



Family Conference

Connecting Families, Improving Lives

Fri, Sept. 21 / Sat, Sept. 22, 2018
Atlanta, Georgia

The American Hotel, a Doubletree by Hilton
160 Ted Turner Dr NW, Atlanta, GA 30303

***Welcome to the GRIN2B Foundation's
first Family Conference!***

This event has been an ambition of our organization since the first board meeting over a year ago. By bringing parents, children and researchers together in one place, we hope to gain a better understanding of how GRIN2B affects all of us and how we can work together to better serve this growing community of families.

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Conference Agenda

Friday, September 21

- 2:00 - 4:00 pm: CHECK-IN TO HOTEL** & Registration with GRIN2B Foundation Board Members
- 4:15 - 5:30 pm: GROUP OUTING TO PLAYGROUND (optional)** - 'All Children's Park' in Centennial Olympic Park (8 min walk from hotel). This playground is designed for universal accessibility.
- 6:00 pm: DINNER MEETUP (optional)*** - Stats Brewpub, 300 Marietta St NW (10 min walk from hotel). We'll also provide a list of additional nearby restaurants if you'd like something different.
*Families responsible for meal cost.

Saturday, September 22

- 8:30 - 8:45 am: ARRIVAL AT CONFERENCE ROOM** - Lunar Room, 2nd floor Mezzanine.
Ice breaker activities & refreshments. **(Conference begins promptly at 8:45 am)**
- 8:45 - 9:00 am: WELCOME** - From GRIN2B Foundation Board Of Directors.
- 9:00 - 9:45 am: PRESENTATION BY SIMONS VIP CONNECT** - **Dr. Jennifer Bain of Columbia University.**
Brief overview of GRIN2B gene and summary of GRIN2B data in Simons VIP registry.
<https://www.simonsvipconnect.org/what-we-study/single-genes.html>
- 9:45 - 10:30 am: SPEAKER** - **Dr. Stephen Traynelis, Professor at Emory University and Director of Center for Functional Evaluation of Rare Variants.** Dr. Traynelis will present info on what roles are played in brain function by GRIN genes, how the function of NMDA receptors they encode can be assessed, how different variants are categorized as "gain-of-function" or "loss-of-function", as well as summarize the opportunities and challenges of developing new strategies for treatment. <http://functionalvariants.emory.edu/index.html>
- 10:30 - 10:45 am: BREAK**
- 10:45 - 11:30 am: SPEAKER** - **Dr. Tim Benke, Pediatric Neurologist at Colorado Children's Hospital.**
Dr. Benke will discuss the efforts to create a registry of patients with changes in GRIN genes, initial findings and suggested next steps.
- 11:30 - 1:00 pm: LUNCH** - Lunar Room. Provided for all families, caregivers and medical professionals.
(Group photo after lunch / prior to 1:00 session)
- 1:00 - 1:30 pm: SPEAKER** - **Dr. Katherine Roche, Senior Investigator, Receptor Biology Section at the National Institute of Health.** Dr. Roche will discuss the molecular mechanisms that regulate NMDA receptor synaptic localization. Her work over the last 2 decades has revealed how the intracellular C-terminal domain of the GluN2B subunit is an important region that determines both receptor function and localization. Her current studies focus on human genetics and rare GRIN2B variants within the C-terminal domain of GluN2B. The goal is to better understand how genetic variation regulates NMDA receptor function and identify targets for future therapeutic intervention.
- 1:30 - 2:30 pm: PANEL DISCUSSION + Q&A SESSION WITH PANEL MEMBERS** - Dr. Stephen Traynelis, Dr. Tim Benke, Dr. Katherine Roche, Dr. Nisha Hakhu (member of GRIN2B Foundation Medical Advisory Board & GRIN2B parent) & members from the Simons VIP Connect team. Attendees will have the opportunity to present questions to our panel on a wide range of topics.
- 2:30 - 3:15 pm: INFORMAL FAMILY DISCUSSION Q&A** - This is a chance for families to share stories and strategies and to ask each other about specific symptoms of their kids.
- 3:15 - 3:30 pm: BREAK**
- 3:30 - 4:15 pm: DISCUSS FUTURE PLANS with GRIN2B Foundation Board** - Fundraising ideas, future events, research goals, how families can get involved, what you would like our help with, etc.
- 5:30 - 7:00 pm: DINNER** - Lunar Room. Pizza party at hotel provided for all families.
- Evening: PARENTS MEETUP (optional)*** - 'Liquid Lounge' hotel bar. Time TBD. *Parents responsible for drink/food costs.



Voluntary Blood Samples by SIMONS *VIP CONNECT*

Simons VIP Connect will be on hand during this event to collect voluntary blood samples from families who have already registered in their database. Please note, if you are a parent attending this event without your child that is diagnosed with a GRIN2B variation, you will not be able to participate in this event.

The blood draws will be conducted in the Studebaker Room, near our Conference room. A member from the Simons VIP Connect team should have already contacted you regarding signing up for a time slot.

Childcare Info

Due to liability reasons, we are unable to provide childcare. We have reserved the Duesenberg Room (2nd floor, Mezzanine) for caregivers and children to meet up in. We will have a few volunteers in the room from the organization, Corrigan Care, to help run activities, but these volunteers are not meant to act as sole care providers. Children must be accompanied by an adult at all times. Please do not bring children into conference sessions.

Thanks to all our presenters and families for attending!

Special thanks to the following families for their generous contributions towards this event:

Joellen Doherty
Franck and Paula Fatras
RJ and Jenny Lasek
Kristopher Patrick
Joseph and Sydney Williams

Please note: portions of the conference will be filmed.

We will share videos of the presentations on our website & our social media pages in the weeks following the Conference. Note: We may film some crowd shots during the day to use in future Awareness videos.