

Dystonia Europe 26th Annual Conference & D(ystonia)-DAYS 2019

SATURDAY 6 July 09:00-18:00

08:30 **Registration open**

LIVING WITH DYSTONIA

WELCOME

09:00 – 09:15 **Welcome** by Presidents Merete Avery, DE and Fiona Ross TDS

Moderator: TBC

Session I: Dystonia & Childhood

09:15 – 09:35 **Meet Sam Chalmers, mum of Isabella**, 6 years old with generalised dystonia.

09:35 – 10:05 **The Genetic Basis of Dystonia**
Dr. Manju Kurian, UCL, Great Ormond Street Institute of Child Health, London

10:05 – 10:35 **Adaptive Technology**, Dr. Tim Adlam, London

10:35 – 11:00 **Finding Your Voice: Speech and Language Therapy and dystonia**, Karen Esposito, Sheffield Teaching Hospital

11:00 - 11:30 Coffee

Session II: Dystonia from Adolescence to Young Adult

11:30-12:10 **Meet Nick, Ellie, Amybel and Tully** & hear them discuss their journey with their diagnosis.

12:10-12:45 **The CO-OP Approach to Occupational Therapy**, Hortensia Gimeno, Evelina's Children's Hospital, London

12:45 – 13:15 **DBS – why is early intervention important?**
Dr. Jean-Pierre Lin, Evelina's Children's Hospital, London

13:15 – 14:00 Lunch

Session III: Dystonia & Adulthood

14:00-14:30 **Meet dystonia patients Lucy and Julia**

14:30-16:00 **Treatment Roundtable** of specialists describing treatments and efficacy.

- **Neurotoxin**, Dr. Marie-Helene Marion, Chelsea Outpatient Center, London
- **Ear, Nose & Throat** – Dr. Lucy Hicklin, St Georges Hospital, London
- **DBS** – Dr. Francesca Morgante, St Georges University Hospital, London
- **Non-motor symptoms of dystonia**, Dr Kathryn Peall, University College Hospital, Cardiff
- **Dystonia & Mental Health**, Prof Marjan Jahanshahi, UCL Queen Square Institute of Neurology, London
- **Rehabilitation**, Prof Mark Edwards, St Georges University Hospital, London

16:00-16:30 Coffee

Session IV: Research & Development

16:30 - 17:00 **David Marsden Award 2019**

17:00 – 17:30 **Latest News of Dystonia Research** Prof Tom Warner, UCL Queen Square Institute of Neurology, London

17:30-17:45 **Dystonia Survey in Europe**, Prof Maja Relja, Zagreb

17:45-18:00 **MyDystonia** Adam Kalinowski and Eelco Uytterhoeven, Dystonia Euorpe

18:00 **Evaluation and thank you**, Merete Avery & Monika Benson DE; Fiona Ross & Andrea West TDS

THANK YOU & END OF CONFERENCE

20:00 Dystonia-DAYs 2019 Dinner & Dance