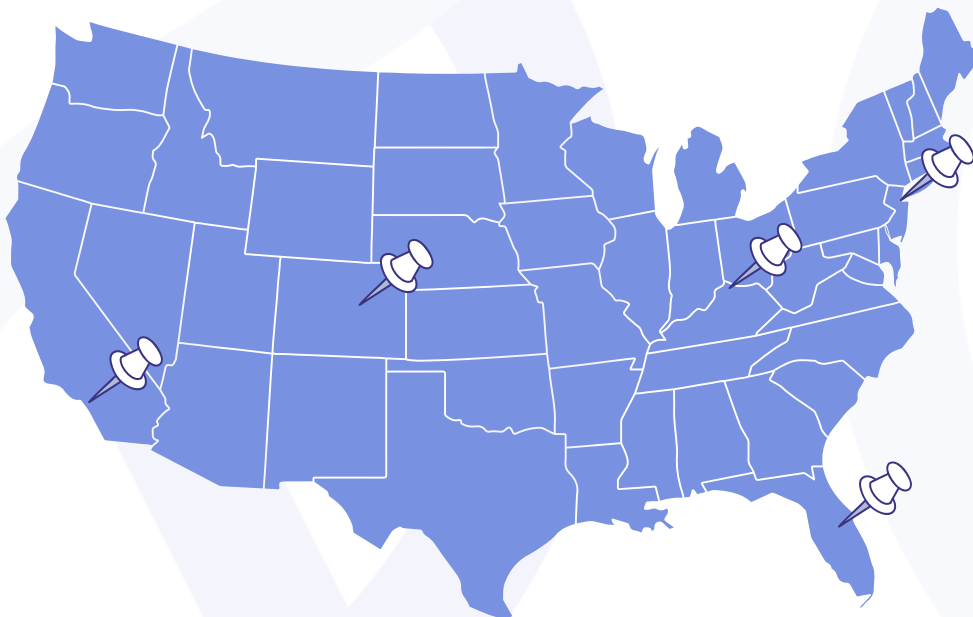
We understand that strength lies in unity, and through our support groups, we are bolstering our community to be one that stands together, offering solace, understanding, and shared wisdom.

## Day of Dravet Workshops



In 2023, we were delighted to resume our Day of Dravet workshops in person. These regional one-day gatherings for patients and families occur biennially in rotation with our conferences and serve as valuable opportunities for families to deeply explore the latest research and treatment options, establish connections with fellow attendees, and collectively advance outcomes for those affected by Dravet syndrome.

Between September and November, our 2023 workshops in **Anaheim, CA; Denver, CO; Newport, KY; Stamford, CT; and Orlando, FL**, welcomed more than **510 attendees**. The diverse locations of these workshops ensured inclusivity, allowing families from various regions to converge and contribute to our shared vision.



***"It's a journey for all of us, but I'm so glad that we're not on an island alone."***

***-Shenique Route, 2023 Day of Dravet Participant***

Reflecting on the success of our 2023 workshops, we eagerly anticipate building upon this momentum in the future. Our commitment remains steadfast in providing this educational, connected, accessible, and supportive forum within the Dravet community.



## Family Ambassador Program

At DSF, our Family Ambassador program stands as a central pillar of support and advocacy for our families.

These passionate volunteers, all of whom are parents and caregivers themselves, are often the first point of contact when newly diagnosed families reach out to DSF. In this way, they become guiding lights, directing families to the crucial assistance and education they're looking for.

Actively engaging across various platforms like social media, online support groups, fundraising initiatives, and both live and virtual events, these ambassadors significantly amplify our impact. The carefully selected Family Ambassadors represent the five regions (West, Mountain, Midwest, Northeast, and Southeast), providing localized support and representation.



Currently, our Northeast boasts two Family Ambassadors, the Midwest has three, and the West has two, while a dynamic team of five Brand Ambassadors contributes to our outreach efforts. Looking ahead, we are eager to expand the Family Ambassador program in 2024 as part of our commitment to build a robust network of advocates that can broaden the impact of DSF.

What sets these Ambassadors apart is their deep involvement and passion for DSF's mission.

