

GRIN2B FAMILY & RESEARCH WEEKEND

JULY 17-19, 2026

Bethesda, Maryland

Hosted By:  **GRIN2B**
Foundation

CONNECT + SUPPORT + EMPOWER

All times in ET	FRIDAY, JULY 17, 2026
9 am-4 pm	Registration (Congressional Entrance E) Blood Collection (Room: Hart) Genetic Counseling Meetings (Room: The Hive, by appointment only) Biogene Study Participation (by appointment only, see Caitlin Hudac for room location)
FAMILY PROGRAM – SALON 1 & 2	
12:45-1:15 pm	Bee Curious Ice Breakers (will not be livestreamed)
1:15-1:25 pm	Welcome to the Hive! Elissa Taylor-Bustillo, Executive Director Phil Ash, Board Member
1:30-2:30 pm	Hive Mind Chats: Roundtable Discussions With Families (will not be livestreamed)
2:30-2:55 pm	NECTAR BREAK
3:00-3:50 pm	Bee-ginners Guide to GRIN2B Kristen Park, MD, Children's Hospital Colorado
3:55-4:15 pm	Bee in the Know: Understanding Loss of Function vs Gain of Function Variants Tim Benke, MD, PhD, University of Colorado
4:20-4:40 pm	Tales From a Queen Bee: GRIN2B Caregivers Share Their Journeys Kelsey Budesha & Allison Dreyer
5:30-6:30 pm	COCKTAIL HOUR - HALLWAY CHARACTER PHOTO OPPORTUNITIES – Meet the Bee and Spiderman!
6:30-8:30 pm	BEE OUR GUEST DINNER & DANCE PARTY

All sessions will be live streamed to GRIN2B Foundation's YouTube channel except where noted.

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SATURDAY, JULY 18, 2026

FAMILY PROGRAM – SALON 1 & 2

6:45-8 am	BREAKFAST – Salon 3
7:30 am-5 pm	Childcare Room Opens Room: Chesapeake/Annapolis Quiet Room / Changing Room: Dirksen
8-8:30 am	It Takes a Hive: Welcome to Day 1 Phil Ash, Elissa Taylor-Bustillo, Liz Marfia-Ash, GRIN2B Foundation Bruce Leuchter, MD, GRIN Therapeutics
8:30-9:30 am	KEYNOTE / I'll Bee There For You: The Sibling Perspective Panel: Zach Hayes, Liam Nelissen, Cate Nelissen, Giselle Hookings (virtual), Zach Ash (virtual) Moderator: Nisha Hakhu, GRIN2B Mom
9:35-10:10 am	Bee Informed, Part 1: Biomarkers 101 & Updates from the Biogene Study Caitlin Hudac, PhD, University of South Carolina
10:15-10:40 am	NECTAR BREAK
10:40-11:20 am	Busy Bees: Meet the GRIN2B Foundation 2026 Grantees Tim Benke MD, PhD, University of Colorado, Hongjie Yuan MD, PhD, Emory University & Andrew Penn, PhD, University of Sussex
11:25 am -12:25 pm	Beeline to the Future: The Next 5-10 Years of GRIN2B Research Panel: Steve Traynelis PhD, Emory University, Katherine Roche PhD, NIH, Tim Benke MD, PhD, University of Colorado Moderator: Quinn Pauli, PhD, CureGRIN Foundation Science Director
12:30-1:30 pm	LUNCH + GROUP PHOTO

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AFTERNOON BREAKOUT SESSIONS

BEE AWARE TRACK: CLINICAL INITIATIVES & DATA

Room: Salon 1 & 2

1:35-2:15 pm

Caring for the Colony: All about the Denver & Boston GRI Centers of Excellence

Kristen Park, MD, University of Colorado + Sonal Mahida, MGC, CGC & Christelle Ackhar, MD, Boston Children's Hospital

2:20-3:10 pm

What's the Buzz? Understanding GRIN2B Data

- GRIN2B Caregiver Priority Survey: Ryan Barash, GRIN2B Foundation
- GRIN2B Disease Concept Model: Liana Cole, MS, CGC, Brigham and Women's Hospital
- GRIN Variant Registry: Tim Benke, MD, PhD University of Colorado
- GRIN2B Research Registry Update: Astrid Rasmussen, MD, PhD, Project Director, Simons Searchlight

BEE PREPARED TRACK: FAMILY SUPPORT

*These sessions will not be livestreamed, but will be recorded & added to YouTube at a later date.

Room: Hart

1:35-2:15 pm

Replenishing the Honey: Caregiver Burnout

Miranda D'Angelo, GRIN2B Mom & Licensed Professional Counselor

2:20-3:10 pm

Bee-cause Knowledge is Power: Transition to Adulthood

Sena Yoon, M.Div. MSW, LCSW, Children's Hospital Colorado (Virtual)

Nisha Hakhu, MD & Donna Hayes, GRIN2B Moms

3:10-3:25 pm

BEE BACK SOON BREAK

SALON 1 & 2

3:30-4:10 pm

Pollinating the Pipeline: Clinical Trial Updates from Lundbeck and GRIN Therapeutics

Amy Lin, PhD, Lundbeck + Marjory Levy, PhD & Hillary Savoie, PhD, GRIN Therapeutics

4:15-4:30 pm

Hive Debrief: Lessons Learned

4:30-5:30 pm

Sweet Treats: Ice Cream Social Gelato provided by Dearly Beeloved

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FAMILY PROGRAM – SALON 1/2

7-8 am	BREAKFAST – Salon 3
7:30-11 am	Childcare Room Opens Room: Chesapeake/Annapolis Quiet Room / Changing Room: Dirksen
8-8:15 am	Bee the Change: How to Get involved with GRIN2B Foundation Liz Marfia-Ash & Elissa Taylor-Bustillo
8:15-9:05 am	Turning Lemons Into Lemonade: How To Make The Best Of An Extremely Rare Diagnosis Panel: Kristen Everett, Aubrey Schrock & Gilianne Nelissen, GRIN2B Moms Moderator: Liz Marfia-Ash, GRIN2B Foundation
9:10-9:35 am	Bee Informed, Part 2: Experiences with Gastrointestinal Symptoms Among Individuals with GRIN2B Calliope Holingue, MPH, PhD, Kennedy Krieger Institute
9:35-9:50 am	NECTAR BREAK
9:50-10:25 am	From Caregiver to Changemaker: Practical Advocacy for GRIN2B Families Shannon von Felden, Vice President of Advocacy, EveryLife Foundation for Rare Diseases
10:30-11:00 am	Hive Mind Q&A
1:30 pm	Optional Family Outing to Smithsonian's National Zoo

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