



MONDAY, JULY 6, 2015
FAMILY PROGRAM AGENDA

CONFERENCE CHAIRS:

Prof. Dr. Jörg Klepper & Juan Pascual, MD. PhD

2015 Conference

ORLANDO 

— meet • share • learn —

TIME	SESSION	PRESENTER
9:00 a.m. – 12:00 p.m.	Registration Open	
9:00 a.m. – 12:00 p.m.	Cooking Demonstrations, Room A <ul style="list-style-type: none"> • Dawn Martenz appearing courtesy of The Charlie Foundation for Ketogenic Therapies • Chef Neil appearing courtesy of KetoCal/Nutricia 	Dawn Martenz – KetoCook Chef Neil – KetoCal
12:00 – 1:00 p.m.	Lunch Buffet	
1:00 – 1:30 p.m.	Welcome and Foundation Updates	Foundation Board Members
1:30 – 2:15 p.m.	Whole Group Presentation: Glut1 Deficiency 2015 Update Room A	Prof. Dr. Jörg Klepper
2:15 – 3:00 p.m.	Whole Group Presentation: Epilepsies of Glut1 Deficiency Room A	Prof. Ingrid Scheffer AO MBBS PhD FRACP FAHMS FAA
3:00 – 3:15 p.m.	Break	
3:15 – 3:45 p.m.	Whole Group Presentation: Movement Disorders of Glut1 Deficiency Room A	Toni Pearson, MBBS
3:45 – 4:15 p.m.	Whole Group Presentation: Cognitive Implications of Glut1 Deficiency Room A	Peter Stavinoha, PhD
4:15 – 5:00 p.m.	Whole Group Presentation: Ketone Esters and Glut1 Deficiency Room A	Dominic D’Agostino, PhD Raffaele Pilla, PhD, PharmD
5:00 – 7:00 p.m.	Dinner (<i>on your own</i>)	
7:00 – 10:00 p.m.	Evening Social Pixar Party	Sponsored by: Glut1 Deficiency Foundation and KetoCal/Nutricia

Children’s activity room and exhibits open 9:00 a.m. to 5:00 p.m.



TUESDAY, JULY 7, 2015
FAMILY PROGRAM AGENDA

CONFERENCE CHAIRS:

Prof. Dr. Jörg Klepper & Juan Pascual, MD. PhD

2015 Conference

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TIME	SESSION	PRESENTER
8:30 – 9:00 a.m.	Whole Group Presentation: Ketogenic Diet – Overview and Updates Room A	Eric Kossoff, MD
9:00 – 9:15 a.m.	Break and Transition	
9:15 – 9:45 a.m.	Breakout Session 1 <i>(choice of three options)</i>	See breakout schedule
9:45 – 10:15 a.m.	Breakout Session 2 <i>(choice of three options)</i>	See breakout schedule
10:15 – 10:45 a.m.	Breakout Session 3 <i>(choice of three options)</i>	See breakout schedule
10:45 – 11:15 a.m.	Breakout Session 4 <i>(choice of three options)</i>	See breakout schedule
11:15 – 11:30 a.m.	Break and Transition	
11:30 a.m. – 12:00 p.m.	Whole Group Presentation: Gene Therapy Research Room A	Darryl De Vivo, MD
12:00 – 1:00 p.m.	Lunch Buffet	
1:00 – 2:00 p.m.	Whole Group Presentation: Research Updates, Patient Registry, Triheptanoin Room A	Juan Pascual, MD, PhD
2:00 – 2:15 p.m.	Break and Transition	
2:15 – 2:45 p.m.	Breakout Session 5 <i>(choice of three options)</i>	See breakout schedule
2:45 – 3:15 p.m.	Breakout Session 6 <i>(choice of three options)</i>	See breakout schedule
3:15 – 3:45 p.m.	Breakout Session 7 <i>(choice of three options)</i>	See breakout schedule
3:45 – 4:00 p.m.	Break and Transition	
4:00 – 5:00 p.m.	Whole Group Presentation: Questions Without Answers Panel Q & A with Audience Room A	Prof. Dr. Jörg Klepper All experts on panel
5:00 – 5:30 p.m.	Meet the Experts <i>(presenters in exhibit/meeting area)</i>	
5:30 – 7:30 p.m.	Dinner <i>(on your own)</i>	
7:30 p.m. – pool closing	Pool Party – Keto-friendly snow cones provided in the hospitality suite from 7:30 – 9:00 p.m., with fun, fellowship, fireworks, and the Electrical Water Pageant	

Children's activity room and exhibits open 8:30 a.m. to 5:30 p.m.

Breakout Session Topics and Presenters:

BREAKOUT TOPICS	PRESENTER
Ketogenic Diet Options and Glut1 Deficiency	Eric Kossoff, MD Johns Hopkins
Ketogenic Diet Best Practices in Glut1 Deficiency	Beth Zupec-Kania, RDN, CD The Charlie Foundation for Ketogenic Therapies
Maximizing Diet Compliance and Palatability	Stacey Bessone RD, LD/N All Children's Hospital
Caring for the Caregivers	Norma Conner, PhD, RN University of Central Florida
Ketogenic Family Support	Emma Williams Matthew's Friends
Glut1 Deficiency in Childhood	Prof. Dr. Jörg Klepper Aschaffenburg Children's Hospital
Glut1 Deficiency in Adolescence and Adulthood	Juan Pascual, MD, PhD UT Southwestern
Strategies that Work: Home, School and Beyond	Ana Hernandez, MS, CBIS CBIS Children's Medical Center Dallas
Navigating the School System: A Guide for Parents	Peter Stavinoha, PhD UT Southwestern
Special Needs Transitions Into Adulthood	Darla Sims and Caroline Lynn Glut1 Deficiency Parents
Genetic Considerations	Kris Engelstad, MS, CGC Genetic Counselor, Columbia

Breakout Session Schedule:

SESSION	ROOM A	ROOM B	ROOM C
1	Genetic Considerations	Strategies that Work	Caring for the Caregivers
2	Glut1 in Childhood	Glut1 in Adolescence/Adulthood	Caring for the Caregivers
3	Navigating the School System	Strategies that Work	Ketogenic Diets
4	Navigating the School System	Special Needs Transitions	Ketogenic Diets
5	Keto Best Practices	Maximizing Compliance	Special Needs Transitions
6	Keto Best Practices	Maximizing Compliance	Ketogenic Family Support
7	Glut1 in Childhood	Glut1 in Adolescence/Adulthood	Ketogenic Family Support