



## The "DEA" PROJECT PIT STOP

Featuring - Genetics, Neurology and Nephrology in Tuberous Sclerosis Complex

The European Tuberous Sclerosis Complex Association  
in collaboration with the Polish Tuberous Sclerosis Association and EPISTOP

**Friday 5 April, 2019**

at

**The Novotel Warszawa Centrum  
Marszałkowska 94/98, 00-510 Warszawa, Polska**

DEA – Dissemination of Expertise and Achievement:

**AIM**

To create a readily accessible, active and sustainable network within and between EU countries, for clinicians treating individuals with Tuberous Sclerosis Complex.

This network will facilitate the sharing of best practice within a relevant clinical speciality as well as across disciplines when the need arises in this multi-system condition.

The project aims to establish a holistic approach to the treatment of TSC and promote multi-disciplinary working across the EU.

**Hosting clinicians:**

**Prof. Sergiusz Jozwiak**, Department of Neurology,  
Medical University of Warsaw, Poland

**Prof. Katarzyna Kotulska**, The Children's Memorial Health Institute and Department of Child Neurology,  
Warsaw, Poland

**Visiting clinicians:**

**Prof. Anna Jansen**: Paediatric Neurology Unit, Department of Paediatrics, UZ Brussels

**Dr. Floor Jansen**: Universitair Medisch Centrum Utrecht, Netherlands

**Dr. J. Chris Kingswood**: St. George's University Hospitals, NHS Foundation Trust, London, UK

**Dr. David Kwiatkowski**, The Brigham and Women's Hospital, Inc. Boston, USA

[www.e-tsc.eu](http://www.e-tsc.eu)



## Programme DOCTORS' DEA

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|-------------|--|
| 8.30 – 9.00 | REGISTRATION   |
| 9.00 - 9.15 | Welcome and introductions<br>ETSC AND THE Polish TSC Foundation<br>Introduction to the DEA Project<br>Dr. J. Chris Kingswood |
| 9.15-10.00  | <u>TSC and the Brain</u><br>Epilepsy in TSC<br>Dr. Katarzyna Kotulska  |
| 10.00-10.45 | EPISTOP: general overview<br>Results and next steps<br>Prof. Sergiusz Jóźwiak  |
| 10.45-11.00 | Questions & Answers  |
| 11.00-11.30 | Coffee break   |
| 11.30-12.00 | Prof. Floor Jansen<br>Neuroimaging findings as biomarkers of epilepsy risk and epileptogenesis in TSC patients               |
| 12.00-12.45 | Prof. Anna Jansen<br>Everolimus as an adjunctive treatment in epilepsy, mTORi, Cannabidiol, SEGA epidemiology                |
| 12.45-13.15 | Overview on TAND (TSC Associated Neuro-Psychiatric Disorders)  |
| 13.15-13.45 | LUNCH  |
| 13.45-14.30 | Dr. J. Chris Kingswood<br>Treatment of renal disease in TSC<br>(Monitoring/guidelines, AMLs, Carcinoma, PKD/Cysts)           |
| 14.30-15.30 | Case studies and discussions   |
| 15.30-16.15 | Dr. David Kwiatkowski<br>Genetic analysis of the NMI group; how mosaicism affects phenotype severity                         |
| 16.15-16.45 | Coffee BREAK   |
| 16.45-17.45 | Panel discussion<br>How to implement the multi-disciplinary approach in practice   |
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