

# 2019 YEAR IN REVIEW

WWW.GRIN2B.COM

FEBRUARY

Attend Rare Disease Day Conference at NIH .....

MARCH

2nd GRIN2B Awareness month

MAY

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

2019



# Launched first Research Grant Cycle

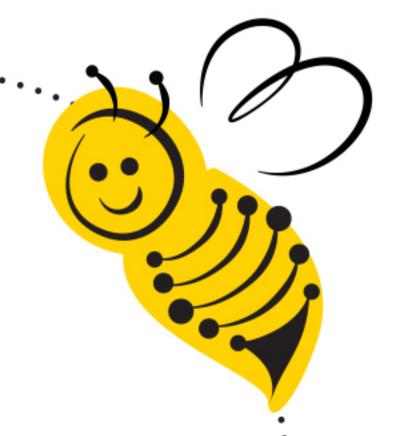
JUNE

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 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.

#### 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.

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.

## 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.



### 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 GRINrelated organizations on future research projects to fund.

#### 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.