



family WEEKEND

CONNECT • SUPPORT • EMPOWER

Chicago, July 15 – 16, 2022

Hyatt Regency O'Hare
9300 W. Bryn Mawr
Rosemont, IL 60018



Title



Diamond



Platinum



Gold



Silver



agenda
FRIDAY,
JULY 15, 2022

All sessions are in
the O'Hare room unless
otherwise specified.

8:30 a.m.
registration begins
+ meet & greet

9:15 a.m.
Welcome from GRIN2B Foundation
Slideshow of GRIN2B Community,
Remarks from Board Member, *Phil*
Ash and President, *Liz Marfia-Ash*

9:35 a.m.
Biogene Study Updates - Dr. Caitlin
Hudac, University of Alabama
Dr. Hudac will be presenting results
from her BioGENE Study** that
examines the brain signatures of
GRIN2B and other genes. She will
highlight all the GRIN2B Warriors
that completed the study on her Fall
2022 road trip, share the results, and
provide context for the next steps.

10:20 a.m.
Radiprodil Clinical Trial - GRIN
Therapeutics, Bruce Leuchter, MD,
Tamara Agajanov, MD,
Hillary Savoie, PhD, Vijay Rai
GRIN Therapeutics is thrilled to
join the GRIN2B Foundation Family
Weekend to: (1) introduce our
team, (2) offer background on our
efforts to develop Radiprodil for
GRIN2B related disorder caused
by gain-of-function (GOF) variants,
and (3) share details about our
upcoming clinical trial.

11:00 a.m. *break*

11:15 a.m.
Sleep Discussion Panel
Dr. Innessa Donskoy, Pediatric
Sleep Medicine Physician
and Ryan Geslani, Pediatric
Occupational Therapist

Does your child struggle with their
sleep? Here's your chance to get
all your sleep questions answered
by a board certified pediatric sleep
medicine physician and a pediatric
occupational therapist who can
speak from both a personal and
professional perspective.

12:10 p.m.
lunch + group photo

1:10 p.m.
Special Needs Legal & Future
Planning - Attorney Brian Rubin
from Rubin Law

Government benefits (SSI, SSDI,
Medicaid & Medicare), Special
Needs Trusts & ABLE Accounts,
Guardianship and Alternatives
to Guardianship, Letters of Intent
and related topics will all be
discussed during the presentation.

2:00 p.m.
Genetics 101 - Rebecca Smith,
MS, CGC, Licensed, Certified
Genetic Counselor and
Research Coordinator, Autism
& Developmental Medicine
Institute, Geisinger

Simons Searchlight genetic counselor
Rebecca Smith will review several
genetics concepts including DNA
and genes, types of genetic mutations
in GRIN2B, and tips on how to read
and make sense of a genetics lab
report. The goal of this talk is to help
in the understanding of your family
member's genetic testing result.

2:50 p.m. *break*

3:20 p.m.
Gain & Loss of Function Variants -
Dr. Steve Traynelis, Emory University
Dr. Traynelis will summarize the
functional analysis performed at
CFERV, and explain the rationale
and utility of this work. He will also
describe gain- and loss-of-function
designations, and discuss how this
information can be used for potential
clinical trials that might be run in the
future. He will also answer general
questions about the consequences
of GRIN variants for brain function.

4:15 p.m.
GRIN2B Foundation Updates -
Board of Directors
Learn about our mission, resources,
goals, fundraising and how you can
get more involved.

4:45 p.m.
Lessons Learned -
Open Forum Discussion with
Parents/Caregivers Only



live streaming

All sessions in the O'Hare Room
will be live streamed, with the
exception of the Open Forum
Discussions with Parents at the end
of both days. A live stream link will
be shared for those that can't attend
in person closer to the event date.

The recorded sessions will also be
added to our YouTube channel at a
later date.



8:30 a.m. breakfast

Bagels, muffins, yogurt, fruit

9:00 a.m.

