



# Dravet Syndrome Foundation

2024 Annual Report



Community | Research | Progress





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# A Message of Hope and Progress

Dear DSF Community,

As we reflect on 2024, one word comes to mind: progress. Thanks to your unwavering support, DSF has reached new milestones in community building, advancing research, and expanding resources for families navigating life with Dravet syndrome.

This year, 135 newly diagnosed families received vital resources through our Newly Diagnosed Kits, while over \$22,000 in Patient Assistance and Disaster Relief Grants provided critical aid during life's most challenging moments. Our Family Network Ambassadors and new caregiver support programs have strengthened the sense of connection within our community, ensuring that no family faces this journey alone.

Your generosity powered \$1.4 million in research grant funding in 2024! Thanks to your support, we're advancing our understanding of Dravet syndrome and making strides toward more effective treatments. Additionally, our 15th Annual Research Roundtable brought together top researchers and medical professionals to collaborate on the future of care and innovation.

The strength of our community has been evident in our record-breaking fundraising efforts. From five galas raising \$1.37 million to our 13 Steps Toward a Cure walks that generated over \$355,000—a remarkable growth of nearly two-thirds more raised over the previous year—your dedication is making a profound impact. And with the launch of our Legislative Advocacy Program, we are ensuring that the voices of Dravet families are heard at both the state and national levels.

While we celebrate these achievements, our work is far from over. The path to a cure requires continued investment, research, and advocacy. Together, we are making progress—one breakthrough, one family, one step at a time.

With gratitude,

*Mary Anne*

Mary Anne Meskis  
Executive



*"Progress is never fast enough. We all want it to be faster. We want to see those new treatments come to us sooner. We want to see those disease modifying treatments get approved, and we want to see the impact on our loved ones. So we never give up. The Odlaugs are never gonna give up. We're gonna keep fighting for Anna, and I want you all to continue to fight for your loved ones too."*

*-Theron Odlaug, PhD, Grandparent*



# 2024 Highlights



**\$1.4** MILLION

INVESTED IN  
RESEARCH

**5** GRANT PROJECTS

ADVANCING  
TOWARDS A CURE

CELEBRATED  
**15**  
**YEARS**  
OF DSF

EMPOWERED  
**188**  
RESEARCHERS  
& CLINICIANS  
AT OUR 15TH  
ANNUAL RESEARCH  
ROUNDTABLE

**5** GALAS  
RAISED OVER  
**\$1.37M**

HOSTED  
**6TH**  
BIENNIAL FAMILY  
& PROFESSIONAL  
CONFERENCE

ATTENDED  
**20+**  
DIVERSE  
PROFESSIONAL  
EVENTS

**13** STEPS  
TOWARDS A CURE  
WALKS RAISING  
**\$355K**

DISTRIBUTED  
**135** KITS  
TO NEWLY  
DIAGNOSED  
FAMILIES

OFFERED  
**\$11K**  
IN CONFERENCE  
**SCHOLARSHIPS**  
TO FAMILIES

PROVIDED  
**\$22K**  
IN PATIENT  
ASSISTANCE &  
DISASTER RELIEF  
**GRANTS**

TRAINED  
**15** FAMILY  
NETWORK  
**AMBASSADORS**

**10** EVENTS  
ORGANIZED BY  
**YOU** RAISING  
**\$617K**

DELIVERED  
**30+**  
**WEBINARS** &  
ENGAGEMENT  
OPPORTUNITIES



## Staff and Board Members

### Senior Leadership

Mary Anne Meskis, Executive Director

Veronica Hood, PhD, Scientific Director

Jamie Cohen, CPA, Finance & Program Director

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Misty Ried, Campaign Director

Meredith Bankston, Event Coordinator

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Karen Masters-Foster, Family & Caregiver Engagement

Austin Watson, Family Network Coordinator

Gloria Rodriguez, MPH, Health Equity Coordinator

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Joseph Sullivan, MD, Board Member



## Charity Ratings and Recognition

DSF is consistently recognized as a top charity for transparency and impact by leading nonprofit evaluators, including Great Nonprofits, Charity Navigator, Candid (GuideStar), and the BBB Wise Giving Alliance (Give.org). These ratings reflect our commitment to accountability, financial stewardship, and making a tangible difference for families affected by Dravet syndrome.

To continue this important work, we rely on the generosity of donors like you. Your support fuels research, advocacy, and direct assistance programs that change lives. Please consider making a donation today to help us drive progress and provide critical resources to the Dravet community.

