2ND EUROPEAN CONFERENCE ON GLUT 1 DEFICIENCY

PROGRAMME

22ND/23RD JUNE 2018

CROWNE PLAZA FELBRIDGE

LONDON ROAD, EAST GRINSTEAD, RH19 2BH, UNITED KINGDOM

MATTHEWS FRIENDS
• Glut1UK •

GLUT1 onlus
Associazione Italiana

GENERAL INFORMATION

Organisers

Matthew's Friends
St Piers Lane
Lingfield
Surrey RH7 6PW, UK

Contact: **Julie Fountain**

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www.matthewsfriends.org/glut1uk/euroconf/
0044 (0)1342 836571

Conference Venue

Crowne Plaza Felbridge
London Road
East Grinstead
West Sussex RH19 2BH, UK
www.cpfelbridgehotel.co.uk

The conference venue hotel has preferential rates for delegates. For more details please visit: www.matthewsfriends.org/glut1uk/euroconf

Registration Open

THURSDAY 21ST JUNE: 4.00pm – 8.00pm
& FRIDAY 22ND JUNE FROM: 8.00am

WELCOME AND OVERVIEW FROM THE SCIENTIFIC ADVISORY BOARD

Following on from the First European Conference on GLUT1 Deficiency that was held in Milan in 2016, we continue with our biennial developmental programme of conferences to increase knowledge and awareness of this specific rare disease by bringing together experts in the field.

TOPICS THAT WILL BE INCLUDED ARE:

1. Basic Science and Current Research
2. Latest Trials
3. Ketogenic Dietary Therapy Global Consensus Statement
4. Cardiovascular Long Term Observational Study
5. Movement Disorder in Glut 1D
6. Workshops: Infants and Paediatrics, Puberty and Adults, Movement Disorder, Triheptanoin and Decanoic Acid (C10) trials.
7. Transition and Adult Glut1D Session
8. Question and Answer Sessions with expert panels.

Healthcare professionals and Glut 1D families are welcome to attend to learn more on the latest research and treatment options that are currently available as well as those being developed for the future. This meeting will bring together Glut 1D families in an environment of support and understanding as well as giving healthcare professionals the chance to network and collaborate further with colleagues on future projects.

We look forward to welcoming you to the UK for our Second European GLUT 1D Conference.

CHAIRMAN

PROFESSOR JÖRG KLEPPER

All Presentations will be conducted in English

SCIENTIFIC COMMITTEE

PROFESSOR HELEN CROSS OBE

PROFESSOR STEPHANE AUVIN

PROFESSOR PIERANGELO VEGGIOTTI

2ND EUROPEAN CONFERENCE ON GLUT 1 DEFICIENCY | SPONSORSHIP PROGRAMME

REGISTRATION FEES

To book visit **www.matthewsfriends.org/glut1uk/euroconf**

FULL PARTICIPANT REGISTRATION £250

- 2 days including social event Friday evening.
- All affiliated health care professionals, ie. Dietitians, Doctors, Nurses, Researchers etc.

DAY REGISTRATION £150

- 1 day only attendance Friday or Saturday excluding social event.
- All affiliated health care professionals, ie. Dietitians, Doctors, Nurses, Researchers etc.

RELATIVES OF PATIENT REGISTRATION

- 1 day, Friday or Saturday, excluding social event. **£45**
- 2 days including social event Friday evening. **£80**

GLUT 1 PATIENT REGISTRATION FREE

- 2 days including social event Friday evening.

SOCIAL EVENT FEE £35

- Friday evening

Rates are in GBP Sterling.

Fees for all conference participants include:

- Participation in scientific sessions
- Entrance to the exhibition area
- Printed programme and other printed materials from the conference
- Certificate of Attendance & HCP CPD
- Lunches and refreshments as detailed in the programme

Exclusions: Hotel accommodation is NOT included in the registrations fees. Visit the booking website for hotel options.

