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PCORI Eugene Washington Engagement Award
The Glut1 Deficiency Foundation welcomes you to Washington D.C.! We treasure these opportunities to come together to meet, share, and learn, and we are so thankful for each of you being here to join us!

We have many people to thank for the experiences we will have over the next few days. We are especially indebted to the families and volunteers who continue to support the work of the Foundation and its mission of education, awareness, advocacy, and supporting research. Your help and support comes in many forms and makes everything we do — including projects like this conference — possible. Thank you.

We are also most fortunate to be surrounded by a team of professionals who are genuinely connected to and concerned about our Glut1 Deficiency community and work hard each day to try to make all our lives easier and better. We appreciate each of them for making time to be here with us, bringing help and hope to our patients and families. Thank you.

**Glut1 Deficiency Foundation Board of Directors:**
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- Kris Engelstad, MS, CGC
  Columbia University Irving Medical Center
- Professor Dr. Jörg Klepper
  Children’s Hospital Aschaffenburg
- Dr. Eric Kossoff
  Johns Hopkins Hospital
- Dr. Juan Pascual
  University of Texas Southwestern Medical Center

**Glut1 Deficiency Foundation Scientific Advisory Board:**
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- Professor Dr. Jörg Klepper, *professional*
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- Dr. Karthik Rajasekaran, *professional*
  Dallas, Texas
- Dr. Tom Rebbecchi, *parent*
  Pine Hill, New Jersey
- Dr. Dong Wang, *professional*
  Atlanta, Georgia
# 8th BIENNIAL CONFERENCE

## THURSDAY, JULY 11, 2019

### NEW INSIGHTS

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 a.m. — 9:00 a.m.</td>
<td>Opening Welcome</td>
<td>Glut1 Deficiency Foundation</td>
</tr>
<tr>
<td>9:00 a.m. — 9:30 a.m.</td>
<td>Past, Present &amp; Future</td>
<td>Dr. Darryl De Vivo</td>
</tr>
<tr>
<td>9:30 a.m. — 10:00 a.m.</td>
<td>Registry &amp; Research</td>
<td>Dr. Juan Pascual</td>
</tr>
<tr>
<td>10:00 a.m. — 10:30 a.m.</td>
<td>Break</td>
<td></td>
</tr>
<tr>
<td>10:30 a.m. — 11:00 a.m.</td>
<td>Consensus Work &amp; Global Updates</td>
<td>Dr. Jörg Klepper</td>
</tr>
<tr>
<td>11:00 a.m. — 11:30 a.m.</td>
<td>Natural History &amp; New Challenges Uncovered</td>
<td>Dr. Michèl Willemsen</td>
</tr>
<tr>
<td>11:30 a.m. — 11:45 a.m.</td>
<td>Update on METAglut1 Blood Test Development</td>
<td>Dr. Vincent Petit</td>
</tr>
<tr>
<td>11:45 a.m. — 1:00 p.m.</td>
<td>Lunch / Group Photo / Cooking Demo with Chef Rachel</td>
<td></td>
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### SYMPTOMS AND TREATMENTS

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<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>1:00 p.m. — 1:30 p.m.</td>
<td>Movement Disorders in Glut1 Deficiency</td>
<td>Dr. Toni Pearson</td>
</tr>
<tr>
<td>1:30 p.m. — 2:00 p.m.</td>
<td>Seizures in Glut1 Deficiency</td>
<td>Dr. Stéphane Auvin</td>
</tr>
<tr>
<td>2:00 p.m. — 2:30 p.m.</td>
<td>Cognitive Considerations in Glut1 Deficiency</td>
<td>Dr. Veronica Hinton</td>
</tr>
<tr>
<td>2:30 p.m. — 2:45 p.m.</td>
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<tr>
<td>2:45 p.m. — 3:15 p.m.</td>
<td>Other Symptoms in Glut1 Deficiency</td>
<td>Dr. Juan Pascual</td>
</tr>
<tr>
<td>3:15 p.m. — 3:45 p.m.</td>
<td>Glut1 Deficiency in Adulthood</td>
<td>Dr. Mackenzie Cervenka</td>
</tr>
<tr>
<td>3:45 p.m. — 4:30 p.m.</td>
<td>Treatments : Old &amp; New Anticonvulsants Gene Therapy</td>
<td>Dr. Jörg Klepper Dr. Nicole Heussinger Dr. Smitha Jagadish</td>
</tr>
</tbody>
</table>

### EXHIBITS AND POSTER SESSION (open to all attendees)

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>4:30 p.m. — 5:30 p.m.</td>
<td>Cooking, sampling, visiting scientific poster session</td>
<td>Virginia Ballroom &amp; Foyer</td>
</tr>
<tr>
<td>5:30 p.m. — 7:30 p.m.</td>
<td>Dinner On Your Own</td>
<td></td>
</tr>
<tr>
<td>7:30 p.m.</td>
<td>Koo Koo Kanga Roo music &amp; movement for the whole family</td>
<td>Virginia Ballroom</td>
</tr>
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</table>
FRIDAY, JULY 12, 2019