***Notably, three Ambassadors have recently transitioned into part-time staff roles within the organization:***



**Shannon Cloud**  
Patient Advocacy  
Director



**Rich Maxey**  
Family & Caregiver  
Engagement Coordinator



**Austin Watson**  
Family Network  
Coordinator



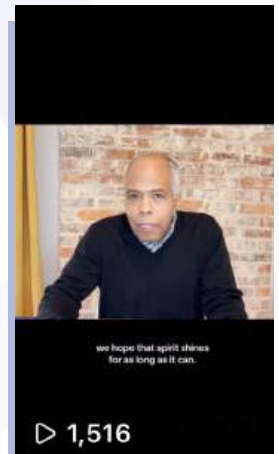
## Dravet Syndrome Awareness Month

Our community - staff, Board of Directors, Family Ambassadors, support group moderators, researchers, volunteers, clinicians, and families - work hard year-round to bring our mission to life.

And in June, Dravet Syndrome Awareness Month, we really get to shine. **This year, the highlight was all the impactful family stories** we were able to share - courageous parents and caregivers coming together to tell the world about their loved ones and their journeys.



**4 videos were posted to Instagram and TikTok, garnering a total of 64,872 views across both platforms. One video on TikTok took up 75% of the views, with 48,600 in total.**



On June 15, we came together for our 3rd Annual Remembrance Day, honoring and remembering those we have lost. We hosted a live video tribute on Facebook for all to join and remember those we've said goodbye to. We invited families to submit their loved ones' information for our ongoing Virtual Remembrance Wall on our website.

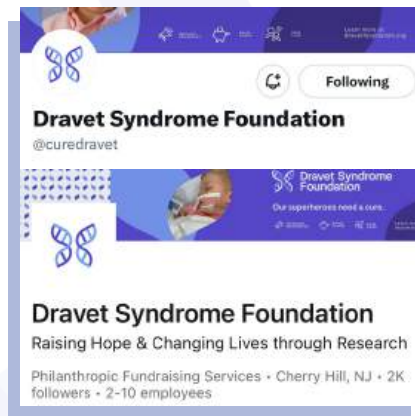
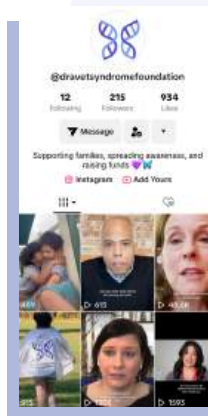
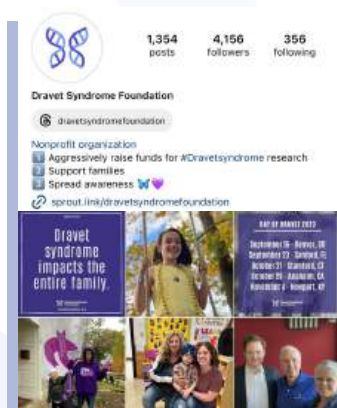
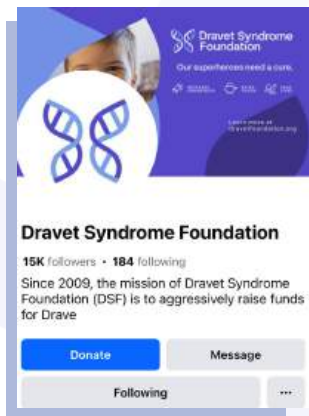


And on June 23, we join the global community in recognizing International Dravet Syndrome Awareness Day. This year, we were honored to receive a proclamation from the City of Sanford, Florida that recognized this special day.

## Social Media

Dravet patients and their caregivers, scattered across the country, often experience feelings of isolation. We work hard to reach out to them in so many ways - support groups, ambassador programs, educational events, fundraising, and more - but we always want to do more to meet our families where they are.

In this day and age, many of them are looking online for sources of hope and community. To provide constant reminders they are not alone, **Dravet Syndrome Foundation is active on:**



## 2023 social media metrics

**1,138,823**  
impressions

**7.4%**  
engagement  
rate

**83,760**  
engagements

**4,039**  
shares

**25,300**  
followers across  
platforms

Families and caregivers turn to our accounts not only for information and support from us, but most amazingly, they use it as a place to lean on and support each other. They celebrate their Warriors' achievements both big and small and find comfort in having others join their joy. Additionally, researchers and healthcare providers refer to their LinkedIn and X for research updates, grant opportunities, and educational opportunities to continue their knowledge. Our email list also delivers news straight to our community's inboxes, reaching 4,460 subscribers with 24 emails in 2023.