**Keynote Speech - Author
Anitra Rowe Schulte**

Anitra Rowe Schulte is the author of the picture book **DANCING WITH DADDY** and the Parent Programming Coordinator for The Nora Project, a nonprofit that promotes disability inclusion by empowering educators and engaging students and communities. Her oldest daughter has a chromosome difference. Anitra will share her family's journey towards accepting their daughter's diagnosis and how it led her to writing a children's book and working with The Nora Project.

9:30 a.m.

GRIN2B Registry Updates - Dr. Cora Taylor, PhD Principal Investigator, from Simons Searchlight, Geisinger

Updates on the Simons Searchlight GRIN2B research registry, including a summary of the medical, behavioral, and developmental data. This talk aims to highlight the value of research participation for you and your family.

10:15 a.m.

GRI Center of Excellence Update - Dr. Kristen Park & Liz Marfia-Ash, GRIN2B Foundation

GRIN2B Foundation is proud to fund and coordinate the first Center of Excellence for patients with GRI-Related Disorders, tentatively scheduled to launch Fall 2022. Dr. Kristen Park will be the Director of this first Center at Children's Hospital Colorado (Denver). Dr. Park and GF President, Liz Marfia-Ash will provide an overview of how the Center will work and updates on the timeline for opening.

10:35 a.m. break

10:50 a.m.

GRIN Variant Patient Registry - Dr. Tim Benke

Dr. Benke is a Pediatric Neurologist and the Principal Investigator of the GRIN Variant Patient Registry. He will explain the importance of this registry and provide an update on the GRIN2B data.

11:25 a.m.

**Seizure Discussion Panel
Dr. Tim Benke and Dr. Kristen Park from Children's Hospital Colorado with GRIN2B parents, Carole Quennessen and Monica Dean**

Hear from two GRIN2B parents whose children have each experienced different types of seizures. Dr. Benke and Dr. Park will also field questions and discuss how this symptom may present in the GRIN2B population.

12:15 p.m. lunch

1:15 p.m. breakout sessions:

O'Hare Room

Challenging Behaviors - Clinical Psychologist Dr. Jennifer Palmar
Dr. Palmer is a licensed clinical psychologist specializing in supporting individuals with various developmental differences, and their parents. She will provide information about current research, treatment services, supports, and strategies related to best supporting children with developmental, learning, emotional, and behavioral differences.

J.F.K. Room

Viewing the Whole Child for Functional Performance - Aliza Soler, MS OTR/L

From an occupational therapist's perspective - how to utilize knowledge about a child to support and utilize strategies to improve their performance. Using a holistic approach, we will look at how a child's individual differences, the environment that they are in and the activity affect performance.

**This session will not be live streamed, but will be recorded for later viewing.*

(continued to next page)





1:55 p.m. *breakout sessions:*

O'Hare Room

AAC Demonstration - Heidi L. Rabe SLP and special guest **Lydia Dawley**, an Adult AAC user and Founder of Click. **Speak.Connect**, a company which creates custom styluses for AAC users. Learn about Augmentative Alternative Communication (AAC) from a person who uses AAC daily and a Speech-Language Pathologist. **Lydia Dawley** will join via Zoom and tell us about her experiences as a person who uses AAC. **Heidi Rabe** is a Speech-Language Pathologist specializing in AAC and will lead the on-site exploration of some of the common AAC options currently available.

J.F.K. Room

Self Care Strategies for Parents - led by Lisa-Stephanie Valme, Clinical Counselor and Art Therapy Intern at InTouch & Motion Learn about Caretaker Fatigue and how to develop opportunities for support, self-care and community.

**This session will not be recorded to respect the privacy of our in-person attendees.*

2:45 p.m. *break*

3:30 p.m. *breakout sessions:*

O'Hare Room

Mom Discussion Group

J.F.K. Room

Dad Discussion Group

4:15 p.m.

