



The "DEA" PIT STOP 2023

**Featuring - Genetics, Neurology and Renal Disease in Tuberous Sclerosis Complex
including notions on TAND (TSC Associated Neuropsychiatric Disorders)**

DEA – Dissemination of Expertise and Achievement:

AIM

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

This network will facilitate the sharing of best practice within a relevant 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.

It is with great pleasure that
[The European Tuberous Sclerosis Complex Association](#)
in collaboration with the [Tuberous Sclerosis Complex Association Ireland](#)
invite you to join us at the DEA Pit Stop in Dublin, Ireland

Friday 7 July, 2023

**The Tercentenary Hall, Trinity Biomedical Science Institute,
150-160 Pearse Street, Dublin, Ireland**



Click [here](#) to register

Hosting clinicians:

Prof. Colin P Doherty MD FRCPI: Ellen Mayston Bates Professor of Epileptology and Head of School, Trinity College Dublin, Ireland

Prof. Andrew Green: Professor of Medical Genetics, UCD School of Medicine and Medical Science; Consultant in Clinical Genetics, Children's Health Ireland (CHI) at Crumlin, Dublin, Ireland.

Mary Vasseghi: Patients for Patient Safety Ireland (WHO Programme), PhD, TSC Researcher, Trinity College, Dublin & FutureNeuro, Dublin, Ireland.

Visiting clinicians:

Dr. Agnies Van Eeghen: TAND Expertise Center, 's Heeren Loo Care Group; the Emma Children's Hospital, UMC, The Netherlands

Prof. Sergiusz Jóźwiak: Coordinator of Rare Disease Program, The Children's Memorial Health Institute, Warsaw, Poland

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

Prof. Angela Peron: Medical Genetics, Meyer Children's Hospital IRCCS, Florence, Italy; Università degli Studi di Firenze, Florence, Italy; Division of Medical Genetics, University of Utah, Salt Lake City, USA



MODERATOR

Dr. Charles Shepherd

Retired Consultant Paediatrician, The Northern Ireland Tuberous Sclerosis Clinic.

PROGRAMME

8.30 – 9.00	REGISTRATION
9.00 - 9.15	Welcome and introductions ETSC and TSC Ireland Introduction to the DEA Project Chris Kingswood
9.15-10.15	TSC in Ireland: Making the invisible visible Colin Doherty & Mary Vasseghi
10.15-10.45	Treatment of renal disease in TSC and when to start (Monitoring/guidelines, AMLs, Carcinoma, PKD/Cysts) Chris Kingswood
10.45-11.00	Case studies and discussions
11.00-11.30	Coffee BREAK
11.30-11.55	Genetic Testing and Genetic Counselling in TSC Andrew Green
11.55-12-20	Mosaicism in TSC; family planning and pre-implantation testing Angela Peron
12.20-13.00	Q&A
13.00-14.00	LUNCH
14.00-14.30	EPISTOP and Vigabatrin Neuroimaging findings as biomarkers of epilepsy risk and epileptogenesis in TSC patients Next steps Sergiusz Jóźwiak
14.30-15.00	TAND, TANDem and Transition Working towards better treatment of TAND over life, and over the world Agnies Van Eeghen
15.00-15.30	Case studies and discussions
15.30-16.00	Coffee BREAK
16.00-17.00	Panel discussion Implementing the multi-disciplinary approach in practice; networking between clinicians involved Local clinicians, all welcome!
17.00-17.30	Red Flags in TSC, what to look out for, when to be concerned, where to go, what to say Guidelines and importance of multidisciplinary practice All panelists and TSC community
	Closing remarks