# Accelerating Research

DSF is committed to advancing research aimed at enhancing the lives of individuals affected by Dravet syndrome. We prioritize funding for research projects that have a clear focus on biological understanding, clinical application, and therapeutic development. Each research application undergoes a meticulous scientific review, with emphasis on novelty, innovation, scientific rigor, approach viability, and potential for success. Equally important, we consider projects that directly address the needs and priorities of our patient community.

Since 2009, **DSF has funded over 65 research grants**, reaching **a value of over \$9.1 million** at the end of 2023. This makes DSF the largest non-governmental funder of Dravet syndrome research worldwide. With guidance from our Scientific and Medical Advisory Boards, we seek to build on successful studies and support risky but exciting new lines of investigation with high potential payoffs. We also bring together a larger group of researchers, epileptologists, neurologists, geneticists, and other professionals during our annual Research Roundtable so they can share their learning and collaboratively chart the path forward for Dravet research. Through these efforts, DSF hopes to help scientists unlock the mysteries of Dravet syndrome.



***By fostering collaboration, facilitating open communication, and providing financial support to our research partners, we work together to accelerate treatment development and, ultimately, a cure.***

## 2023 Research Grants

Dravet Syndrome Foundation's Research Grant Programs provide essential funding for research focusing on Dravet syndrome and related disorders. These grants support early-stage research endeavors exploring hypotheses that have not been thoroughly investigated. The outcomes of this research serve as a crucial stepping stone, positioning it to be considered for larger-scale government funding in the future.

### Transformational Science Grants

*Intended for projects that have substantial preliminary data, investigate hypotheses directly related to Dravet syndrome, and have the potential to significantly impact the field of research.*

### Research Grants

*Intended for early-stage projects from established researchers investigating hypotheses directly related to Dravet syndrome.*

### Clinical Research Grants

*Intended for early-stage projects from established researchers with a clinical focus that investigate hypotheses directly related to Dravet syndrome.*

### Postdoctoral Fellowships

*Designed to support early-career researchers under the mentorship of an independent investigator.*

### Clinician-Research Awards

*Designed to support early-career clinician-researchers with a clinically-focused project while under the mentorship of an established investigator.*







## 14th Annual Research Roundtable

Every year, DSF hosts a Research Roundtable that brings together researchers, geneticists, neurologists, and other professionals with a strong interest in Dravet syndrome and related epilepsies.

This roundtable aims to help DSF prioritize funding for research projects that will address the most critical challenges of Dravet syndrome and offer the most promising breakthroughs at the fastest pace. By convening this consortium of specialists, DSF is staying ahead of the curve and supporting the development and implementation of the best treatment options.

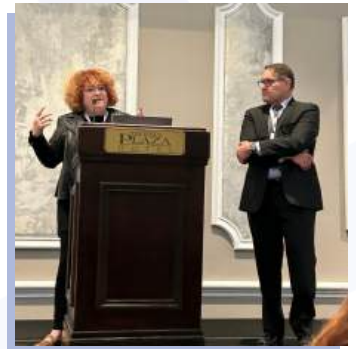
Starting in 2010, the first meeting was a true roundtable of less than 25 individuals gathered to discuss advancements and current gaps in the field of research. In 2023, the **Research Roundtable has grown to almost 200 attendees.**

DSF used the night to announce their 2023 grant awards and featured a focus on the patient experience. DSF Board President, Dr. Theron Odlaug, shared his granddaughter's experience with Dravet syndrome and underlined the need for improved algorithms to guide treatments.

Dr. Joseph Sullivan detailed the recent prospective observational studies that have sought to better characterize the clinical presentation, spectrum, and progression of Dravet syndrome. Dr. Cameron Metcalf, a 2020 DSF Grant Awardee, updated the audience on his laboratory's progress investigating how breathing may be impacted in a mouse model of Dravet syndrome and how changes in the brain and respiratory system may be connected with SUDEP (sudden unexpected death in epilepsy).