Donate now at [dravetfoundation.org](https://dravetfoundation.org)







## 2024 Conference

The 2024 DSF Family & Professional Conference was held from June 20th to 22nd at the JW Marriott Minneapolis Mall of America in Minnesota. This gathering united over 500 individuals - ranging from patient families, clinicians, researchers, and industry professionals - to connect, share knowledge, reflect on progress, and address the ongoing needs of individuals living with Dravet syndrome. Over the course of three days, attendees participated in engaging educational sessions and had valuable opportunities for meaningful conversations and connections.

Our patient activity room provided a fun, engaging, and inclusive space where individuals with Dravet syndrome could enjoy creative play, sensory-friendly activities, and social interactions tailored to their unique needs. Additionally, our sibling camp offered a special opportunity for brothers and sisters to connect with peers who understand their experiences, while participating in exciting group activities at Nickelodeon Universe, and enjoying a supportive environment designed just for them. Both programs ensured that all members of the family felt valued, included, and supported throughout the conference experience.

*"Since the earliest days of diagnosis, I ached to meet other families experiencing the things that we were going through. Being in a room filled with so many others who truly understand the challenges and triumphs of Dravet syndrome brought my family an indescribable sense of peace and healing. The sibling camp was an incredible experience for my oldest daughter who was finally able to connect with other kids who understand. We cannot thank DSF enough for this opportunity."*

*-Brianne Trechter, 2024 Family Scholarship Recipient*



*"We are beyond grateful that we were a recipient of the family scholarship to the DSF conference in 2024! We were able to connect with other families as well as learn so much about Dravet that has been really helpful in taking care of our son. We would not have been able to come to the conference without your help. Thank you so much."*

*-Lauren DeBerry, 2024 Family Scholarship Recipient*





## Dravet Syndrome Awareness Month

June 2024 was another milestone year for Dravet Syndrome Awareness Month, bringing our community together in powerful ways. This year, we had the incredible opportunity to celebrate in person at our biennial conference, making it our largest gathering to date for Dravet Syndrome Awareness Day on June 23rd. The energy and support shared among families, advocates, researchers, and medical professionals created an unforgettable experience.

On June 15th, Remembrance Day, we paused to honor and remember the members of our patient community who have passed. Through our Remembrance Day video, we paid tribute to their lasting impact and reaffirmed our shared commitment to advancing better treatments and finding a cure.

Throughout the month, our social media campaign engaged the broader community with daily Dravet facts, empowering individuals to share and spread awareness across their networks. This initiative helped to educate others about the realities of Dravet syndrome while fostering a sense of solidarity within our community.







# 5-Year Strategic Plan: Goals and Progress Updates

Launched in 2023, our current five-year strategic plan builds upon the foundation of past efforts and serves as a roadmap for the future of DSF. This plan not only reaffirms our commitment to advancing the mission of the organization but also establishes a clear and focused vision for the years ahead.

The development of this strategic plan involved a comprehensive analysis of the Dravet syndrome landscape, including recent advancements in research, treatment options, and care strategies. We also conducted a thorough review of the evolving needs within the Dravet community from our key stakeholders - patient families, caregivers, healthcare providers, researchers, and industry members - were central to the process. Through discussions and surveys, we were able to identify pressing priorities, emerging challenges, and areas for growth and innovation.

As we look toward the future, this plan will guide our initiatives, partnerships, and resource allocation, ensuring that every action taken is aligned with our ultimate goal: to improve the lives of individuals living with Dravet syndrome and accelerate the search for better treatments and a cure. Our full 2023-2028 Strategic Plan and Year 1 Update can be found on our website by scanning the QR code.



Scan to access  
our 2023-2028  
Strategic Plan  
and Year 1  
Update



# Research: Driving Innovation for Better Treatments

## 2024 Research Grants

DSF's Research Grant Programs provide essential funding for research focusing on Dravet syndrome and related disorders. These grants support early- and mid-stage research endeavors exploring questions related to the underlying biology, clinical presentation, and treatment of Dravet syndrome. The outcomes of this research serve as a crucial stepping stone, positioning it to be considered for larger-scale government funding in the future.

The 2024 application cycle resulted in the allocation of \$1.4 million across five research grants all focused on novel, targeted treatment approaches for Dravet syndrome. DSF awarded a Research Grant for \$250,000 to a collaborative research project between Ethan M. Goldberg, MD, PhD (Children's Hospital of Philadelphia) and David R. Liu, PhD (MIT and Harvard) investigating the use of a technology called base editing- a newer application of CRISPR technology that allows for correction of mutations that change a single letter in the DNA code.

