

**Thursday, July 11**

**7:30-8:30 registration open, buffet breakfast**  
**8:00-5:30 exhibits and children's activity room open**



new insights		general session
8:30-9:00	opening welcome	Glut1 Deficiency Foundation
9:00-9:30	past, present, and future	Dr. Darryl De Vivo
9:30-10:00	registry and research	Dr. Juan Pascual
10:00-10:30	<b>BREAK</b>	<b>BREAK</b>
10:30-11:00	consensus work and global updates	Dr. Jörg Klepper
11:00-11:30	genetic testing and prevalence	Dr. Sameer Zuberi
11:30-12:00	natural history and new challenges uncovered	Dr. Michel Willemsen
12:00-1:00	<b>LUNCH</b>	<b>LUNCH</b>
symptoms and treatments		general session
1:00-1:30	movement disorders in Glut1 Deficiency	Dr. Toni Pearson
1:30-2:00	seizures in Glut1 Deficiency	Dr. Stephane Auvin
2:00-2:30	cognitive considerations in Glut1 Deficiency	Dr. Veronica Hinton
2:30-2:45	<b>BREAK</b>	<b>BREAK</b>
2:45-3:15	other symptoms in Glut1 Deficiency	Dr. Juan Pascual
3:15-3:45	Glut1 Deficiency in adulthood	Dr. Mackenzie Cervenka
3:45-4:30	treatments old and new gene therapy	Dr. Jörg Klepper Dr. Smitha Jagadish
exhibits and poster session		open to all attendees
4:30-5:30	cooking, sampling, visiting scientific poster session	exhibit area location TBD

**1:00-4:30 special sibling and patient activities**

## DINNER ON YOUR OWN

**7:00 Social Event: Koo Koo Kanga Roo** (music and movement for the whole family)

# Friday, July 12

**7:30-8:30** registration open, buffet breakfast

**8:00-5:30** exhibits and children's activity room open

## ketogenic diets general session

8:30-9:15	ketogenic diets in Glut1 Deficiency	Dr. Eric Kossoff, Dr. Mackenzie Cervenka
9:15-10:00	best practices and fine tuning Influences on ketosis	Wesley Lowman, RDN, LDN Dr. Dominic D'Agostino
10:00-10:30	<b>BREAK</b>	<b>BREAK</b>

## workshops 10:30-12:00 breakout sessions

choose one workshop

<b>workshop 1</b> <b>keto sessions</b> 10:30-12:00	<b>simple &amp; sustainable keto</b> Dawn Martenz <b>keto kitchen tips</b> Maria Rebbecchi <b>Q &amp; A session</b>	<b>keto independence</b> Leslie Holleman <b>feeding tube tips</b> Kelly Jones <b>moderator</b> Dominic D'Agostino
<b>workshop 2</b> <b>new families</b> 10:30-12:00	<b>Glut1 101</b> Dr. Darryl De Vivo <b>cognitive strategies</b> Dr. Veronica Hinton <b>Q &amp; A session</b>	<b>therapy options and strategies</b> TBD <b>family advocacy</b> Erin Meisner <b>moderator</b> April York
<b>workshop 3</b> <b>adult sessions</b> 10:30-12:00	<b>survey insights</b> Dr. Mackenzie Cervenka <b>registry insights</b> Dr. Juan Pascual <b>Q &amp; A session</b>	<b>identifying and meeting needs discussion</b> <b>moderator</b> Kris Engelstad
12:00-1:00	<b>LUNCH</b>	

## research roundup general session

1:00-2:15	<b>research updates</b> panel discussion	Dr. Adam Hartman - NIH programs Dr. Umrao Monani Dr. Dominic D'Agostino	Dr. Juan Pascual Dr. Karthik Rajasekaran <b>moderator:</b> Dr. Tom Rebbecchi
2:15-2:30	<b>BREAK</b>	<b>BREAK</b>	

