



The "DEA" PROJECT PIT STOP

REMEMBERING *LOREN LECLEZIO*

It is with great pleasure that
[The European Tuberos Sclerosis Complex Association](#)
in collaboration with [be-TSC](#) - the Belgian Tuberos Sclerosis Association
invites you to join us for the DEA Pitstop in Leuven, Belgium

FOCUS ON

NEUROLOGY, EPISTOP & TAND (TSC-Associated Neuro-Psychiatric Disorders)

Friday 19 October:

The [Beguinage](#) (world heritage), Faculty Club,
Groot Begijnhof 14, 3000 Leuven, Belgium
and

Saturday 20 October, 2018

University Hospital Leuven, Administrative Building Bruckner, Herestraat 49, Belgium
Leuven has a direct train connection (13') to Brussels National Airport.

Hotel: [Begijnhof hotel](#), Tervuursevest 70, 3000 Leuven, Belgium
For reservations please use the form ([to be found via this link](#))

DEA – Dissemination of Expertise and Achievement : what does it aim at?

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

The project outline:

Creation of a network which 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. Anna Jansen: Head of Clinics, Paediatric Neurology Unit, Department of Paediatrics, UZ Brussels

Prof. Liesbeth De Waele: Deputy Head of Clinics, Paediatric Neurology Unit, Department of Paediatrics, UZ Leuven

Visiting clinicians:

Dr. Sergiusz Jozwiak, Head of the Department of Neurology and Epileptology, The Children's Memorial Health Institute, and Department of Child Neurology, Warsaw Medical University, Warsaw, Poland.

Prof. Petrus J de Vries, Sue Struengmann Professor of Child & Adolescent Psychiatry, Division of Child & Adolescent Psychiatry, Department of Psychiatry and Mental Health, University of Cape Town, South Africa

Dr. Lucy Wilde, Research fellow, The Cerebra Centre for Neurodevelopmental Disorders, School of Psychology. University of Birmingham, UK

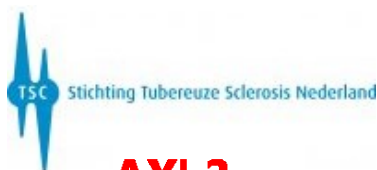
Dr. Agnies van Eeghen, MD PhD, Erasmus MC Rotterdam.

The Dutch TSC-and-behaviour expert team (ETSCG)

Organizing partners



Sponsored by



Program

Friday, Octobre 19

The first day will be held at Groot Begijnhof 14, 3000 Leuven, Belgium

9h00 – 9h30	REGISTRATION AND COFFEE – zaal Van Hamaele
9h30 – 10h20	1. TSC and the brain <ul style="list-style-type: none">• General introduction with a.o. update on clinical recommendations for TSC epilepsy + latest data on SEGA from TOSCA prof. Liesbeth De Waele, University Hospital Leuven, Belgium• Epilepsy surgery dr. Vaz, UCL/Saint-Luc , Belgium• Q&A
10h20 – 11u10	2. EPISTOP <ul style="list-style-type: none">• EPISTOP: general overview Prof. Sergiusz Józwiak, Medical University of Warsaw, Children’s Memorial Health Institute, Warsaw, Poland• EPISTOP: EEG results Prof. Lieven Lagae, University Hospital Leuven, Belgium• Q&A
11h10 – 11h30	BREAK
11h30 – 12h40	3. TSC Associated Neuro-Psychiatric Disorders - TAND organized around the natural TAND clusters as identified as part of Loren Leclezio’s work <ul style="list-style-type: none">• General introduction on TAND, TAND-checklist, TAND-clusters prof. Petrus de Vries, University of Cape Town, South Africa• Overactive/impulsive cluster & neuropsychological cluster prof. Petrus de Vries, University of Cape Town, South Africa• Behavioral Dysregulation cluster Lucy Wilde, research fellow, Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK• Q&A
12h40 – 13h40	LUNCH BREAK

