Saturday, April 25, 2026 (all times in ET)

9:00am **Simons Searchlight Update**
Astrid Rasmussen, MD, PhD

9:20am **Welcome & Opening Remarks**
Keith McArthur, Executive Director
Lauren Williams, Director of Family & Donor Experience
Quinn Pauli, PhD, Science Director
Brittany Schrock, Project Coordinator
Bruce Leuchter, President, GRIN Therapeutics

9:35am **Keynote 1: GRI Speaks**
In our own words: Individuals and Parents Share Their GRI Disorder Journeys
***Moderator**: Dr. Kristen Park, Prof. of Pediatrics and Neurology, Children's Hospital Colorado*
***Panel**: Amanda Billings, GRIK2 Mom*
Steven Horita, GRIN2A Dad
Katie Gritzmacher, GRIA2 Mom
Ben Gritzmacher, GRIA2

10:35am **5 Minute Break**

Breakout Session: *Attendees may choose one track to attend.*		
	Living GRI Track Family Session	**Learning GRI Track** Expert Level
10:40am	**Behavior Management & Safety** *Daniel NoackLeSage, M.A., BCBA, LBA* *Under The Oak Psychological Assessment, Treatment, and Consultation* *Patty Sanders, GRIA3 Mom* ***Moderator**: Brianna Kupras, CureGRIN Board Member*	**Rethinking Iglurs** *Dr. Derek Bowie (Professor, Department of Pharmacology & Therapeutics, McGill University; co-Director, Cell Information Systems)* *Dr. Karen Zito (Professor of Neurobiology, Physiology and Behavior, UC Davis Center for Neuroscience)* ***Moderator**: Quinn Pauli, PhD, Science Director*

11:40am **5 Minute Break**

11:45am **Keynote 2: Clinical Trials Update & Phase 3 Breakthroughs**
Sponsored by GRIN Therapeutics
***Moderator**: Keith McArthur, Executive Director*
Panel**: Anne-Marie Li-Kwai-Cheung, Chief Commercial Officer, and Hillary Savoie, Director of Community Engagement & Communication, **GRIN Therapeutics
*Raquel Miralles, Clinical and Medical Science Liaison, **Praxis Precision Medicines, Inc.***
*Amy Lin, Medical Affairs Neuro rare III**, Lundbeck***

1:10pm **5 Minute Break**

Breakout Session: *Attendees may choose one track to attend.*		
	Living GRI Track Family Session	**Learning GRI Track** Intermediate Level
1:15pm	**Transitioning to Adulthood** *Felicia Agbanyo, Residential Supervisor with the Department of Developmental Services, State of Massachusetts* *David Downing, GRIN1 Dad* ***Moderator**: Brittany Schrock, Project Coordinator*	**ASOs & Genetic Therapies** *Dr. Amy Ramsey (Associate Professor, Department of Pharmacology and Toxicology, University of Toronto)* *Dr. Geoff Swanson (Professor and Vice Chair, Department of Pharmacology, Northwestern University Feinberg School of Medicine)* *Dr. Richard Huganir (Bloomberg Distinguished Professor & Director, Department of Neuroscience, Johns Hopkins University School of Medicine)* ***Moderator**: Keith McArthur, Executive Director*

2:15pm **5 Minute Break**

2:20pm **Keynote 3: How to of Hope Part 2 - Guide to Treating and Curing GRI Disorders and Census Update**
Keith McArthur, Executive Director
Quinn Pauli, PhD, Science Director

3:05pm **5 Minute Break**

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Breakout Session: *Attendees may choose one track to attend.*		
	Living GRI Track Family Session	**Learning GRI Track** Intermediate Level
3:10pm	**MAPS: Taking an Active Role in Your Child's Educational & Life Planning** *Rachel Vella, GRIN2A Mom, Special Education Teacher* ***Moderator**: Lauren Williams, Director of Family & Donor Experience*	**Functional Analysis Panel** *Dr. Steve Traynelis (Professor, Department of Pharmacology and Chemical Biology, Emory University School of Medicine)* *Dr. Ian Coombs (Experimental Officer & Lecturer, Department of Pharmacology, University College London)* *Dr. Lonnie Wollmuth (Professor, Department of Neurobiology and Behavior, Stony Brook University)* ***Moderator**: Quinn Pauli, PhD, Science Director*
4:00pm	**Closing Remarks & Introductions to Networking Breakouts** *Keith McArthur, Executive Director* *Lauren Williams, Director of Family & Donor Experience* *Quinn Pauli, PhD, Science Director* *Brittany Schrock, Project Coordinator*	