Final Lessons Learned - Parent Discussion Group

additional optional
ACTIVITIES THROUGHOUT THE WEEKEND:

FRIDAY & SATURDAY

Family Interviews for GRIN Therapeutics - Directors Room A
Email rubimiderski@outlook.com to schedule an appointment

****Biogene Study Participation with Dr. Hudac** - Room TBD

It is not too late to participate in the BioGENE study! Contact **Dr. Hudac** (cmhudac@mailbox.sc.edu) for more information. There are research slots this weekend if your child is here.

SATURDAY

Blood Draws - Directors Room C

By appointment only, 10:00 a.m. - 1:00 p.m. We are collecting blood samples from GRIN2B patients to be stored in a biorepository through our membership in the consortium, Combined Brain. These samples will be available for use in future research studies.

Family Dinner - Restaurant TBD



We have reserved **Directors Room B** for caregivers and children to meet up in.

Children must be accompanied by an adult at all times. We will have activities available in this room all day long, as well as the following scheduled activities:

FRIDAY

Morning activities with volunteers, Angel Martinez and Karla Martinez.

SATURDAY

Music Therapy courtesy of Prospect Music Therapy: 10:00 a.m. - 10:45 a.m.

Face Painting with Rosa: 1:00 p.m. - 4:00 p.m.

COVID guidelines

By attending the **2022 GRIN2B Family Weekend**, you voluntarily assume all risks related to exposure to COVID-19 and agree to abide by our COVID policies for the event.

We kindly suggest you respect each individual's comfort level with regards to social distancing. Masks, frequent hand washing and sanitizing are highly **recommended**.

For our full Covid Policy, scan here.



SPONSOR BIOS

GRIN Therapeutics, Title Sponsor

GRIN Therapeutics is a well-resourced biotech company and team of experts dedicated to developing Radiprodil as a potential treatment for GRIN2B-related disorders.

Horiba, Diamond Sponsor

The HORIBA Group of worldwide companies provides an extensive array of instruments and systems for applications ranging from automotive R&D, process and environmental monitoring, in-vitro medical diagnostics, semiconductor manufacturing and metrology, to a broad range of scientific R&D and QC measurements. www.horiba.com

Simons Searchlight, Diamond Sponsor

Simons Searchlight is an international research program with the goal of accelerating science and improving lives for people with rare genetic neurodevelopmental disorders. www.simonssearchlight.org

Lending Point, Platinum Sponsor

We believe everyone deserves the opportunity to explore what's possible. We're a FinTech platform simplifying financial services to provide access to money when and where our customers need or want it.

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HELPING MAKE OUR CONFERENCE A SUCCESS!

Conference Planning Committee:

Liz Marfia-Ash, Nisha Hakhu, Donna Dunn, Carole Quennessen, Phil Ash, Brittaney Crider and Lauren Hookings

Audio Equipment courtesy of Greg Reuhs

Livestream Equipment courtesy of Maine East High School

Livestream Video Crew: Logan Gerald, Quintin Lasky, Pallavi Raju, Adam Syukur,

GRIN2B Foundation Videography

Suzan Georges

GRIN Therapeutics Videographer

Nicholas Worpole

GRIN Therapeutics Photographer

Tori Soper

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

Carole and Bernard Quennessen, The Brien Family, Tommy Perkins, Rene Sinclair, Judy Swanton, Liz Marfia-Ash and Phil Ash, Ki Baek Kim and Gilianne and Nino Nelissen.

Thank you to the following vendors for donating items for our Gift Bags:

Fun and Function, Ark Therapeutic, Autism Brain Net and GeneDx



photography & videography

GRIN Therapeutics is pleased to provide a photographer and videographer for the event and will be sharing all photos and videos with GRIN2B Foundation. They will also be conducting video interviews with families about life with GRIN2B during the weekend. Your participation in this activity is optional.

Additionally, GRIN2B Foundation will have a videographer on site filming footage of families and attendees. The audio from this footage will not be used. This video will be used for future promotional videos for GRIN2B Foundation. Kindly let us know if you prefer not to be filmed.

THANK YOU
FOR JOINING US
THIS WEEKEND
and
FOR SUPPORTING
THE WORK
OF GRIN2B
FOUNDATION!