KETOCIC DIETS

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 a.m. — 9:15 a.m.</td>
<td>Ketogenic Diets in Glut1 Deficiency: Childhood</td>
<td>Dr. Eric Kossoff, Dr. Mackenzie Cervenka</td>
</tr>
<tr>
<td></td>
<td>Ketogenic Diets in Glut1 Deficiency: Adulthood</td>
<td></td>
</tr>
<tr>
<td>9:15 a.m. — 10:00 a.m.</td>
<td>Ketogenic Best Practices &amp; Fine Tuning, Influences on Ketosis</td>
<td>Wesley Lowman, RDN, LDN, Dr. Dominic D’Agostino</td>
</tr>
<tr>
<td>10:00 a.m. — 10:30 a.m.</td>
<td>Break</td>
<td></td>
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</tbody>
</table>

SESSIONS 10:30 a.m. — 12:00 p.m. (choose one)

<table>
<thead>
<tr>
<th>Session 1: Keto Sessions</th>
<th>Washington III</th>
<th>Simple &amp; Sustainable Keto – Dawn Martenz, Keto Kitchen Tips – Maria Rebbecchi, Q&amp;A Session – Moderator: Dominic D’Agostino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 3: Teen/Adult Patients &amp; Parents</td>
<td>Virginia Ballroom</td>
<td>Survey Insights – Dr. Mackenzie Cervenka, Registry Insights – Dr. Juan Pascual, Identifying &amp; Meeting Needs Discussion, Q&amp;A Session – Moderator: Kris Engelstad</td>
</tr>
</tbody>
</table>

12:00 p.m. — 1:00 p.m. Lunch

RESEARCH ROUNDCUP 1:00 p.m. — 2:15 p.m.

<table>
<thead>
<tr>
<th>Research Updates: Panel Discussion</th>
<th>Virginia Ballroom</th>
<th>General Session: Virginia Ballroom</th>
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</thead>
<tbody>
<tr>
<td>Dr. Adam Hartman - NIH Programs</td>
<td>Dr. Juan Pascual</td>
<td>Dr. Umrao Monani</td>
</tr>
<tr>
<td>Dr. Umrao Monani</td>
<td>Dr. Karthik Rajasekaran</td>
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<tr>
<td>Dr. Dominic D’Agostino</td>
<td>Moderators: Dr. Tom Rebbecchi, Dr. HC Glick</td>
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</tr>
</tbody>
</table>

2:15 p.m. — 2:30 p.m. Break

FOCUS SESSIONS (choose one – additional details on next page)

<table>
<thead>
<tr>
<th>2:30 p.m. — 4:30 p.m.</th>
<th>Patients: Adult Experiences, Parents: Planning for the Future, Professionals: Closing the Gaps, Children: Special Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Washington I and II, Virginia Ballroom, Washington III, Crystal Ballroom</td>
</tr>
</tbody>
</table>

CLOSING

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>4:30 p.m. — 5:00 p.m.</td>
<td>Patient and expert panel take-aways, closing remarks and 2021 announcement</td>
</tr>
<tr>
<td>5:00 p.m. — 6:30 p.m.</td>
<td>Dinner on Your Own</td>
</tr>
<tr>
<td>6:30 p.m.</td>
<td>Twilight Monument Tour (ticketed event)</td>
</tr>
</tbody>
</table>

For questions or help during the conference, please contact:

- Glenna Steele 859-585-2538
- Jason Meyers 225-315-8228
- Shelley Park 859-200-2450
- John Steele 859-585-2435
- Keri Meyers 225-315-8526
- Maria Rebbecchi 859-912-7801

continue to the next page for focus session details
Focus Session Details  2:30 p.m. — 4:30 p.m.

**Patients: Adult Experiences**  Washington I and II  
*Moderators: Kris Engelstad and Leslie Holleman*  
- School Experiences & Vocational Experiences  Jennifer Fitzhugh  
- Diet & Self Care  Leslie Holleman  
- Medical & Genetic Discussions  Kris Engelstad  
- Independence  Dana Pottschmidt  
- Staying Connected – Social & Media Tips  Dana Pottschmidt  
- Q&A, roundtable discussions, additional needs  led by moderators

**Parents: Planning for the Future**  Virginia Ballroom  
*Moderators: Rob Rapaport and Jason Meyers*  
- Fostering Independence  Dana Pottschmidt  
- Social Security, Benefits & Waivers  Stacy Cloyd  
- ABLE Accounts  Nicholas Hancart  
- Special Needs Trusts  Kelly Thompson  
- School Experiences & Vocational Experiences  Jennifer Fitzhugh  
- Caregiver & Sibling Support  Lauren Furtner, Holly Senn  
- Q&A, roundtable discussions, additional needs  led by moderators

**Professionals: Closing the Gaps**  Washington III  
*Moderators: Dr. Jörg Klepper and Dr. Juan Pascual*  
Roundtable discussions with all professionals in attendance. Suggested topics include:  
- Consensus Paper  
- Best Practice Diet Guidelines  
- Treatment Challenges & Shortfalls  
- Greatest Research Needs  
- Research Consortium & the Registry  
- Adult Centered Needs  
- Diagnostic Challenges  
- Next Steps

**Children: Special Activities**  Crystal Ballroom  
Special entertainment and structured activities. Supervision required.