4:10pm **Networking Breakout Sessions**

Families, Clinicians, & Researchers *Networking:* ***Moderator*** *Sarah Johnson, CureGRIN Ambassador*

Sibling Networking Youth ages 5-11: ***Moderators*** *Jackie Coleman, GRIN2a Mom and John Coleman, GRIN2A Brother*

Young Adult ages 12-above: ***Moderators*** *Sonny Mullen, GRIN1 Sister*

Detailed session descriptions

Simons Searchlight Update

Navigate the ecosystem of rare disease research with an expert guide to the Simons Foundation. Learn how the biorepository, Research Match, and SFARI Base work together to fuel discoveries. Plus, get the latest by-the-numbers look at GRI participants, genetic variants, and the vital data shaping our community's future.

Keynote 1: GRI Speaks

This deeply personal and essential session offers a powerful platform for the GRI community to share their authentic stories. Hear directly from individuals living with GRI disorders and their parents as they recount their unique diagnostic journeys, the daily realities of living with GRI, and their hopes for the future. This is an opportunity to gain invaluable insight into the lived experience of GRI disorders, fostering understanding, empathy, and connection within our collective journey.

Behavior Management and Safety

This practical session focuses on the at home realities of managing the complex behavioral landscape associated with GRI Disorders. The session bridges the gap between clinical theory and daily survival, providing families and caregivers with a toolkit for creating a stable, secure environment.

Rethinking Iglurs - Expert Level

Learn more about the recent scientific discoveries that challenge the fundamental, traditional assumptions of how ionotropic glutamate receptors (iGluRs) behave. These discoveries may have implications for how certain variants in GRI genes that encode iGluRs affect iGluR functioning and lead to specific symptoms.

Keynote 2: Clinical Trials Update & Phase 3 Breakthroughs

This keynote session offers an unprecedented look at the forefront of therapeutic development for GRI Disorders. We bring together executives from three leading biopharma companies currently conducting Phase 3 clinical trials for which GRI Disorder patients are eligible. Hear directly from representatives of GRIN Therapeutics, Lundbeck, and Praxis Precision Medicines as they share critical updates on their pivotal studies. This is a unique opportunity to gain insights into the progress, potential, and next steps for these late-stage trials, representing a significant stride towards new treatments for the GRI community.

Transitioning to Adulthood

Building on the foundation laid during GRICON25, this session serves as a vital continuation of our Adulthood series. As our children grow, the questions shift from early intervention to long-term

independence and quality of life. This panel brings together experts and veteran families to navigate the specific complexities of the transition to adulthood.

ASOs and Genetic Therapies - Intermediate Level

Leading researchers in GRI Disorders provide an overview of the latest research on gene therapies for treating GRI Disorders in mouse models, including the use of Antisense oligonucleotides (ASOs). These therapies are particularly promising as they are designed to address the root cause of GRI Disorders and significantly improve the lives of affected individuals.

How to of Hope Part 2: Guide to Treating and Curing GRI Disorders and Census Update

Get an exclusive sneak peek into CureGRIN's soon-to-be-released, groundbreaking "How to Cure GRI Disorders" guide. This pivotal session will highlight the vital contents of this comprehensive new resource, meticulously designed to chart a tangible path forward for the entire GRI community. Discover how this guide goes into specifics for 11 different GRI genes, detailing strategies for diverse genetic variations including haploinsufficiency, gain-of-function, and loss-of-function dominant negative effects. This deep dive into actionable strategies and essential knowledge is invaluable for empowering families, researchers, and clinicians in the urgent quest for effective treatments and cures, and provides critical insights for those in pharmaceuticals and biotech driving therapeutic development.

MAPS: Taking an Active Role in Your Child's Educational & Life Planning

Oftentimes, parents/caregivers sit at planning tables are unsure of what to ask for or how to participate in a meaningful way. School teams will ask for "parent input," but what does that really mean? How are you supposed to respond to the request for input? What are they actually asking for?

Participants in this workshop will walk away with a practical planning strategy that can be used regardless of the age of your child or what country you live in. This planning strategy, called MAPS (Making Action Plans), will help families and caregivers take on a more active voice in the planning process and empower them in advocating for the best services and goals for their children. Participants will also be provided with possible solutions and action steps for common pitfalls some families may experience in the planning process.

Functional Analysis Panel - Intermediate Level

This session is focused on how variants are functionally characterized - for example, as gain-of-function or loss-of-function, and implications for treatment approaches.

Networking Breakout Sessions

Networking Breakouts: Find Your Circle Real-time connection for the GRI community. Join tailored sessions for Families, Siblings, and Researchers/Clinicians to exchange experiences, bridge the gap between lab and life, and strengthen our collective journey.