



AUGUST 2019

STRATEGIC PLAN PROGRESS REPORT

In 2018, Dravet Syndrome Foundation (DSF) developed a 5-year strategic plan to articulate the long-range direction and priorities for our organization. The content for our strategic plan was derived by examining the Dravet syndrome landscape. We listened to a broad range of input from key stakeholders within our community regarding current community priorities, emerging needs, and organizational strengths and vulnerabilities.

We are pleased to offer our 1st annual update on our progress from July 2018 - July 2019.

GOAL 1: RESEARCH AND PROFESSIONAL EDUCATION

Through collaboration and communication with our research community, we can improve the timeline for better treatments and a cure. By supporting opportunities that allow for greater education on Dravet syndrome throughout the healthcare system, we can increase diagnosis and assure the best quality of life.

Accomplishments from July 2018 - July 2019

- Awarded a grant for a genetic approach of treatment through a special request for applications.
- Sponsorship of several professional meetings with a focus on research approaches that would benefit the field of study of Dravet syndrome.
- Exhibited at professional meetings to raise awareness of Dravet syndrome within the medical and research communities.
- Hosted our 2018 conference and offered CME accredited sessions for professionals.
- Hosted our 9th annual Research Roundtable and began planning the 10th annual event that will take place in December 2019.

GOAL 2: INCREASE REVENUE TO SUPPORT OUR PROGRAMS

Funding growth is challenging particularly for a rare disease nonprofit. By increasing and diversifying our revenue streams we can ensure we have a sustainable operating model that meets the demands of our continuously growing community, and guarantee our success and longevity.

Accomplishments from July 2018 - July 2019

- Hosted two new gala events in St. Louis, MO, and Boston, MA.
- Developed a Birthday Facebook Fundraiser program for our constituents to easily fundraise for us via social media.
- Developed an Investment Committee to oversee our investment-related activities and set best practices to assure the financial strength and longevity of the organization.



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GOAL 3: EXPAND FAMILY EDUCATION & ADVOCACY

We will continue to support patients and families with disease education and advocacy needs through maintenance and expansion of patient resources, as well as family-to-family support.

Accomplishments from July 2018 - July 2019

- DSF brochures have been translated to Spanish and are available on our website for download.
- 14% increase in listings on our *Find a Doctor* webpage.
- Increased membership in our private parent support group by 9.8%.
- Establishment of the *Connect Grants* program, to increase regional patient and family gatherings.
- Offered peer-to-peer support training for *DSF Family Ambassadors* to better equip them with the tools they need to best serve our community.
- Awarded \$18,695 through our *Patient Assistance Grant Program*.
- Began planning for our 3rd annual *Day of Dravet* regional workshops.
- Began planning for 4th biennial conference that will take place June 18-20, 2020 at Cook Children's Hospital in Fort Worth, TX.
- Developed an English and Spanish webinar to educate our community on the importance of the patient voice in research development.
- Hosted a live session on the importance of the patient voice in research at 2018 conference.
- Developed a Dravet Community Stakeholder Group, comprised of caregivers, clinicians, researchers, and industry members to discuss gaps of care and potential collaborations to benefit our patient community.
- Continued our efforts for the approval of a Dravet syndrome-specific ICD-10 billing code.
- Established a webpage identifying *Dravet Comprehensive Care Centers* to assist families in finding institutions that offer comprehensive medical care for Dravet syndrome.

GOAL 4: ENHANCE COMMUNITY DEVELOPMENT & COMMUNICATIONS

By increasing the leadership roles of our staff, board, volunteers, and donors we can build on current strengths through internal capabilities and resources, while strengthening our community connections. We recognize the importance of an ongoing assessment of our role within the community and the most effective use of our resources, as well as the need to continually communicate our priorities, goals, strategies, and accomplishments to inform and engage our stakeholders.

Accomplishments from July 2018 - July 2019

- Development of our monthly *News & Notes* to keep our community up to date on news that is important to them.
- Development of our *Decoding Dravet* blog to promote understanding on topics important to our community.
- Relaunched our *Research Review* to offer overviews of current scientific publications related to Dravet syndrome.
- Addition of a new part-time staff member to help with administrative tasks.
- Establishment of a Board Member Recruitment Committee.
- Addition of a new board member.
- Addition of a new Medical Advisory Board member.



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RESEARCH STRATEGY

Our 5-year strategic plan addresses the three highest priorities for research in our community. 1) Cure 2) Treat and 3) Learn. By distributing resources among these arms, DSF will continue to balance the need for progress toward a cure and the immediate need for better treatments and new pathways toward that cure.

Since drafting our 5-year strategic plan in 2018, DSF has awarded an additional \$640k in research grants, \$240k of which has been invested into research on genetic approaches to treating Dravet syndrome. Three projects comprise the largest single focus of DSF's research dollars since the strategic plan's development.

- DSF awarded one of the largest grants in 2018 to a clinical researcher studying human echocardiograms in more detail than ever before.
- Awarded grant money to a researcher studying a cell model of metabolic deficits in Dravet syndrome, in hopes of developing a novel therapeutic drug target.
- Established a Request for Proposals for Genetic Approaches in 2019 and awarded a grant.
- Prepared our patient community for involvement in research through sessions at our conference; at our Day of Dravet workshops; and through webinars presented in English and Spanish.
- Basic science continues to flourish, with research on neuronal networks and the balance of excitation and inhibition.
- Understanding of the natural course and comorbidities of Dravet syndrome has been the focus of key stakeholder meetings, including gait study development and input on natural history studies.
- The Clinician Researcher Award (\$150k, 2 yrs) was established in 2018 to encourage doctors to prioritize Dravet syndrome in their pursuit of clinical research and to expand the number of clinicians available to learn about our patients.
- Continued support of industry projects aimed at better treatments for Dravet syndrome.