---

**everyone reassembles at 4:30 p.m. for closing**

**MEET THE 2019 CONFERENCE EXHIBITORS**

**STABLE ACT**  
The Charlie Foundation  
Medica Nutrition  
KetoCal  
KetoVie  
Metafora Biosystems  
Coriell Research Institute  
A phlebotomist will be available Thursday from 9-4 to collect samples from patients and non-patients interested in participating in an important research project.

Open Thursday and Friday in the Virginia Ballroom foyer.
CHILDREN’S ACTIVITIES & SOCIAL EVENTS

Wednesday, July 10, 2019
• Early Registration, 4:00 – 6:00 p.m., Commonwealth Ballroom
• Red Carpet Event, 6:00 – 9:00 p.m.
  — patients will be introduced and spotlighted with a brief story as they walk the red carpet
  — music/dance party afterwards
  — photo booth
  — Kona Ice Snow Cones

Thursday, July 11, 2019
• Children’s Activity Room, 1:00 – 4:30 p.m. (supervision required)
  — Capital Music Therapy, 1:00 – 3:00 p.m.
  — arts and crafts
  — games
  — Ferrets and Friends, 3:00 – 4:30 p.m.
• Koo Koo Kanga Roo, 7:30 p.m.
  — sing and dance with the stars of Go Noodle

Friday, July 12, 2019
• Sibling Session, 1:00 – 2:00 p.m., Monroe I
• Children’s Activity Room, 2:30 – 4:30 p.m. (supervision required)
  — Science activities with Mr. Bond’s Science Guys – Fizz, Pop, Boom
• Twilight Monument Tour, 6:30 p.m. (ticketed event)
  please arrive to the lobby a few minutes early to allow time to find and board your bus
  — guided tour of monuments along the National Mall
  — chartered bus transportation (ADA compliant, AC, restrooms)
  — pick up and drop off at conference hotel
  — several stops to get out and explore hotel
  — 3.5 hours total tour time

Saturday, July 13, 2019
• US Capitol Tour, 8:30 a.m. (ticketed event)
  please arrive to the lobby a few minutes early to allow time to find and board your bus
  — chartered bus transportation (ADA compliant, AC, restrooms)
  — pick up and drop off at conference hotel
  — 60-minute guided tour (15 minute video, 45 minute walking tour)
  — extra time for exploring on your own or visiting the gift shop
  — return time 1:00 p.m.

For medical emergencies, please call 911 and give your location.
MEET THE 2019 CONFERENCE PRESENTERS

Stéphane Auvin MD, PhD, FAES
Mackenzie Cervenka MD
Stacy Cloyd

Dominic D’Agostino PhD
Daryl De Vivo MD
Kris Engelstad MS, CGC

Jennifer FitzHugh M.Ed
Lauren Furtner CCLS II
HC Glick MD
MEET THE 2019 CONFERENCE PRESENTERS

Nicholas Hancart

Adam Hartman MD, FAAP, FANA, FAES

Nicole Heussinger MD

Veronica Hinton PhD

Leslie Holleman BS, QIDP

Smitha Jagadish PhD

Kelly Jones

Prof. Dr. Jörg Klepper

Eric Kossoff MD
MEET THE 2019 CONFERENCE PRESENTERS

Wesley Lowman RDN, LDN
Dawn Martenz
Erin Meisner

Jason Meyers
Umrao Monani PhD
Juan Pascual MD, PhD

Toni Pearson MBBS
Vincent Petit DVM, PhD
Dana Pottschmidt MSW, LSW, RBC
MEET THE 2019 CONFERENCE PRESENTERS

Karthik Rajasekaran PhD
Rob Rapaport PhD
Maria Rebbecchi RN

Thomas Rebbecchi MD
Rachel Salazar PT, DPT, PCS
Holly Senn CCLS III

Kelly Thompson Esq
Prof. Dr. Michèl Willemsen
April York DVM
Stéphane Auvin MD, PhD, FAES
Professor Auvin is an Epileptologist and Child Neurologist and a full professor at Robert Debré University Hospital and Paris-Diderot University in Paris, France. He oversees the epilepsy program and the center for rare epilepsies at Robert Debré University Hospital, APHP Paris. He is also conducting experimental research in the INSERM U1141 in Paris.

His clinical and research activities are focused on pediatric epilepsy and its treatments. His research team is working on inflammation-epilepsy, on the ketogenic diet and antiepileptic drugs in the developing brain. The epilepsy program at Robert Debré Children Hospital is involved in antiepileptic drug development and clinical trials (PK, Phase II, Phase III and Phase IV). Professor Auvin is the author of more than 150 peer-reviewed papers or book chapters.

He gladly serves the ILAE (International League Against Epilepsy) as the chair of the Pediatric commission (2017-2021) and as Associate Editor for Epilepsia (Journal of ILAE, IF: 5.295) (2017-2021). He is a member of the board of the ILAE French Chapter and the President (2019-2022) of the French Pediatric Neurology Society.