## focus sessions (choose one session, additional details on the following page) breakout sessions

2:30-4:30	<b>PATIENTS: adult experiences</b>
	<b>PARENTS: planning for the future</b>
	<b>PROFESSIONALS: closing the gaps</b>
	<b>CHILDREN: special activities</b>

## closing

4:30-5:00	patient panel, closing remarks, announce 2021
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## DINNER ON YOUR OWN

**6:30 Social Event:** Twilight Monument Tour (ticketed event)

Friday, July 12

focus sessions (choose one session)

2:30-4:30	<p><b>Patients: adult experiences</b></p> <p><b>Moderators:</b> Kris Engelstad and Leslie Holleman</p> <p><b>topics:</b></p> <p><b>school experiences and vocational experiences:</b> Jennifer Fitzhugh</p> <p><b>diet and self care:</b> Leslie Holleman</p> <p><b>medical and genetic discussions:</b> Kris Engelstad</p> <p><b>independence:</b> TBD</p> <p><b>staying connected - social and media tips:</b> - TBD</p> <p><b>Q &amp; A, roundtable discussions, additional needs:</b> led by moderators</p>
2:30-4:30	<p><b>Parents: planning for the future</b></p> <p><b>Moderators:</b> Rob Rapaport, Jason Meyers</p> <p><b>topics:</b></p> <p><b>social security, benefits, and waivers:</b> TBD</p> <p><b>ABLE accounts and special needs trusts:</b> Eric Ochmanek</p> <p><b>school experiences and vocational experiences:</b> Jennifer Fitzhugh</p> <p><b>fostering independence:</b> TBD</p> <p><b>caregiver and sibling support:</b> TBD</p> <p><b>Q &amp; A, roundtable discussions, additional needs:</b> led by moderators</p>
2:30-4:30	<p><b>Professionals: closing the gaps</b></p> <p><b>Moderators:</b> Dr. Jörg Klepper and Dr. Juan Pascual</p> <p>roundtable discussions with all professionals in attendance</p> <p><b>suggested topics:</b></p> <p>consensus paper</p> <p>research consortium and the registry</p> <p>best practice diet guidelines</p> <p>adult centered needs</p> <p>treatment challenges and shortfalls</p> <p>diagnostic challenges</p> <p>greatest research needs</p> <p>next steps</p>
2:30-4:30	<p><b>Children: special activities</b></p> <p>special entertainment and structured activities</p> <p>supervision required</p>

everyone reassembles at 4:30 for closing

## social events

**Wednesday**  
**July 10**

**EARLY REGISTRATION OPEN 4:00-6:00**

**Red Carpet Event 6:00-9:00 pm**

unique social event to kick off the conference

- patients will be introduced and spotlighted with a brief story as they walk the red carpet
- music/dance party afterwards
- refreshments, Kona Ice

**Thursday**  
**July 11**

**Sibling and Patient Activities 1:00-4:30 pm**

structured activities

- music therapy
- art therapy
- arts and crafts
- games
- supervision required

**Koo Koo Kanga Roo 7:00 pm**

music and movement

- sing and dance with the stars of Go Noodle
- party with the whole family

**Friday**  
**July 12**

**Children's Activities 2:30-4:30 pm**

structured activities

- special activities and visitors
- special entertainment
- supervision required

**Twilight Monument Tour 6:30 pm**

guided tour of monuments along the National Mall (ticketed event)

- chartered bus transportation (ADA compliant, air conditioning, restrooms)
- pick up and drop off at conference hotel
- several stops along the tour to get out and explore the monuments
- 3.5 hours total tour time

**Saturday**  
**July 13**

**US Capitol Tour 10:00 am**

**(times approximate - unable to officially book tour until 4 months in advance)**

guided tours of United States Capitol Building (ticketed event)

- chartered bus transportation to and from the conference hotel
- 60 minute guided tour of US Capitol (15 minute video, 45 minute walking tour)
- extra time for exploring on your own or visiting the gift shop