DSF awarded \$500,000 each to two Transformational Science Grants, one to researchers at The Allen Institute and the other to a collaborative project involving four top research institutions led by Institut de Génétique Moléculaire de Montpellier. Both of the awarded projects focused on unique approaches to treating the genetic underpinnings of Dravet syndrome while adding considerable knowledge to the understanding of how, where, and when genetic interventions may be beneficial.



— John K. Mich, PhD  
2024 Transformational Science  
Grant Recipient

*The DSF funding is a great opportunity to understand how whole SCN1A gene delivery can boost the health of the inhibitory neurons, which are dysfunctional in Dravet syndrome, and how that relates to the seizure control we see. These are really important questions that will guide any gene therapy approach for this terrible disease.*

DSF recognizes the importance of investing in early career scientists and encouraging their long-term research to focus on Dravet syndrome. This year we awarded two exceptional applicants a \$75,000 fellowship for projects exploring genetic regulation and targeted neuromodulation. DSF has now supported 18 postdoctoral fellows, an investment totaling over \$1M.



— Xu Zhang, PhD  
2024 Postdoctoral Fellow

*As an early-career researcher, receiving this fellowship from DSF is truly transformative. It carries special meaning because it represents a direct partnership with the community my research aims to serve. I can now rigorously investigate this technique's therapeutic potential, potentially opening up an entirely new treatment avenue for individuals with Dravet syndrome.*



## *15th Annual Research Roundtable*

In December, we hosted our 15th annual DSF Research Roundtable. This event is a crucial forum for collaboration and knowledge exchange, bringing together researchers, clinicians, and other community stakeholders. This year's event focused on the immense progress in genetic and disease modifying-therapies for Dravet syndrome, including those that have entered clinical studies in patients - something that felt like almost an impossible goal at the first Roundtable in 2010. In addition to exciting talks about cutting-edge advancements, DSF also used the night to announce our 2024 Grant Awards- proudly awarding \$1.4M to five research grants that, on par with the theme for the evening, all focused on preclinical testing of targeted therapeutics.

In recognition of the reality of genetically-targeted treatments for Dravet syndrome, industry members were included in the program for the first time to report on first in-human studies of novel approaches to treating Dravet syndrome at the genetic source and exciting new cellular therapies being tested in other forms of epilepsy. Stoke Therapeutics detailed the development of their antisense oligonucleotide, called zorevunersen, that is designed to increase expression of SCN1A; they presented data from their clinical studies showing not only reductions in seizures but also improvements in measurements related to cognition, development, and behavior. This is a milestone, not only for this specific therapy, but as a proof-of-concept that the broader symptoms of Dravet syndrome can be improved with genetically targeted therapies. Encoded Therapeutics also spoke about the development of ETX101, an AAV-based gene regulation therapy for Dravet syndrome. Encoded began clinical studies in patients mid-2024; while results are still forthcoming, several patients have been dosed with ETX101 and the trials are progressing safely. Presentations from academic researchers also exemplified that while incredible progress has occurred, even more approaches to treating the genetic cause of Dravet syndrome are in development. The rest of the program continued to focus on exciting new therapeutic approaches for Dravet syndrome that are being successfully tested in mouse models, holding promise for the future translation to human patients.

The entire evening was a demonstration of how DSF's early investment in targeted research studies combined with our strategic role as a convener of stakeholders in Dravet syndrome research has coalesced into a new reality of treatments for patients that could be truly life-changing.





## *The Dravet Genome Study*

Following a special grant call in 2023, DSF directed our largest ever grant (\$1M distributed over 3 years) to researchers at Children's Hospital of Philadelphia (CHOP) to create the Dravet Genome Study. This study aims to better understand the broad presentation of symptoms that occur in individuals with SCN1A-related epilepsy and whether the rest of an individual's genetic information may play a role in how symptoms appear.

Researchers are collecting cheek swabs from 500 individuals with Dravet syndrome and closely-related epilepsies caused by mutations in the gene SCN1A, and then sending those samples for whole genome sequencing. Additionally, they will request consent to pull each participant's electronic health record in order to create a reconstruction of symptoms and treatments over time. This clinical dataset can be used to pair with the genomic information to ask if background genetics can explain any of the differences in symptoms like seizure frequency, medication responses, or onset of developmental or behavioral issues.