Mackenzie Cervenka MD
Dr. Mackenzie Cervenka is an Associate Professor of Neurology at Johns Hopkins University School of Medicine. She completed her undergraduate studies at the University of Virginia and received her medical degree from the University of Virginia School of Medicine. She then completed her internship in internal medicine and residency in neurology at the University of Maryland Medical Center. Dr. Cervenka completed a 2 year fellowship in epilepsy and clinical neurophysiology at Johns Hopkins and has remained there on faculty in the Epilepsy Division since 2010. She is Medical Director of the Johns Hopkins Adult Epilepsy Diet Center and the Epilepsy Monitoring Unit. The Adult Epilepsy Diet Center is the first of its kind, providing ketogenic diet therapies to adults with intractable epilepsy including Glut1 Deficiency syndrome and smoothly transitioning children from a pediatric to a comprehensive adult diet center. She is a member of the Glut1 Deficiency Foundation Medical Advisory Board.

Dr. Cervenka’s research focuses on the efficacy of ketogenic diets in the treatment of adults with epilepsy and refractory status epilepticus.

Stacy Cloyd
Stacy Cloyd is the Deputy Director of Government Affairs for the National Organization of Social Security Claimants’ Representatives (NOSSCR). In her role at NOSSCR, Ms. Cloyd advocates for laws, regulations, policies, and public perceptions that preserve and strengthen Social Security.

Prior to working at NOSSCR, Ms. Cloyd was an attorney at a nonprofit legal clinic in Washington, DC, where she represented low-income individuals in a variety of pre- and post-eligibility Social Security and other public benefits matters, as well as rental housing cases. She also served as the senior domestic policy analyst at Bread for the World Institute, an anti-hunger and anti-poverty advocacy organization.

Ms. Cloyd graduated from Smith College and received her law degree and a Master’s degree in urban planning from the University of Michigan.

Dominic D’Agostino PhD
Dr. Dominic D’Agostino is an Assistant Professor in the Department of Molecular Pharmacology and Physiology at the University of South Florida Morsani College of Medicine and also a Senior Research Scientist at the Institute for Human and Machine Cognition. The primary focus of his laboratory is developing and testing metabolic therapies, including ketogenic diets, ketone esters and natural and synthetic molecules to target metabolic processes. These metabolic therapies are formulated and tested to enhance neurological and physiological resilience under environmental extremes associated with changes in oxygen and pressure. His research also explores the use of these metabolic therapies for a broad range of disorders linked pathophysiologically to metabolic dysregulation, including seizures, neurological disorders, inborn errors in metabolism, muscle wasting and cancer. D’Agostino’s laboratory uses in vivo and in vitro techniques to understand the physiological, cellular and molecular mechanism of metabolic therapies. His research is supported by the Office of Naval Research (ONR), Department of Defense (DoD), private organizations and foundations.

Daryl De Vivo MD
Dr. Darryl C. De Vivo, M.D., is the Sidney Carter Professor of Neurology, Professor of Pediatrics, and Director Emeritus (1979-2000) of the Pediatric Neurology Service at Columbia University Medical Center in New York City. Dr. De Vivo received his M.D. Degree from the University of Virginia Medical School. Residency training in Medicine, Pediatrics, Neurology and Pediatric Neurology followed at Harvard, National Institutes of Health and Washington University. He then joined the Medical School Faculty at Washington University and over the next decade was promoted from Assistant Professor to Professor as he developed his clinical research skills in neurochemistry, metabolic diseases and neuromuscular disorders. He joined the Columbia University Faculty in 1979 as the Sidney Carter Professor of Neurology and Pediatrics and Director of the Pediatric Neurology Service. Currently he continues to fulfill his duties as Founding Director, Colleen Giblin Research Laboratories; Founding Director, Pediatric Neuromuscular Disease Center, Co-Director of the Center for Motor Neuron Biology and Diseases (MNC) and Associate Chairman (Neurology) for Pediatric Neurosciences. Dr. De Vivo was a Director for Neurology and President of the American Board of Psychiatry and Neurology, Secretary of the American Academy of Neurology, and President of the Child Neurology Society. He has published more than 500 original articles and reviews, lectures extensively in the U.S. and abroad, serves on several editorial boards and advisory committees, and is a former associate editor for Rudolph’s Textbook of Pediatrics. He is a current editor of “Neuromuscular Disorders in Infancy, Childhood and Adolescence: A Clinician’s Approach”, recognized as the standard reference in the field. Dr. De Vivo receives funding from the NIH, DOD, SMA Foundation, MDA, Hope for Children Research Foundation, Milestones for Children, Glut1 Deficiency Foundation and the Will Foundation. He serves as the Director for the PNCR Clinical Trials Network for SMA and he oversees several other sponsored clinical trials involving rare diseases such as MELAS, spinal muscular atrophy, muscular dystrophy and Glut1 deficiency.

Kristin Engelstad MS CGC
Kristin Engelstad MS CGC is a board certified genetic counselor at Columbia University. She has a long history of involvement with natural history studies and clinical trials for patients with Glut1 Deficiency Syndrome. She is also involved with various clinical studies in mitochondrial disorders. In addition, Kris provides genetic counseling services for the Columbia University Neuromuscular Clinic and for various clinical trials.