Annagabriela Figueroa spoke about her work in the laboratory of Dr. Manisha Patel, a 2021 DSF Grant Awardee, to understand metabolic changes in Dravet syndrome using animal models as well as cells from patients. The final presentation from Dr. Moran Rubinstein and Dr. EJ Kremer, 2021 DSF Grant Awardees, described the success of their novel approach to a genetic therapy in a mouse model of Dravet syndrome.

The talks on cutting-edge science led to an engaging discussion about the progress that has been made, as well as what outstanding questions should be focused on in the immediate future.



## Unique Tools for Research

While funding for Dravet research is critical, DSF doesn't stop there in supporting our scientific community.

### ***AI-powered Dravet Ontology***

In 2023, DSF funded a project to develop an AI-powered Dravet syndrome ontology under the guidance of Satya Sahoo, PhD, and Jeffrey Buchhalter, MD, PhD.

An ontology works as a framework to show connections between words. It can be used to derive information from existing data sources and help identify places where critical information is needed. This Dravet-specific ontology would build off the existing Epilepsy Ontology but will add in Dravet-specific terms.

The ultimate goal of these ontologies is to provide the framework for artificial intelligence (AI) analyses of existing data and literature. As the information and research about Dravet syndrome grows, it becomes increasingly difficult to search every information source. However, with AI, these deep searches to find information or literature gaps related to a specific question become easier.

***"The purpose of this project is to create a Dravet ontology (an artificial intelligence (AI) model that includes the most important concepts and their relationships to a topic). The ontology will be used to develop an AI engine capable of finding and analyzing articles in the basic and clinical science literature."***

***-Dr. Jeff Buchalter  
and Dr. Satya Sahoo***

As part of the project's initial phase, we assembled an expert panel of scientists and clinicians. We held an in-person meeting in Denver, CO, to review the ontology, add essential terms, and discuss initial questions with which to pilot the first iteration of the ontology. It was a productive and engaging meeting that will strengthen the eventual outcomes and lead to the next stage of development for this approach.

### ***Biobank of patient-derived iPSCs***

In partnership with the Orphan Disease Center Biorepository at the University of Pennsylvania and Coriell Institute for Medical Research, DSF is leading an initiative to establish iPSCs - a critically important patient-provided cellular model - that will be available commercially at a very low cost.

Many iPSC lines from patients with Dravet syndrome exist, but they are siloed in individual research laboratories. Researchers have been incredibly collaborative in sharing, but the extra steps required can be burdensome on research labs and create barriers to the ease of access, delaying progress.

Researchers can collect skin or blood cells from a patient and then put those cells through a process called 'reprogramming' that induces them to become stem cells. In a laboratory, iPSCs can be directed to turn into specific cell types by exposure to special factors and growth conditions, allowing researchers to study a range of relevant cell types, such as neurons or heart cells.

# Building & Strengthening the Organization

## New Staff & Board Members

DSF is proud to have made four strategic hires in 2023 to support our organization's growing impact and further build out our advocacy and outreach efforts.

Notably, three out of our four hires are parents of Dravet syndrome patients, giving them a unique empathy for the struggles that many families in our community face.



**Shannon Cloud**  
Patient Advocacy  
Director



**Rich Maxey**  
Family & Caregiver  
Engagement Coordinator



**Austin Watson**  
Family Network  
Coordinator

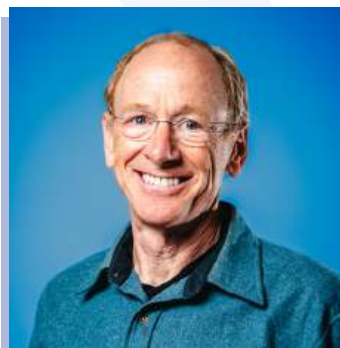


**Cheyenne Wolf**  
Development  
Coordinator

Additionally, we were excited to welcome two new board members to our team in 2023.