The project hit the ground running in 2024! With a goal of recruiting 500 patients, they already have over 400 individuals signed-up, and over 300 of those have already returned their sample for sequencing. The team from CHOP presented at our 2024 Biennial Family & Professional Conference and will be attending 2025 Day of Dravet regional events to continue sharing the project with the community and recruiting participants. They were also able to present some of the initial data from the clinical reconstruction of 80 participants at the 2024 American Epilepsy Society Meeting, exemplifying the power of this data to reconstruct information about the course of disease.



*Scan to learn about how you can help  
shape the future of Dravet syndrome*





## *Prioritizing the Patient Voice in Research*

DSF continues to be a leader in amplifying the patient voice in research and advocacy, ensuring that the needs, experiences, and perspectives of those living with Dravet syndrome are heard and prioritized at every level.

In professional settings, DSF representatives regularly engage with researchers, clinicians, and policymakers, advocating for greater attention and resources for Dravet syndrome. By attending and speaking at key conferences and symposia, we not only share the lived experiences of patients but also help shape the direction of research and clinical trials, ensuring that patient needs remain central to the development of new therapies and interventions. Through our educational events, we provide families and caregivers with critical information about the latest advancements in Dravet syndrome care and research. These events offer a platform for patients and families to connect, share stories, and raise their collective voice, creating a sense of community and empowerment. In turn, these gatherings serve as valuable opportunities for researchers and healthcare professionals to gain first-hand insights into the challenges faced by individuals with Dravet syndrome, further informing the design of future clinical trials and treatment approaches.

DSF remains committed to ensuring that patient families are not just participants but key contributors to the conversation surrounding research, care, and policy change. By amplifying the patient voice, we aim to accelerate progress toward better treatments and a brighter future for all those impacted by Dravet syndrome.



*Scan to learn how you can get involved with current legislative initiatives and calls to action*





## *Newly Diagnosed Kits*

A Dravet syndrome diagnosis can be overwhelming for families, bringing uncertainty and countless questions. Many initial resources they encounter may be outdated or based on studies of individuals diagnosed later in life. Additionally, the symptoms and severity of Dravet syndrome vary widely from person to person, making it even more challenging for families to navigate the journey ahead.

To provide immediate support and reliable information, DSF invites families to join our DSF Family Network. This network is open to parents, legal guardians, and adult siblings seeking advocacy, education, and community connections.

As a first step in their journey, every family that registers with the DSF Family Network receives a Newly Diagnosed Kit. These kits include a comprehensive guide for newly diagnosed families, a specialized medication bag, and other essential materials designed to equip caregivers with the tools and knowledge they need to provide the best care for their child.

In 2024, 135 Newly Diagnosed Kits were distributed, ensuring that families facing this life-changing diagnosis had access to critical resources and a supportive community from day one.

"The Dravet Syndrome Foundation helped save us. Two new parents to a then 5 month (now 3) old seizing uncontrollably, in and out of the hospital, a million questions, lost and scared, until we received the Dravet syndrome diagnosis and found this community. This foundation, these people, give us hope, community, a shoulder to cry on. They are a safe place. We could not be any more thankful."

-The Murray Family

"Dravet Syndrome Foundation has been a lifeline to my daughter during her battle with Dravet syndrome. They have helped guide us to the best specialist, provided mental and emotional support, and also assisted us with purchasing seizure alert items that our insurance wouldn't cover. I am forever grateful and thankful"

-Eliana's Cure



## Providing Critical Support: Patient Assistance Grants

At DSF, we recognize the financial strain that comes with caring for a loved one with Dravet syndrome. While we cannot eliminate these challenges, our Patient Assistance Grants (PAGs) and Disaster Relief Grants provide essential support, helping families access critical resources and navigate unexpected crises.

Since 2009, DSF's need-based PAG program has helped families secure vital medical equipment, therapy devices, and educational tools that are not covered by insurance. In 2024, we awarded 13 grants totaling \$15,000, supporting families across the United States, as well as Mexico and Canada. Families can apply for up to \$1,500 per year (with a lifetime cap of \$5,000 per patient), ensuring long-term access to essential care items.