Jennifer Fitzhugh M.Ed
Jennifer is an Advocacy Consultant in San Antonio, Texas. She is a former Special Education teacher and administrator of 22 years. She earned her Master’s Degree in Special Education in 2011 and has been assisting hundreds of families with the ARD process in public schools throughout Texas since 2013.

Lauren Furtner CCS II
Lauren Furtner is a certified child life specialist at Inova Children’s Hospital in Falls Church, Virginia. Lauren has been a child life specialist at Inova for the past 3 years, currently working on the medical/surgical unit. Lauren graduated with two Bachelors of Science in Psychology and Human Development from Virginia Tech and completed her clinical child life internship at Children’s Healthcare of Atlanta. Lauren has presented at conferences around Washington, D.C. in regards to coping with a chronic illness, coping with procedures in the outpatient hospital setting, and child life services at Inova Children’s Hospital. Lauren leads a Type-1 support group at Inova Children’s Hospital that meets once a month with patients recently diagnosed with diabetes and their siblings. She also co-leads the Patient Experience committee for the medical/surgical unit at Inova Children’s Hospital.
HC Glick MD
HC Glick is a Glut1 Deficiency parent and member of the Glut1 Deficiency Foundation’s Scientific Advisory Board. He completed his medical school training, internship, and residency at Mount Sinai Hospital in New York and his fellowship at Beth Israel Medical Center. He is a non-invasive and clinical cardiologist at St. Francis Hospital – The Heart Center, New York.

Nicholas Hancart
Nick is a member of the Outreach Team for STABLE Accounts, Ohio’s ABLE Program. He began with the Treasurer’s Office in 2017 after two summers of internships in the office working in the Public Affairs Department. Nick travels throughout Ohio and more speaking to professionals, families and other groups on the valuable impact that STABLE Accounts have for people with disabilities. He is an alumnus of the University of Dayton and currently lives in Worthington. STABLE Accounts for the first time, provide tax-advantaged savings and investment opportunities to individuals with disabilities without risk of losing means-tested benefits.

Adam Hartman MD, FAAP, FANA, FAES
Dr. Adam Hartman is a Program Director in the Division of Clinical Research at NINDS (National Institute of Neurological Disorders and Stroke) with a background in child neurology and epilepsy. Before joining NINDS, he was an Associate Professor of Neurology and Pediatrics at Johns Hopkins School of Medicine, with a joint appointment in the Johns Hopkins Bloomberg School of Public Health Department of Molecular Microbiology and Immunology. He also was Co-Director of the Neurosciences Intensive Care Nursery and Associate Program Director for the Child Neurology residency at Johns Hopkins.

Dr. Hartman earned a bachelor’s degree in Chemistry from Northwestern University and an MD from Northwestern University Medical School. During medical school, he was an HHMI-NIH Research Scholar at NIMH. After completing a residency in Pediatrics in the National Capital Uniformed Services Pediatric Residency Program, he served as a general pediatrician in the US Navy for five years (the last as Division Head of General Pediatrics at Naval Medical Center San Diego). He completed his residency in child neurology and a fellowship in clinical neurophysiology/pediatric epilepsy, both at Johns Hopkins.

During his training, he studied the mechanism of the ketogenic diet at NINDS. As a faculty member at Johns Hopkins, his lab and clinical research on novel metabolism-based treatments for epilepsy was funded by NIH, the State of Maryland, and private sources. His current interests include clinical trials in child neurology, epilepsy, and rare diseases. He is clinically active as a consultant in the Un diag nosed Diseases Program and other select protocols at the NIH Clinical Center.

Nicole Heussinger MD
Dr. Nicole Heussinger is the Assistant Medical Director in Pediatrics and Neuropediatrics at the Paracelsus Medical Private University in Nuremberg, Germany. She earned her medical degree from the University of Erlangen in Nuremberg in 2006 and did her specialist clinical fellowships at Erlangen and Paracelsus. She has served as a consultant pediatric neurologist at the University of Erlangen and as Assistant Medical Director in Pediatrics and Neuropediatrics at Children’s Hospital Aschaffenburg. Dr. Heussinger is a board member of the German Child Neurology Society.

Veronica Hinton PhD
Dr. Hinton is a developmental neuropsychologist and Professor of Psychology at the City University of New York (CUNY). She received her PhD in Psychology (specialization in Neuropsychology) from CUNY, completed a clinical internship in neuropsychology at Long Island Jewish Hospital/Hillside Hospital, and postdoctoral fellowships at the Consortium for Medical Education in Developmental Disabilities at the New York State Institute for Basic Research in Developmental Disabilities and the Psychobiology Training Program at Columbia University. She was appointed an Assistant Professor in Neuropsychology at the G.H. Sergievsky Center and Department of Neurology at Columbia University in 1996. Dr. Hinton worked at Columbia University for over 20 years. She worked on multiple NIH and foundation funded studies investigating the neuropsychological profile in children with neurodevelopmental disorders and ran the Pediatric Neuropsychology Clinical Service in Child Neurology at the Columbia University Medical Center. During this time, she worked closely with Dr. Darryl De Vivo and was privileged to work with many families diagnosed with Glut1 DS, characterizing the neuropsychological profile associated with the disorder. Dr. Hinton has recently returned to CUNY to help oversee the development of their graduate program in neuropsychology. Dr. Hinton considers herself a scientist and a clinician focused on investigating the development of brain-behavior relationships whose main objective is to improve the quality of life for the children and families she works with.

