



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
invite you to the DEA Pit Stop in Leuven, Belgium

FOCUS

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

Friday 19 October, 2018

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

Saturday 20 October, 2018

University Hospital Leuven, Administrative Building Bruckner, Herestraat 49, Belgium



REGISTRATION to the [DEA](#) Pit Stop is COMPLETELY FREE.

To confirm your participation simply email info@e-tsc.eu

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

Direct train connection (13') to/from Leuven from/to Brussels Airport

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.

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.

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.

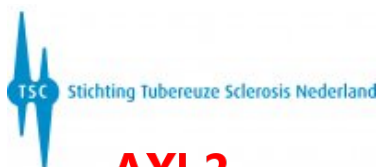
The Dutch TSC-and-behaviour expert team (ETSCG)

The full programme is attached here below and can also be accessed via this link:
<http://www.betsc.be/nl/be-tsc-in-beweging/agenda/19-wat-nog-komt/135-2018-dea-pitstop-neurology-epitop-tand-19th-octobre>

Organising partners



Sponsored by



Programme

Friday, October 19

Venue: Groot Begijnhof 14, 3000 Leuven, Belgium

Morning Sessions

9h00 - 9h30	REGISTRATION AND COFFEE - zaal Van Hamaele
9h30 - 10h20	1. TSC and the brain <ul style="list-style-type: none">• General introduction; 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 - 11h10	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, identified in Loren Leclerio's investigations <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

Programme

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Afternoon Sessions

13h40 - 15h10

- **ASD-like cluster (focusing primarily on pediatric care)**
Prof. Ilse Noens, University of Leuven, Belgium
- **Mood/anxiety cluster (primarily focussing on adult care)**
Dr. Liesbeth Santermans/Dr. Nathalie Vanderbruggen, adult Psychiatrists
TSC Team in Brussels, Belgium
- **Scholastic cluster**
Prof. Annick Vogels, paediatric psychiatrist, University of Leuven, Belgium
- **Eat/sleep cluster**
Prof. Anna Jansen, University Hospital Brussels, Belgium
- **Q&A**

15h10 - 15h25 BREAK

15h25 - 16h40

- **From 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 Andel, research fellow, UMC Utrecht, the Netherlands
- **Q&A**

16h40 - 17h00 NETWORK RECEPTION

17h00 -
18h00

Guided walking tour of the historic town of Leuven - Optional

19h00 - 21h00 DINNER

Location: Faculty Club, Beguinage, Leuven

Programme

Saturday, October 20

Venue: the University Hospital of Leuven,
Administrative Building Bruckner, Herestraat 49, 3000 Leuven

Day 2 offers an extension to 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, day 2 will be open to patients, parents, carers and professionals in family support, etc.

Plenary sessions and panel discussions on case studies will be followed by the possibility of to take part in a series of workshops.

9h00 - 9h30	REGISTRATION AND COFFEE
9h30 - 11h00	<ul style="list-style-type: none">• Patient and parent perspective: narrative resulting from in depth interviews during The Mind the Gap project by The 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• Support for families living with TSC: making use of the 'competence model for balance between skills and vulnerabilities Expertise team TSC & Behaviour (Leonore Kuijpers, physician - Richard Slinger, system coach - Marije Offringa, psychologist)• Q&A
11h00 - 11h15	BREAK

11h15 - 12h45	<p>Panel discussion of case studies illustrating the various clusters in TAND Issues when investigating 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, family support, ...• Expected outcomes and long term management <p><i>The case studies will illustrate the diverse clusters and age groups. <u>You are kindly invited to submit in advance a case study for discussion.</u> Interactive discussion with the audience is welcome.</i></p>
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12h45 - 13h45 LUNCH

simultaneous information market

Family support organisation

- Social worker
- Centre for school support (CLB)
- Family Support Organisation

13h45- 14h20

- **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 Andel, research fellow, UMC Utrecht, the Netherlands
- **Q&A**

14h20 - 15h45

Workshops for patients / parents / carers

Please choose between one of the following:

- **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, Expertise team TSC and behaviour
- **Young adults / adults - making use of the competence model for balance between skills and vulnerabilities**
Richard Slinger, system coach, Expertise team TSC and behaviour

15h45 - 16h00

Closing remarks

16h00 - 16h45

Farewell and cocktails

For further information please email info@e-tsc.eu