



2019 YEAR IN REVIEW

WWW.GRIN2B.COM

2019

FEBRUARY

**Attend Rare Disease Day
Conference at NIH**



MARCH

2nd GRIN2B Awareness month

MAY

**1st Golf Outing Fundraiser
in NJ raises \$27k**

2019



JUNE

**Launched first Research
Grant Cycle**

AUGUST

**Hired Samuel Kwon, PhD
as first Science Director**

**Joined National Organization
for Rare Disorders (NORD)**

2019



SEPTEMBER

**Participated in 1st
Conference for GRIN Variants
at Emory University**

**Attended Global Genes
Rare Patient Advocacy
Summit in San Diego**



2019

OCTOBER

Awarded first grant to Dr. Caitlin Hudac for her EEG-based biomarker study

1st cocktail reception fundraiser, Gather for GRIN2B, in IL raises \$37k



NOVEMBER

Provided funding for the University of Colorado's GRIN Variant Patient Registry



**ADDITIONAL 2019
ACCOMPLISHMENTS**

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OPERATIONAL & ADMINISTRATIVE

- **Raised \$125,000+ in income.**
- **Families hosted various fundraisers for us in the United States, Australia and France.**
- **Created new pages on website for Fundraising, Awareness and Logo Policy.**
- **Created Fundraising Guidelines .pdf.**
- **Attended Global Genes Rare on the Road in Denver and Global Genes Data DIY Workshop #3 in Philadelphia.**
- **Started Grants committee.**
- **Trademarked logo.**

2019

SUPPORT

- **Private parent support group grew from 364 to 481 members, representing 43 countries.**
- **Launched family registry on website.**
- **Shared 4 blog posts on grin2b.com.**
- **Produced several episodes of our podcast, Celebrating Rare: A GRIN2B Podcast.**
- **Updated and re-designed our GRIN2B symptoms infographic.**
- **Brochure created.**



2019

AWARENESS

- **Shared 15 facts about GRIN2B during March Awareness month.**
- **Created and sold new Awareness apparel and accessories.**
- **1100+ followers on public Facebook page.**
- **Shared four Newsletters.**
- **Launched 2 new social media campaigns:**
 - **#SuperpowerSaturday, featuring individuals impacted by a GRIN2B diagnosis.**
 - **#FeaturedFamilyFriday, featuring family stories.**





RESEARCH



- **Recruited 2 new members to our Medical Advisory Board.**
- **Encouraged families to enroll in Simons Searchlight GRIN2B registry and University of Colorado's GRIN Variant registry.**
- **Visited Samuel Kwon Lab at the University of Michigan and observed GRIN2B mouse models.**
- **Connected with GRIN Researchers and Clinicians, as well as representatives from pharma.**

2019



RESEARCH CONTINUED



- **Joined initiatives related to GRIN2B symptoms:**
 - **RELA (Rare Epilepsy Landscape Analysis)**
 - **AGENDA (Autism initiative)**
 - **Combined Brain (Consortium of Nonverbal Genetic Disorder groups)**
- **Began collaboration with newly formed GRIN organizations, GRIN2B Europe, CureGRIN Foundation and others.**

2019



ON THE HORIZON FOR 2020

- **3rd year celebrating GRIN2B Awareness in March.**
- **Host 2nd Golf Outing Fundraiser in Boonton, NJ, May 21st.**
- **Host GRIN2B Family Meetup July 2020 in Chicago.**
- **Continue to collaborate with medical community and GRIN-related organizations on future research projects to fund.**



2020

2020

ON THE HORIZON FOR 2020

- **Brainstorm new in-person and virtual fundraisers with fundraising committee.**
- **Attend GRIN-related and Rare Disease Conferences.**
- **Create more newsletters, Awareness videos, podcasts and blog posts.**
- **Continue to recruit new volunteers, board members and advisors.**