Leslie Holleman BS, QIDP
Leslie Holleman is both a parent and professional in the Glut1 world. Leslie has spent the last 23 years working with individuals with special needs and has a special interest in working with teens and adults to create independence, self direction and advocating for those she works with achieve meaningful lives. She is the mother of Chris who is 21 years old and has Glut1. Leslie and her husband, Lloyd, live in Westfield, Indiana with their 4 sons, Chris, Ryan, Luke and Sam. In her spare time, she coaches Special Olympics and serves on her county board.

Smitha Jagadish PhD
Dr. Jagadish is a lab head in the Rare and Neurologic Diseases Research Therapeutic Area at Sanofi, Inc., based in Framingham, Massachusetts. She received her PhD in Neuroscience from Columbia University, NY in Richard Axel’s lab studying neural circuits in the brain. She did her postdoctoral fellowship in Allisson Doupe’s lab at University of California in San Francisco, CA where she studied the neural basis of reward learning and motor performance. She then joined the Whitehead and Picower Institutes at MIT to study Alzheimer’s disease. Smitha joined Sanofi in 2016 and has focused her work on neurologic diseases. She is the project team leader for Gene Therapy for Glut1 deficiency syndrome at Sanofi and works in close collaboration with Dr. Darryl De Vivo at Columbia University and Dr. Umrao Monani. She has served on many internal governance committees at Sanofi and is a member of the Society for Neuroscience and the Society for Cell and Gene Therapy.

Kelly Jones
Kelly is a Glut1 Deficiency parent and a member of the GID Foundation Board of Directors, where she serves as the Communication Director. Kelly has been married for 15 years to Matt Jones and is the mother of son Reece, age 12.

Reece was diagnosed with Glut1 in 2015, three days before his eighth birthday. After two years on the ketogenic diet, Reece had a g-tube placed to aid with diet compliance and to improve his quality of life.

The Jones family lives in Rancho Cordova, California.

Prof. Dr. Jörg Klepper
Jörg Klepper, MD, is the Medical Director of Aschaffenburg Children’s Hospital in Aschaffenburg, Germany. Dr. Klepper’s clinical interests include disorders of brain energy metabolism such as Glut1 Deficiency and pyruvate dehydrogenase. His research interests include the mechanisms and adverse effects of the ketogenic diet on these disorders and establishing international protocols for the use of the ketogenic diet for epilepsy and metabolic disorders.

Dr. Klepper earned his medical degree at Frankfurt/M and Würzburg University and completed his pediatric training at Würzburg and Essen University in Germany. He then completed his fellowship at Columbia University in New York City.

In addition to his role at Aschaffenburg Children’s Hospital, Dr. Klepper serves as a consultant for pediatric neurology at Essen University and a lecturer on pediatrics at Essen University and Würzburg University. He is a board member of the Neuropaediatric Society and a member of the German Paediatric Society.
Eric Kossoff MD
Dr. Kossoff is a Professor of Neurology and Pediatrics at Johns Hopkins University in Baltimore, Maryland USA. He received his medical degree from SUNY at Buffalo School of Medicine in New York, followed by a residency in pediatrics at Eastern Virginia Medical School in Norfolk, Virginia. He completed a fellowship in child neurology and then pediatric epilepsy at The Johns Hopkins Hospital in Baltimore. He has been at Johns Hopkins for over 20 years, since 1998. His research and clinical practice focuses on the diagnosis and treatment of childhood seizures and epilepsy, particularly treatments other than medications such as diet, neurostimulation and surgery. Currently the Medical Director of the Pediatric Ketogenic Diet Center at Johns Hopkins, Dr. Kossoff is one of the world experts on ketogenic dietary therapy for neurologic disorders and developed the Modified Atkins Diet for children and adults in 2003. He is dedicated to bringing the use of diet therapies for the Atkins Diet for children and adults in 2003. He is a coauthor of *The Ketogenic and Modified Atkins Diets: Treatments for Epilepsy and Other Disorders*, now in its 6th edition, and helped innovate new, flavorful, and aesthetically pleasing ketogenic cooking demonstrations. She also recently authored a second cookbook, "The Modified Keto Cookbook", dedicated to 2:1 ratio ketogenic recipes. She is dedicated to creating enjoyable, reliable recipes and to help others achieve success with ketogenic diet therapies.

Erin Meisner
Erin Meisner is the Advocacy Director for the Glut1 Deficiency Foundation. She lives in the Philadelphia area with her husband, Walter, and daughters Gabriella and Millie. Millie was diagnosed with Glut1 Deficiency in 2012 at the age of 3. Erin is a pediatric occupational therapist and graduate of Thomas Jefferson University. She is a member of the Children’s National Rare Disease Institute Advocacy Committee and the Team Captain for the Glut1 DS team in Penn Medicine’s Orphan Disease Center’s annual Million Dollar Bike Ride.