*Gail brings over 25 years of pharmaceutical development and regulatory rare disease experience with large and small pharmaceutical companies. She is the chief executive officer of ProMIS, a biotechnology company focused on generating antibody therapeutics for neurodegenerative diseases. Gail was formerly the executive vice president and global chief development officer at Zogenix, Inc., where she led all product development activities to bring Fintepla (fenfluramine) to market to treat seizures in Dravet syndrome. It was through Zogenix that Gail learned the important work of the DSF, and she is proud to join the board to share her expertise to aid the advance toward better treatments and a cure for Dravet syndrome. Before Zogenix, Gail held executive roles at Marinus Pharmaceuticals, Novartis Corporation, and Pfizer.*

**Gail Farfel, PhD**  
Board Member



**Bill Kirshner, MD**  
Board Member

*After 37 years as a family practitioner, Bill is enjoying retirement with his wife, Ileen, five children, and five grandchildren. His youngest grandchild, Zoe, was diagnosed with Dravet syndrome after recurrent seizures at 6 months of age. This all-consuming diagnosis changed the focus of his family. In his words: "We gathered our bearings and found support, community, and a way forward in Dravet Syndrome Foundation."*

*As Bill joins the Dravet Syndrome Foundation team, he hopes his commitment to improving care and support of the Dravet community will reduce the isolation and burdens that patient families carry.*



## Partnerships

We are so proud of everything we accomplish together at Dravet Syndrome Foundation. But we know the needs of our patient and family community are great and that we can do better for them when we work together.

Collaborating with other nonprofits is pivotal in advancing our mission and accomplishing mutual objectives, ultimately fostering a more robust community. These relationships have empowered us to amplify our advocacy efforts, extend our influence, enhance visibility, promote innovative ideas, and provide an expanded array of services for our patient community.

Through these strategic collaborations, we are better equipped to address the multifaceted needs of those affected by Dravet syndrome and work towards a brighter future together.



NeurologyLive

**To learn more about our partnerships, scan the QR code or visit [www.dravetfoundation.org/about-dsf/partnerships/](http://www.dravetfoundation.org/about-dsf/partnerships/)**



DSF has recognized the impact that convening experts to discuss cutting-edge research can have on progress and the development of novel research questions. To that end, DSF was able to sponsor three professional meetings in 2023 that focused on topics of importance to Dravet syndrome:

DSF sponsored the **2023 Gordon Research Seminar “Inhibition in the Central Nervous System,”** a 2-day event focused on advancing junior researchers in the epilepsy field held in conjunction with the prestigious Gordon Research Conference on the same topic.

DSF also supported the **Park City Epilepsy Meeting**, held in October, which brought together scientists, industry, government representatives, and advocates to discuss the most cutting edge advancements in research tools and our understanding of epilepsy.

DSF was also proud to sponsor the **2023 Partners Against Mortality in Epilepsy (PAME) meeting**, which focuses on research into understanding the high rates of mortality associated with epilepsy, particularly sudden unexpected death in epilepsy (SUDEP). In addition to a robust scientific program providing updates on our current knowledge of these issues, PAME also provides a place for support and connection for families who have lost loved ones to epilepsy-related causes.



## Fund Development

None of what we do would be possible without the fantastic community of patient families who support our fundraisers. This was a milestone year for many of our annual events.

***"We wanted to host because we know that the power is within us to help fund research for a cure. Dravet Syndrome Foundation has helped my family in so many ways, and without them, I would not be as knowledgeable about Dravet syndrome as I am today. DSF is truly a by-the-family, for-the-family organization that I am proud to be a part of."***

***-Kayci Capps***



***"Being able to raise funds and awareness for Dravet syndrome benefited us, my son, and the entire Dravet community. We can't wait to get started planning for next year."***

***-Nathan Hanovich***

## Steps Toward a Cure

In 2023, Dravet Syndrome Foundation orchestrated a **remarkable series of twelve "Steps Toward a Cure"** fundraising and awareness walks. These included a virtual event in Colorado, a dynamic Race for Research, and 10 vibrant in-person gatherings across our West, Southeast, and Midwest regions.

The collective dedication of the participants culminated in an impressive **fundraising total exceeding \$208,000**, which can cover the costs of training grants for two early-career innovative researchers in the DSF community.

