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Thanks to you we are **91%** of the way to our **\$50,000** end of year match goal!

You've heard the phrase, 'every dollar counts,' right? At the FamilieSCN2A Foundation every dollar counts **double** until the end of the year (and year round with employer matching through Double the Donation)! And, we can show you how every dollar GROWS.

This year at the American Epilepsy Society meeting, we presented a poster evaluating the Return On Investment (ROI) of every small seed grant we have awarded over the last 5 years. This research, much of which was "basic science" has led to the "translational science" work being done now—AND several biotechs have launched thanks to this seed funding.

So, plant a seed today, water it with the year-end match, then watch it grow when your employer matches your donation. Look at it blossom as scientists receive larger grants and investment from industry that grow into the fruit of more effective SRD treatments and cures.

It all starts here. See the difference 'Families' make. (Click on poster for larger view.)

Patient-advocacy funded research in SCN2A-related disorders: A return on investment for FamilieSCN2A Foundation



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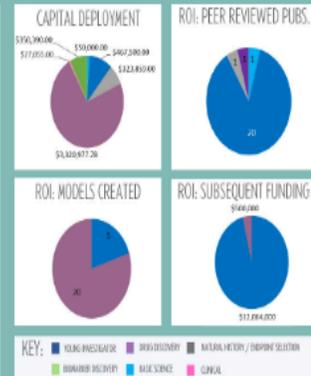
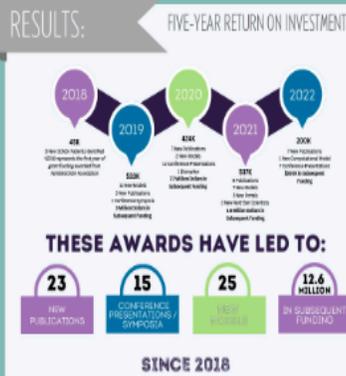


FamilieSCN2AFoundation

INTRODUCTION: Patient advocacy groups have a growing importance in the strategic decisions that help accelerate research in the rare epilepsies, particularly with the FDA's increased emphasis on patient-focused drug development, clinical outcomes assessments (COAs) and patient-centered outcomes. The FDA has issued guidance that promotes the inclusion of patients, caregivers, and patient advocacy organizations. Thus, the importance of thoughtful capital deployment by advocacy organizations in the epilepsies is paramount.

BACKGROUND: Since 2018, The FamilieSCN2A Foundation has awarded ~\$4.5 million dollars in grants supporting 22 projects with the purpose of advancing and accelerating SCN2A-related disorder (SRD) research. This funding has established a foundation of knowledge and resources that have become self-perpetuating and are rapidly propelling The FamilieSCN2A Foundation towards its vision of a world with effective treatments and cures for all SRDs.

METHODS: A grant tracking system, curated by The FamilieSCN2A Foundation's scientific director, measured the return on investment of each grant awarded by the organization since 2018. Deliverables over time have been grouped into four categories: 1) number of corresponding publications, 2) number of models developed, 3) number of conference presentations / symposia / posters, and 4) amount of subsequent funding.



Type of Investment	Capital Deployed	Subsequent Funding	Models	Publications (Peer Reviewed)
Basic Science	\$ 50,000	\$ -	0	1
Young Investigator	\$ 487,500	\$ 12,064,000	5	20
Natural History/Endpoint Assessment	\$ 428,889	\$ -	0	1
Clinical	\$ 27,255	\$ -	0	0
Drug Discovery/Development	\$ 5,325,978	\$ 500,000	20	1
Biomarker Discovery	\$ 395,382	\$ -	0	0
TOTAL	\$ 4,539,762	\$ 12,564,000		

2.8X ROI

CONCLUSION: Patient advocacy groups are instrumental in advancing research in the epilepsies and thoughtful capital deployment by advocacy organizations is essential to their return on investment. Given the increased interest by the FDA and other stakeholders to include patient advocacy organizations in the drug development process, it is imperative that patient advocacy organizations consider the impact of their dollars and how these investments may generate further research in their respective diseases.

Increase your charitable ROI, help us find and fund more research with a small gift today.

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WITH US THIS YEAR!



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is part of our name for a reason

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