Umaro Monani PhD
Dr. Monani did his undergraduate studies at St. Xavier’s College in India and received his PhD from the Ohio State University. After a brief stint in the biotech sector, he joined the faculty of the Department of Neurology and the newly formed Center for Motor Neuron Biology and Disease at Columbia University. His lab carries out pre-clinical work on infantile-onset neurological diseases. In particular, he has been instrumental in work that led to the development of treatments for spinal muscular atrophy. Over the last decade, Dr. Monani has spent considerable time studying the biology of Glut1 DS. Most recently, his lab used Glut1 DS model mice to demonstrate that repletion of the Glut1 protein using a gene replacement strategy is an effective way to treat the disorder. His current research focuses on translating these and other pre-clinical findings on Glut1 DS into viable treatments for the human disease. Dr. Monani is an associate professor of pathology & cell biology and neurology at Columbia University.

Jason Meyers
Jason is a registered professional engineer and holds a degree in Mechanical Engineering. He has been President of the Board of Directors of the Glut1 Deficiency Foundation for the past 5 years and has employed with the Louisiana Department of Environmental Quality for 22 years. He lives in Denham Springs, Louisiana with his wife, Keri, two sons, Cote and Scott, and daughter, Katie. Katie was diagnosed with Glut1 Deficiency in 2008 at the age of 4.

Juan Pascual MD, PhD
Juan M. Pascual is the inaugural The Once Upon a Time Foundation Professor in Pediatric Neurologic Diseases and the Ed and Sue Rose Distinguished Professor in Neurology. He is a tenured professor in four Departments at The University of Texas Southwestern Medical Center at Dallas: Neurology and Neurotherapeutics, Physiology, Pediatrics and the Eugene McDermott Center for Human Growth & Development /Center for Human Genetics, and is Director of the Rare Brain Disorders Program (Clinic and Laboratory). He is also a member of the Division of Pediatric Neurology, of the graduate Ph.D. programs in Neuroscience and Integrative Biology, and of the postgraduate clinical training programs in Neurology, Pediatric Neurology, Pediatrics and Medical Genetics. He also teaches at the UT Southwestern Medical School.

In addition, Dr. Pascual is an adjunct professor in the Department of Biological Sciences at the School of Natural Sciences and Mathematics, The University of Texas at Dallas.

Dr. Pascual directs a highly collaborative research laboratory and is credentialed campus-wide at Children’s Medical Center Dallas, UT Southwestern University Hospitals and Clinics and Parkland Memorial Hospital, where he consults on inpatients and outpatients with particularly complex or severe diseases. Much of his research is funded by the National Institutes of Health.

Dr. Pascual received his MD degree from the Universidad de Granada, Spain. He received his PhD in Molecular Physiology and Biophysics from Baylor College of Medicine in Houston, Texas, under Arthur M. Brown, MD, PhD, McCollum Professor and Chair. His postdoctoral research was conducted under Arthur Karlin, PhD, Higgins Professor and Director of the Center for Molecular Recognition, College of Physicians and Surgeons of Columbia University and, later, at the Colleen Gibson Research Laboratories for Pediatric Neurology at the same institution under a Neurological Sciences Academic Development Award from the National Institute of Neurological Disorders and Stroke. He also received residency training in Pediatrics at Washington University School of Medicine - St. Louis Children’s Hospital and in Neurology and Pediatric Neurology at the Neurological Institute of New York - Columbia University Medical Center. He received certification in Neurology with Special Qualification in Child Neurology from the American Board of Psychiatry and Neurology.

As one of few actively practicing pediatric neurologists in the nation who is also a laboratory scientist, Dr. Pascual is interested in the molecular mechanisms that cause inherited metabolic and excitability disorders using electrophysiology and nuclear magnetic resonance (MRI) both in human subjects and in models of human diseases. His laboratory is located in the newest biomedical research building.
Vincent Petit DVM, PhD

Vincent earned his Doctor of Veterinary Medicine (DVM) from the National Veterinary School of Alfort (France) and completed a PhD in cell biology and microbiology from the Pasteur Institute and Paris VII University (Paris, France). He then worked as research scientist at the National Center for Scientific Research (CNRS, France), within Marc Siboni’s lab, where the concept of using viral-derived probes to characterize cell metabolism has been developed.

Vincent intensively worked on the incubation phase of the start-up METAфора, both on basic science, translational research and company incorporation. He is presently the CEO of the company which is developing the METAGlut™ test dedicated to the early diagnosis of the Glut1 Deficiency Syndrome, with the ultimate goal to make it available for the daily practice of neurologists worldwide. Vincent is author of 8 peer-reviewed scientific publications.

**Karthik Rajasekaran PhD**

Karthik Rajasekaran, Ph.D., is a medical affairs specialist with Greenwich Biosciences. Prior to joining Greenwich Biosciences, he was served on faculty of the Department of Neurology and Neurotherapeutics at UT Southwestern Medical Center, Dallas as Instructor with the Rare Brain Disorders Program. Dr. Rajasekaran received his doctoral degree from the University of Madras, India in Neurochemistry & Toxicology, and completed his postdoctoral training at the University of Virginia, Charlottesville in electrophysiology. He has a long standing interest in the neurobiology of epilepsies. He has published several articles on the topic, and his research was funded by multiple organizations, including the Epilepsy Foundation and the American Epilepsy Society. Dr. Rajasekaran serves as peer reviewer for many neuroscience journals and is humbled to serve the Glut1 community as a member of its scientific advisory board.