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FRIDAY 22ND JUNE 2018

PROGRAMME

8.45am	**WELCOME** | Joerg Klepper (Germany) and Emma Williams (UK)
9:00am	**KEYNOTE LECTURE - "NOVEL TREATMENT OPTIONS FOR GLUT 1D"** TBC

SESSION I: RESEARCH & CLINICAL TRIALS | CHAIR: HELEN CROSS (UK)	
9:45am	**BASIC SCIENCE AND RESEARCH OVERVIEW** | Stephane Auvin, France
10:15am	**C7 14Y EXPERIENCE +UX007 EPILEPSY** | TBC
10:45am	**UX007 PED** | TBC
11:15am	**COFFEE**
11:45am	**NIH C7 STUDY** | TBC
12:15pm	**DECANOIC ACID (C10) STUDY** | H. Cross, UK
12:45pm	**QUESTIONS AND ANSWERS WITH PANEL**
1:00pm	**LUNCH**

SESSION 2: RESEARCH & CLINICAL TRIALS | JOERG KLEPPER (GERMANY)	
2:00pm	**THE 2018 KETOGENIC DIETARY THERAPY REVISED GLOBAL CONSENSUS STATEMENT. WHAT DOES THIS MEAN FOR GLUT 1?** | Eric Kossoff, USA
2:30pm	**CARDIOVASCULAR B KETOGENIC DIET IN GLUT 1D? LONG TERM OBSERVATIONAL STUDY** | TBC
3:00pm	**MOVEMENT DISORDER IN GLUT 1** | TBC
3:30pm	**TEA**
4:00pm	**INCIDENCE OF GLUT 1D IN SCOTLAND & VARIABLE PHENOTYPES** | TBC
4:30pm	**GLUT 1D IN SCANDINAVIA** | TBC
5:00pm	**QUESTION AND ANSWER SESSION WITH PANEL**
5:30pm	**CLOSE FOR THE DAY**
7:00pm	**SOCIAL EVENING AND BUFFET (GRAND BALLROOM)**

RCPCH CPD PENDING | THIS PROGRAMME IS SUBJECT TO CHANGE.

SATURDAY 23RD JUNE 2018

PROGRAMME

ASK THE EXPERTS – WORKSHOP SESSION **Delegates to choose at time of booking which one to attend:**		
9:00-10:00am	**A. KETOGENIC DIETARY THERAPIES - INFANTS AND PAEDIATRICS** Expert Panel: • Professor Eric Kossoff, USA • TBC • TBC	**B. KETOGENIC DIETARY THERAPIES – PUBERTY AND ADULTS** Expert Panel: • Associate Professor Mackenzie Cervenka, USA • TBC • Sue Wood RD, UK
10:00-11:00am	**C. MOVEMENT DISORDER IN GLUT 1D PAEDIATRICS** Expert Panel: • Professor Joerg Klepper • Professor Stephane Auvin, • Professor Pierre Angelo Veggiotti	**D. TRIHEPTANOIN AND DECANOIC ACID (C10)** Expert Panel: • Professor Helen Cross, • TBC • TBC
11:00am	**COFFEE**	

SESSION 3: TRANSITION AND ADULT GLUT 1D | CHAIR: STEPHANE AUVIN	
11:30am	**ADULT GLUT 1D – CURRENT KNOWLEDGE** | TBC
12:00pm	**ADULT KD CLINIC – US EXPERIENCE** | Mackenzie Cervenka, USA
12:30pm	**ADULT GLUT 1D – ITALIAN EXPERIENCE** | Pierangelo Veggiotti, IT
1:00pm	**LUNCH**
2:00pm	**ADULT KD CLINIC – EXPERIENCE IN OSLO** | TBC
2:30pm	**SURVIVING PUBERTY AND THE THINGS WE DON'T WANT TO TALK ABOUT!** TBC
3:00pm	**QUESTION AND ANSWER SESSION WITH PANEL**
3:30pm	**GLUT 1 SUPPORT GROUPS AND GLUT 1 FEDERATION** Massimiliano Barone, Italy & Emma Williams, UK Invitations for brief overview from European representatives
4:00pm	**SUMMARY AND CLOSING REMARKS** | Helen Cross, UK
4:15pm	**INVITATION TO PARIS 2020** | Stephane Auvin, France
4:30pm	**CLOSE OF MEETING**

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