*"This is the first time ever Sabrina was able to do the boardwalk for an extended period of time with no issues! Not one seizure. She loved the fresh air riding in her wagon. Thanks again for making my little warrior the happiest little girl."*

*— Jaclyn Boudidy, 2024 Patient Assistance Grant*

## Disaster Relief Grants

When natural disasters strike, families managing Dravet syndrome face even greater hardship. The DSF Disaster Relief and Recovery Fund, established to provide immediate financial relief, awarded 14 grants totaling \$7,000 in 2024, primarily in response to hurricanes and floods across Texas, Pennsylvania, Georgia, North Carolina, and Florida. Grants of \$500 Visa or Amazon E-cards help families secure lodging, food, and essential supplies during these difficult times.

These programs are made possible by generous donors and continue to provide meaningful, immediate assistance to families when they need it most. As DSF grows, we remain committed to expanding these resources to ensure no family faces these challenges alone.





# Family Network Ambassador Program

The Family Network Ambassador (FNA) Program is a vital part of DSF’s mission, empowering dedicated parent volunteers to support families, raise awareness, and contribute to fundraising efforts. Originally launched in 2018 as the Parent Ambassador Program, it has since evolved to reflect the diverse roles caregivers play in our community.

FNAs act as a bridge between DSF and families, offering guidance on resources, organizing Caregiver Connect events, assisting with social media outreach, and participating in industry partnerships and surveys. Their efforts directly support DSF’s three pillars: awareness, support, and research funding. Each ambassador commits to a two-year term, receives ongoing training, and plays a key role in DSF’s Facebook support groups, email outreach, and direct one-on-one connections.

In 2024, we welcomed 15 new FNAs from across the U.S., including three dads. Representing a range of professions—teachers, engineers, scientists, social workers, and stay-at-home parents—these ambassadors provide countless hours of peer support to families navigating Dravet syndrome.

We look forward to expanding the program, with applications for the 2026-2027 cohort opening in Fall 2025.



Brenda Ferrell, Family Network Ambassador, Southeast Region

*“Serving as an FNA is very rewarding. I’ve met, connected with, and found a lot of support from the other FNAs and seen how we are making a difference in the lives of other Dravet families.”*



Amy Lopez, Family Network Ambassador, Northeast Region

*“One of my favorite things about being an FNA is the support I am able to give to newly diagnosed families.”*



Morgan Turpin, Family  
Network Ambassador, West  
Region

*"Being an FNA has allowed me to  
give back to a community that  
has given so much to our family  
over the years."*



Allen Golec, Family  
Network Ambassador,  
Southeast Region

*"Serving as an FNA has given me  
a meaningful opportunity to give  
back to the Dravet Community  
while being an ear to those who  
feel like they don't have a voice. It  
has also empowered me to  
contribute in the Dravet  
community and support  
fundraising efforts - something I  
never imagined I could do."*



Sara Reyes, Family  
Network Ambassador,  
Mountain Region

*"Being an FNA means using my  
voice to raise awareness and  
support families, while  
advocating for a better future  
for our children."*





# Social Media and Communications Growth

## Social Media: Expanding Our Reach and Strengthening Our Community

At DSF, social media is more than just a communication tool - it's a lifeline for families seeking support, connection, and critical resources. Through our online presence, we provide education, advocacy, and a sense of belonging to those navigating the challenges of Dravet syndrome.

In 2024, DSF's social media presence continued to expand, strengthening connections and providing critical resources to families affected by Dravet syndrome. With a 9% increase in followers, our platforms now reach 27,464 people, including 15,000 on Facebook, 4,790 on Instagram, and 3,551 on X (Twitter). Engagement surged on Facebook and Instagram, with a 168% increase in reach, 179% more content interactions, and 133% more profile visits.

Beyond public pages, our moderated Facebook support groups remain a vital peer-driven resource, with over 3,500 members in our Dravet Parent & Caregiver Support Group. We also offer regional and specialized groups tailored to meet families' unique needs. We hosted over 30 virtual community-building sessions in 2024, including 22 Chat & Connect meetups for caregivers, three meetups just for grandparents, two advocacy webinars, and four Caregiver Connect discussions, offering valuable opportunities for education and support.

Our relaunched Brand Ambassador Program further expanded DSF's reach, with 25 ambassadors driving 366,000+ social media impressions, generating an advertising-equivalent value of more than \$36,000 between June and October.

DSF's email communications also saw growth, with a 7% increase in subscribers, rising from 4,460 in 2023 to 4,768 in early 2024, and 24+ emails sent annually.

With a growing and engaged digital community, DSF continues to leverage social media and online communications to inform, connect, and empower families navigating Dravet syndrome.