During our in-person events, we introduced eye-catching butterfly garden signs, now adorning the gardens and yards of participating Dravet families. These signs symbolize unity and hope, reflecting the strength of our community.



Looking ahead to 2024, our goal is to increase the number of Steps Toward a Cure events. This expansion underscores our dedication to raising awareness, fostering connections, and generating critical funds that will advance research.

One step at a time, we'll continue to move closer to our shared goal of making a meaningful difference in the lives of those affected by Dravet syndrome.

## Galas

In 2023, we saw the *most successful year for our galas yet*. Alongside our established annual events in Frisco, TX, St. Louis, MO, and Boise, ID, we proudly introduced two new galas - Strike Out Dravet in Boston, MA, and Dance Away Dravet in Jamison, PA. This expansion led to a significant increase in funds raised, **soaring from \$772,000 in 2022 to an impressive \$1.3 million in 2023**.

The events were graciously hosted by **21 families**, all intimately connected to a loved one living with Dravet syndrome.

Collectively, these **five galas welcomed over 1,200 attendees**, many of whom were new to our cause and previously unaware of Dravet syndrome. Witnessing the community's growth, especially as each gala was hosted by local families, was truly heartening. The remarkable attendance also served as proof of the increasing awareness we are creating for Dravet syndrome.



## Marlins for Mason



The First Annual Marlins for Mason Billfish Release Tournament, held on August 4-5 in Ocean City, MD, was a fundraising event like no other.

Marlins for Mason was planned and brought to life by Amanda Prather, the devoted mother of a resilient 5-year-old fighting Dravet syndrome, and a team of cherished family friends, with the goal of raising both funds and awareness for this condition.



Marlins for Mason was born from the dreams Amanda and her family had for Mason, imagining him partaking in the family's tradition of offshore fishing with his dad, grandfather, and uncles. However, Mason's journey took an unexpected turn with the onset of seizures, a common experience for many families affected by Dravet syndrome. Despite the challenges altering Mason's daily life, the Prather family is determined to provide him with the best life possible.

The inaugural Marlins for Mason tournament achieved tremendous success, **raising over \$315,000 for Dravet Syndrome Foundation** and contributed to *funding for the first-ever DSF Transformational Science Grant* that will investigate a disease-modifying therapy in new animal model of Dravet syndrome.



# Financials

## Statement of Activities

Net Assets Without Donor Restrictions		2023	2022
<b>Revenues and Other Support:</b>			
Special events	- revenue	\$ 1,629,770	\$ 1,010,374
	- expenses	(283,205)	(217,673)
	- net	1,346,565	792,701
Program service revenue		473,472	662,596
Contributions and grants		1,156,863	758,182
Investment return, net		278,332	35,591
Total Unrestricted Revenues and Other Support		3,255,232	2,249,070
Net Assets Released from Restrictions		246,154	103,310
Total revenue and other support		3,501,386	2,352,379
<b>Expenses:</b>			
Program services		1,660,926	1,638,551
Management and general		371,392	311,273
Fundraising		130,735	79,015
Total expenses		2,163,053	2,028,839
Change in net assets without donor restrictions		1,338,333	323,540
<b>Net Assets With Donor Restrictions</b>			
Contributions		61,781	213,941
Net assets released from restriction		(246,154)	(103,310)
Change in net assets with donor restrictions		(184,373)	110,632
Change in net assets		1,153,960	434,172
<b>Net assets at beginning of year</b>		<b>5,760,776</b>	<b>5,326,604</b>
<b>Net assets at end of year</b>		<b>\$ 6,914,736</b>	<b>\$ 5,760,776</b>



# Financials

## Statement of Financial Position

<b>Assets</b>	<b>2023</b>	<b>2022</b>
Cash and cash equivalents	\$ 940,715	\$ 1,008,939
Investments	6,443,875	5,167,263
Contributuions receivable	36,608	54,682
Prepaid expenses	83,285	11,792
Other assets	5,418	6,472
Total Assets	\$ 7,509,902	\$ 6,249,149
<b>Liabilities and Net Assets</b>		
<b>Liabilities:</b>		
Accounts payable	\$ 531,404	\$ 337,230
Deferred revenue	63,762	151,143
Total Liabilities	595,166	488,373
<b>Net Assets:</b>		
Net assets without donor restrictions	6,887,248	5,548,915
Net assets with donor restrictions	27,488	211,861
Total Net Assets	6,914,736	5,760,776
<b>Total Liabilities and Net Assets</b>	<b>\$ 7,509,902</b>	<b>\$ 6,249,149</b>

DSF annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2023 and 2022 financial statements to DSF's Board of Directors. These statements were prepared from the audited statements of DSF.