**Rob Rapaport PhD**

Rob is a retired (2012) Product Safety and Regulatory Manager of Procter & Gamble with 30 years of industrial experience. Rob earned a PhD in Environmental Engineering and Chemistry from the University of Minnesota and BS and MS degrees from Rutgers University. He does a limited amount of consulting for companies on product safety and regulatory needs and volunteers for several non-profit organizations, including serving as Secretary on the Board of Directors for the Glut1 Deficiency Foundation. Rob lives in Cincinnati, Ohio with his wife, Paula, and has a daughter, Sara, and son, JR. JR was diagnosed with Glut1 Deficiency in 2008 at the age of 17.

**Maria Rebbeck RN**

Maria is a mother to an 8-year-old girl who was diagnosed with Glut1 Deficiency in 2010. She has been managing the ketogenic diet for her son for nearly 6 years. She is a registered nurse and volunteers her time to the Glut1 community as much as she can. She loves to educate the general public, families of ketogenic diet programs, and Glut1 families about the ketogenic diet; sharing strategies in the kitchen that have made her life easier, making the longevity of this rigorous diet more successful.

**Thomas Rebbeck MD**

Tom is the father of Dominic, an 8-year-old Glut1 Deficiency patient who was diagnosed in 2010. Being a physician himself, Tom has used his experiences and knowledge not only to assist in the care of his son but to also help the Glut1 community by educating medical professionals about G1D as well as serving the G1D Foundation to assist in fulfilling its mission. He serves on the Scientific Advisory Board of the Foundation as well as serving in a liaison function with the medical community and pharmaceutical industry. At home, Tom and his family support Dominic and help him adhere to the ketogenic diet that has been so successful for him for nearly 6 years.

**Rachel Salazar PT, DPT, PCS**

Rachel Salazar is a board-certified clinical specialist in pediatric physical therapy currently working as part of the multidisciplinary team at the Pediatric Neuromuscular Research Center at Columbia University. She is involved in the evaluation and treatment of children with variety of disorders including Glut1 deficiency syndrome. As a clinical evaluator in single and multi-center clinical research studies, she studies children and adults with Spinal Muscular Atrophy, Duchenne Muscular Dystrophy, Glut1 deficiency syndrome and other neuromuscular disorders. Rachel coordinates a seating and mobility equipment and orthotic clinic specific for the neuromuscular research center. Rachel’s clinical research interests focus on range of motion, adherence to rehabilitation care considerations, outcome measures, motor function and exercise in neuromuscular disorders.

**Holly Senn CCLS III**

Holly Senn is a certified child life specialist who has been in practice for over 15 years with most of those years spent at Inova Children’s Hospital in Falls Church, VA, where she primarily works with the hematology, oncology, orthopedic, and trauma populations on the inpatient unit. Holly graduated with her BS from the University of Southern Mississippi, continues to keep up her child life certification every 5 years through the Association of Child Life Professionals (ACLP).
The Glut1 Deficiency Foundation is honored to welcome this exceptional group of speakers to lead the way as we come together to meet, share, and learn.

Their presence here reflects their concern for and commitment to our community. We are grateful for all they do to bring help and hope to us and to so many others.
Research Opportunity

The Coriell Institute for Medical Research collects, banks and supplies biomedical materials for research. The Glut1 Deficiency Foundation is working with Coriell to establish a collection of Glut1 Deficiency patient samples to be made available to researchers. Stop by the exhibit booth to learn more. A phlebotomist will be available Thursday from 9-4 in the Old Dominion Board Room to collect samples from patients and non-patients who are interested in participating in this project.
Introducing KetoCal® 2.5:1 LQ with MCT

- The first and only nutritionally complete 2.5:1 ketogenic formula with MCT for the dietary management of intractable epilepsy
- Specifically designed for children over 8 years of age and adults

- GREAT VANILLA FLAVOR
- MCT OIL
- MULTI-FIBER BLEND

KetoCal 2.5:1 Raspberry Smoothie (2.5:1 Ratio)

Ingredients:
- 237 mL KetoCal 2.5:1 LQ (1 drink box)
- 30 g raspberries, raw, unsweetened
- 4 g canola oil
- 4 ice cubes

Directions:
- Place KetoCal 2.5:1 LQ, raspberries, canola oil, and about four ice cubes into a blender.
- Simply blend until smooth & enjoy!

Nutrition Information:

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Need help with product access and coverage?
Visit www.nutricia-na.com/navigator or call 1-800-365-7354

KetoCal® 2.5:1 is a medical food and is intended for use under medical supervision.
MARK YOUR CALENDARS to meet, share and learn with us in sunny San Diego as the Glut1 Deficiency Foundation’s 9th Biennial Conference heads to the west coast. The gathering moves to the month of June, which delivers perfect weather and smaller crowds.

The conference will be held at the beautiful Kona Kai Resort on Shelter Island. It promises to be a one-of-a-kind experience and we want you to be there, too!