## Follow Us & Stay Connected

Facebook: @DravetSyndromeFoundation  
X (Twitter): @curedravet  
Instagram: @dravetsyndromeFoundation  
YouTube: @DravetSyndromeFoundation  
LinkedIn: @DravetSyndromeFoundation  
TikTok: @dravetsyndromeFoundation  
Bluesky: @curedravet.bsky.social





## Key Partnerships and Industry Engagement

As the needs of our community continue to evolve and grow, we actively pursue partnerships and collaborations with other organizations and companies working in the biotechnology and pharmaceutical industry to ensure that individuals living with Dravet syndrome have access to the latest advancements in treatment and care. By engaging with industry leaders, we work to accelerate research, advocate for innovative therapies, and support the development of new treatment options that address both the urgent and long-term needs of our community. These partnerships also allow us to stay informed about emerging scientific discoveries, influence drug development processes to prioritize patient-centered outcomes, and ensure that families not only have access to available treatment options but also receive the support they need to navigate them effectively. Through these efforts, we remain committed to improving the quality of life for individuals with Dravet syndrome and their families.

For a full list of DSF partners, please visit:  
[dravetfoundation.org/about-dsf/partnerships](https://dravetfoundation.org/about-dsf/partnerships)





## Fundraising Events

Each year, our volunteer event coordinators host fundraising events that unite families, friends, and supporters in the fight against Dravet syndrome. In 2024, our Steps Toward a Cure walk series and gala events saw tremendous growth, both in attendance and fundraising success. These events continue to serve as powerful platforms for raising awareness, fostering community, and driving critical research forward.



## Steps Toward a Cure: Expanding Our Footprint, Strengthening Our Impact

In 2024, DSF expanded its “Steps Toward a Cure” fundraising walk series, hosting thirteen events across the United States—including four new locations in Florida, California, and Pennsylvania. Thanks to the incredible support of families, friends, sponsors, and donors, the series exceeded expectations, raising an impressive \$355,000 to fund critical research projects, such as our Postdoctoral Fellowship Grant Program.

*“Our first Steps Toward a Cure fundraiser was more than just an event—it was a deeply personal milestone for our family. Hosting this fundraiser allowed us to turn our love for our son into action, bringing together our community to support vital research, raise awareness, and move closer to a cure.”*

*— Reagan King, 2024 Steps Toward a Cure Host*

*“Hosting a DSF walk was a positive experience for our whole family, especially my daughter’s siblings. Seeing them walk alongside other families, knowing they are part of something bigger, was incredibly powerful.”*

*— Clare Carey, 2024 Steps Toward a Cure Host*



# Galas: A Year of Unprecedented Growth and Success

In 2024, DSF's gala fundraising events reached new heights, bringing in a record-breaking \$1.37 million across four major events. The continued success of our annual galas in Frisco, TX, and St. Louis, MO, combined with the launch of new events in Atlanta, GA, and San Francisco, CA, has helped broaden DSF's reach and impact. These galas, hosted by 14 families deeply connected to Dravet syndrome, provided a meaningful opportunity for guests—many new to our cause—to learn about Dravet syndrome while supporting research and patient programs.



## City Bash: Uniting Our Community in San Francisco

The 2024 City Bash gala, hosted by the Chang and Coombe families, brought together over 200 guests for an evening of fundraising and awareness.

Thanks to the generosity of attendees, sponsors, and donors, City Bash raised over \$341,000—a true testament to the power of community-driven fundraising.



## Spotlight: Dance for Dravet – A Leading Force for Change

Among all fundraising events in 2024, the 6th Annual Dance for Dravet in St. Louis once again led the way, raising an astonishing \$564,000. Since its inception, this event—hosted by Jim Brennan in honor of his great-niece Anna Odlaug—has raised over \$2.3 million, making it a driving force behind DSF's research and patient support programs.

In 2024, Dance for Dravet played a key role in funding one of DSF's two Transformational Science Grants, a \$500,000 investment over three years supporting groundbreaking gene therapy research.

DSF's fundraising events continue to unite our community, raise awareness, and fund cutting-edge research. Whether you walked, attended a gala, volunteered, or made a donation, your support is fueling progress toward better treatments and, ultimately, a cure.

Together, we are taking bold steps toward a brighter future.