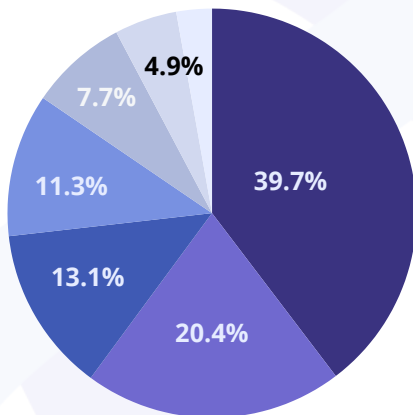
# Financials

For a closer look at our financial statements,  
scan the QR code or visit  
[www.guidestar.org/profile/27-0924627](http://www.guidestar.org/profile/27-0924627)



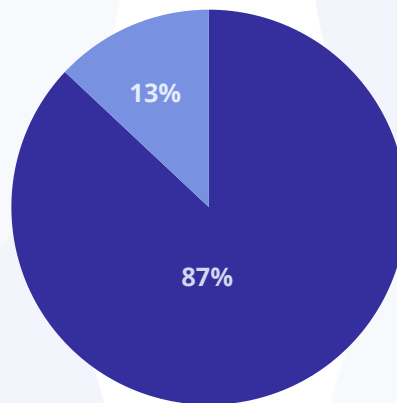
## Revenue Sources

- Individual Donors
- Corporate/Small Business
- Program Service Revenue
- Family Funds/Trust
- Investment Income
- Industry
- Matching Gifts



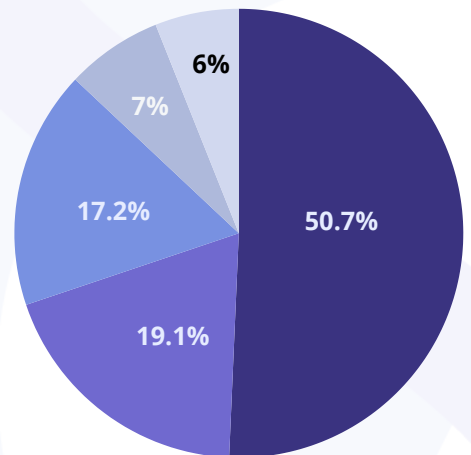
## Expense Ratio

- Program Expenses
- Admin and Fundraising

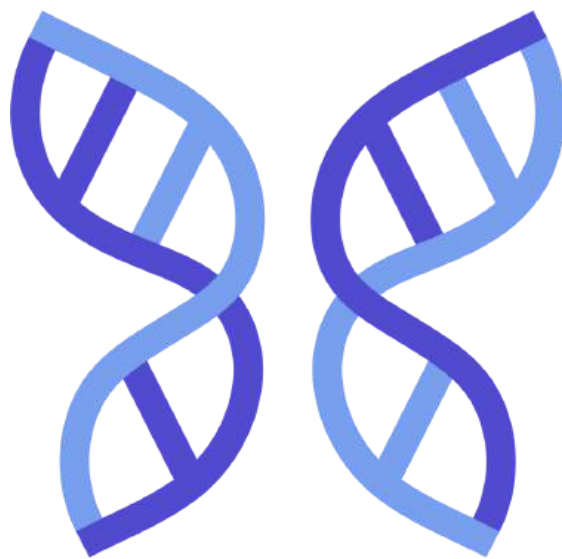


## Total Expenses

- Research
- Patient and Family Services
- Administrative
- Prof. Education & Meetings
- Fundraising



**77% of every donor dollar**  
contributed in 2023 went directly  
toward patient and research-focused  
programs and services



## **Dravet Syndrome Foundation | 2023 Annual Report**

Dravet Syndrome Foundation  
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***Community. Research. Progress.***