



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

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

Programme
DOCTORS' DEA
Friday April 5, 2019

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