## *Growth in Non-Cash Giving*

In 2024, DSF expanded its fundraising reach by launching new non-cash giving options, allowing supporters to contribute via IRAs, stock gifts, Donor-Advised Funds (DAFs), and cryptocurrency donations. We also saw growth in legacy giving, monthly giving, and employer donation matching, strengthening long-term funding.

### Maximizing Impact Through Matching Gifts

Last year, DSF donors leveraged employer matching gifts, unlocking \$75,850 in additional funding—far exceeding the nonprofit average. This participation highlights our community’s dedication to maximizing every donation toward research and support programs.

### A New Milestone: The DSF Endowment Fund

In 2024, DSF’s Endowment Fund grew to over \$900,000, ensuring long-term support for research, patient assistance, and advocacy efforts. This fund is a crucial step toward sustainable progress and the ultimate goal of finding a cure for Dravet syndrome.

### Thank You for Leading the Way

DSF’s mission is driven by the passion and generosity of our community. Whether hosting a benefit event, running a marathon, making a legacy gift, or securing a donation match, every effort brings us closer to a cure. We extend our deepest gratitude to every family, friend, and advocate who has stepped up to fundraise in 2024. Your dedication fuels hope and progress for all those affected by Dravet syndrome.

Together, we are making a difference.





## *A Record-Breaking Year for Peer-to-Peer Fundraising*

The strength of DSF lies in our passionate and dedicated community. In 2024, grassroots fundraising efforts reached new heights, demonstrating the incredible impact of families, friends, and advocates coming together to fuel research and support initiatives.

In 2024, DSF saw an unprecedented increase in peer-to-peer fundraising efforts. Ten community-led benefit events, collectively raising over \$617,000—nearly double the previous year’s total of \$326,487.

### Spotlight: DSF’s NYC Marathon Charity Team

In 2024, DSF was thrilled to be named an official charity partner of the TCS New York City Marathon. Our inaugural marathon team featured six dedicated individuals—a group of Dravet dads, a nurse, an occupational therapist, and a teacher—all running in honor of loved ones affected by Dravet syndrome. Before hitting the streets of New York, they collectively raised \$39,881 to support groundbreaking research. Their journey was a testament to the strength of our community and the power of endurance in the face of challenges.

### Spotlight: Marlins for Mason – Fueling the Future of Dravet Research

One of the most remarkable community-led fundraising efforts in 2024 was Marlins for Mason, now in its second year. This event raised an astonishing \$505,279, providing the critical funding needed to award one of DSF’s Transformational Science Grants, a \$500,000 investment over three years.

The Transformational Science Grant Program is designed to advance bold, high-impact projects that could significantly shape the future of Dravet syndrome research and clinical care. The 2024 grant, supported by Marlins for Mason, is dedicated to developing whole SCN1A gene therapy—a promising new approach to restoring the function of the gene at the root of Dravet syndrome.





## Financials: Statement of Activities

Net Assets Without Donor Restrictions	2024	2023
<b>Revenues and Other Support:</b>		
Special events -revenues	\$1,789,877	\$1,629,770
-direct benefits to donors	(301,705)	(283,205)
Net special events revenue	1,488,172	1,346,565
Contributions and grants	734,789	1,156,864
Program service revenue	1,292,286	473,472
Investment return, net	403,243	278,332
Total unrestricted revenues and other support	3,918,490	3,255,233
Net assets released from restrictions	390,820	246,154
Total Revenue and Other Support	4,309,310	3,501,387
<b>Expenses:</b>		
Program services	3,557,818	1,653,706
Management and general	418,901	374,423
Fundraising	237,361	129,212
Total expenses	4,214,080	2,157,341
Change in net assets without donor restrictions	95,230	1,344,046
<b>Net Assets With Donor Restrictions</b>		
Contributions	401,999	61,781
Net assets released from restriction	(390,820)	(246,154)
Change in net assets with donor restrictions	11,179	(184,373)
Change in net assets	106,409	1,159,673
<b>Net assets at beginning of year (restated)</b>	<b>6,920,447</b>	<b>5,760,774</b>
<b>Net assets at end of year</b>	<b>\$7,026,856</b>	<b>\$6,920,447</b>

