



## The "DEA" PROJECT PIT STOP

Featuring - Genetics, Neurology and Nephrology in Tuberous Sclerosis Complex

It is with great pleasure that  
[The European Tuberous Sclerosis Complex Association](#)  
in collaboration with the [Polish Tuberous Sclerosis Association](#) and [EPISTOP](#)  
invite you to the DEA Pit Stop in Warsaw, Poland

on

**Friday 5 April, 2019**

at

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



Please register your interest in this unique event by contacting us  
before **11 March 2019** at: [info@e-tsc.eu](mailto:info@e-tsc.eu)

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



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

Thursday 4th April, 2019

Arrivals

20.00 - 22.00

Welcome dinner

For queries or further information please email [info@e-tsc.eu](mailto:info@e-tsc.eu)

**Programme**  
**DOCTORS' DEA**  
**Friday April 5, 2019**

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