13h40 – 15u10	<ul style="list-style-type: none"> • ASD-like cluster (primarily focussing of pediatric care) prof. Ilse Noens, University of Leuven, Belgium • Mood/anxiety cluster (primarily focussing on adult care) Liesbeth Santermans/Nathalie Vanderbruggen, adult psychiatrists on the TSC team in UZ Brussels, Belgium • Scholastic cluster prof. Bea Maes group, University of Leuven, Belgium, to be confirmed • Eat/sleep cluster prof. Anna Jansen, University Hospital Brussels, Belgium • Q&A
15h10 – 15h25	SHORT BREAK
15h25 – 16h40	<ul style="list-style-type: none"> • Adolescent to adult-care dr. Agnies van Eeghen, Expertisecentre ENCORE, Erasmus Medical Centre, Rotterdam, the Netherlands • RAPIT research results: the effect of Everolimus on children with learning and behavioural disabilities Iris Overwater, research fellow, Department of Neuroscience, Erasmus MC, Rotterdam, the Netherlands • BATSCH-study (Bumetanide to Ameliorate TSC-Associated Hyperexcitable Behaviours) Dorinde van Anandel, research fellow, UMC Utrecht, the Netherlands • Q&A
16h40 – 17h00	NETWORK RECEPTION
17u00 – 18u00	<i>Optional : guided walk in the historic town of Leuven</i>
19h00 – 21h00	DINNER Faculty Club, Beguinage, Leuven

Program

Saturday, October 20

The second day will be held on the location of the **University Hospital of Leuven**,
Administrative Building Bruckner, Herestraat 49, 3000 Leuven

Day 2 offers an extension of the DEA meeting with a closer focus on quality of life and case studies illustrating all possible manifestations of TAND. In addition to the professional public of day 1, the day will also be open to patients, parents and a broad range of caretakers, professionals in family support, etc.

Plenary sessions and discussion of cases by a panel, will be followed by the possibility of taking part in a workshop.

Simultaneous translation will be provided for all participants (Dutch, French, English)

9h00 – 9h30	REGISTRATION AND COFFEE
9h30 – 11h00	<ul style="list-style-type: none">• Patient and parent perspective: narrative resulting from in depth interviews during project Mind the Gap by King Baudouin Foundation Annemie T'Seyen, King Baudouin Foundation• TSC and quality of life : results from the TOSCA register + results from 2016 survey by ASTB Prof. Anna Jansen, University Hospital Brussels, Belgium + Eva Schoeters, be-TSC vzw• TAND (TSC Associated Neuro-Psychiatric Disorders): setting the scene: why and what? prof. Petrus de Vries, University of Cape Town, South Africa• Family support for families living with TSC: making use of the 'competence model' for balance between skills and vulnerabilities - Expertiseteam TSC & Behaviour (Leonore Kuijpers, physician - Richard Slinger, system coach - Marije Offringa, psychologist)• Q&A
11h00 – 11h15	BREAK

11h15 – 12u45	<p>Panel discussion of cases illustrating the various clusters in TAND</p> <p>Issues when discussing each case:</p> <ul style="list-style-type: none"> • Identifying the problem methodology (hospital setting vs home setting, questionnaires, observations, ...), expertise required, multidisciplinary approach, ... • Best practices in addressing the problem: methodology, toolkits, families support, ... • Expected outcomes and long term management <p><i>The case studies will illustrate the diverse clusters and age groups. All are invited to submit a case study for discussion in advance. Interactive discussion with the audience will be welcomed and stimulated.</i></p>
12h45 – 13h45	<p>LUNCH BREAK</p> <p>simultaneous information market</p> <p>Family support organisation</p> <ul style="list-style-type: none"> • Social worker • Centre for school support (CLB) • Family Support Organisation
13h45– 14h20	<ul style="list-style-type: none"> • RAPIT research results: the effect of Everolimus on children with learning and behavioural disabilities Iris Overwater, research fellow, Department of Neuroscience, Erasmus MC, Rotterdam, the Netherlands • BATSCH-study (Bumetanide to Ameliorate TSC-associated Hyperexcitable Behaviors) Dorinde van Anandel, research fellow, UMC Utrecht, the Netherlands • Q&A
14h20 – 15h45	<p>Workshops for patients / parents / caretakers</p> <p>Choice between one of the following three</p> <ul style="list-style-type: none"> • TAND in young children (0 – 12 years) prof. Petrus de Vries, University of Cape Town, South Africa • Children (12 -18 years) - making use of the competence model for balance between skills and vulnerabilities Leonore Kuijpers, physician, + Marije Offringa, psychologist, Expertiseteam TSC and behaviour • Young adults / adults - making use of the competence model for balance between skills and vulnerabilities Richard Slinger, system coach, Expertiseteam TSC and behaviour
15h45 – 16h00	Wrapping up
16h00 – 16h45	Closing reception