## Financials: Statement of Financial Position

<b>Assets</b>	<b>2024</b>	<b>2023</b>
Cash and cash equivalents	\$2,079,863	\$940,715
Investments	6,345,617	6,443,876
Contributions receivable	36,352	36,608
Prepaid expenses	56,059	83,285
Other assets	19,025	5,418
<b>Total assets</b>	<b>\$8,536,916</b>	<b>\$7,509,902</b>
<b>Liabilities and Net Assets</b>		
Liabilities:		
Grants payable, net	\$1,442,946	\$457,122
Accounts payable and accrued expenses	50,233	68,571
Deferred revenue	16,881	63,762
<b>Total liabilities</b>	<b>\$1,510,060</b>	<b>\$589,455</b>
Net Assets:		
Net assets without donor restrictions	6,988,189	6,892,959
Net assets with donor restrictions	38,667	27,488
<b>Total Net Assets</b>	<b>\$7,026,865</b>	<b>\$6,920,447</b>
<b>Total Liabilities and Net Assets</b>	<b>\$8,536,916</b>	<b>\$7,509,902</b>



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)

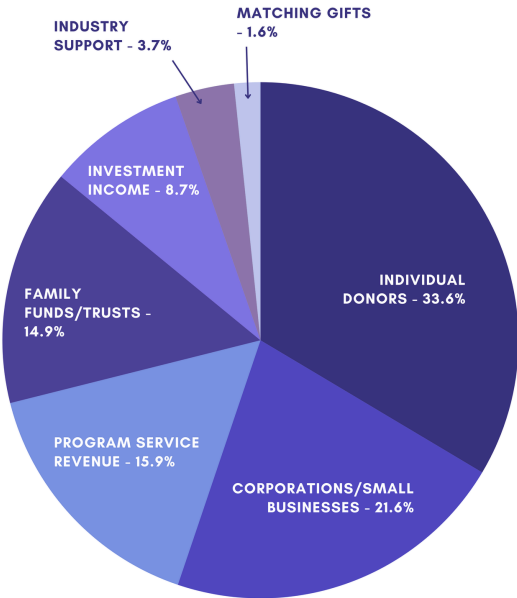
DSF annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2024 and 2023 financial statements to DSF's Board of Directors. These statements were prepared from the audited statements of DSF.



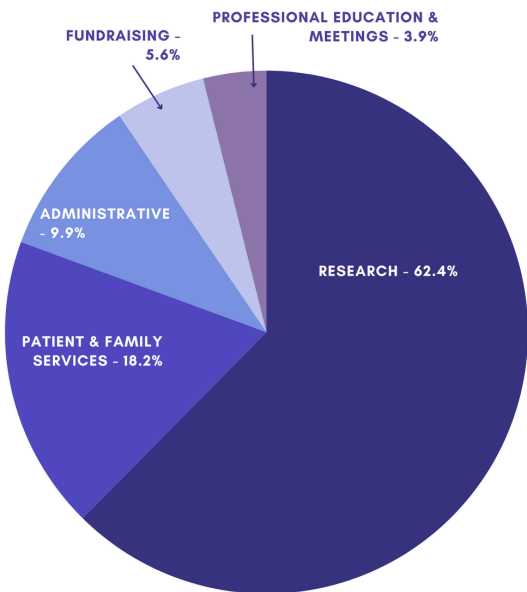


# Financials: Transparency and Accountability

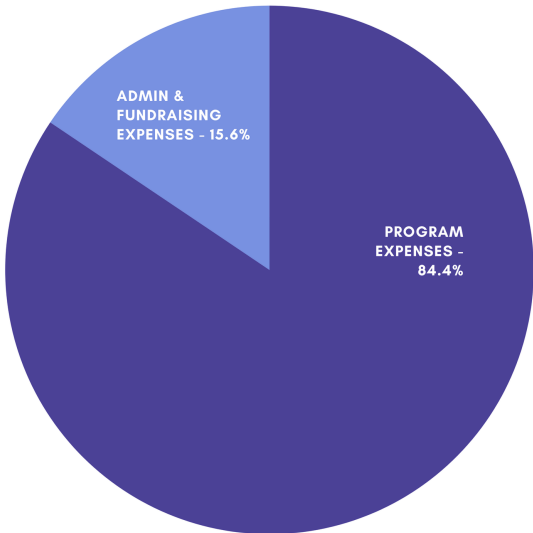
## Revenue Sources



## Total Expenses



## Expense Ratio



**84.4% of every donor dollar**  
contributed in 2024 went  
directly toward patient and  
research-focused programs  
and services



# Dravet Syndrome Foundation

PO Box 3026, Cherry Hill, NJ 08034 | (203) 392-1955 | [www.dravetfoundation.org](http://www.dravetfoundation.org)

*2024 Annual Report: Community | Research | Progress*