



Programme

Thursday, 21 May 2026

CONFERENCE ROOM

12:00-12:15

Opening addresses

Sergiusz Józwiak, Paolo Curatolo

12:15-13:55

Session I Tuberous sclerosis

Chairs: Paolo Curatolo, Sergiusz Józwiak

12:15-12:35

Are Clinical Diagnostic Criteria Still Useful in the Era of Genetic Testing?

Steve Roach

12:35-12:55

Genetics and Pathogenesis of TSC

David Kwiatkowski

12:55-13:15

TSC-associated neurodevelopmental disorders: screen — act — repeat

Anna Jansen

13:15-13:35

Epilepsy matters. Distinct cognitive and psychiatric profiles in high-functioning TSC Adults

Anna Marcinkowska

13:35-13:55

Discussion

13:55-14:25

Coffee break

14:25-15:25

Jazz Pharmaceuticals Sponsored Symposium

15:25–17:25	<p>Session II Epilepsy in TSC <i>Prowadzący: Lieven Lagae, Katarzyna Kotulska-Jóźwiak</i></p>
15:25–15:45	<p>Epilepsy in TSC — natural course, impact of early treatment <i>Paolo Curatolo</i></p>
15:45–16:05	<p>Treatment of Lennox-Gastaut syndrome in TSC <i>Lieven Lagae</i></p>
16:05–16:25	<p>Postnatal preventive trials of epilepsy treatment <i>Sergiusz Jóźwiak</i></p>
16:25–16:45	<p>Is prenatal treatment of epilepsy possible? <i>Darcy Krueger</i></p>
16:45–17:05	<p>The Changing Trajectory of TSC in the Post-mTORi Era: Long-term Outcomes from Hong Kong <i>William Ching-Yuen Chu, Wai Lan Yeung, Godfrey Chi Fung Chan</i></p>
17:05–17:25	<p>Discussion</p>
19:15–21:45	<p>Refreshments</p>

Friday, 22 May 2026

CONFERENCE ROOM

08:00–10:00	<p>Session III Tumors in TSC <i>Chairs: Alicja Dębska-Ślizień, Wojciech Młynarski</i></p>
08:00–08:20	<p>SEGA Diagnosis and Management — 23 years of mTOR inhibitor therapy <i>David Franz</i></p>

08:20–08:40	Pathogenesis and management of kidney lesions in TSC <i>John Bissler</i>
08:40–09:00	Diagnostic challenges of renal cell carcinoma in TSC <i>Piotr Skrzypczyk</i>
09:00–09:20	Cardiac tumors in TSC — an update <i>Maria Respondek-Liberska</i>
09:20–09:40	Lymphangiomyomatosis — sirolimus and other treatment options <i>Elżbieta Radzikowska</i>
09:40–10:00	Discussion
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10:00–10:30	Coffee break
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10:30–12:30	Session IV Treatment of Drug resistant epilepsy in TSC <i>Chairs: Elizabeth Thiele, Katarzyna Kotulska-Jóźwiak</i>
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10:30–10:50	Epilepsy surgery in TSC <i>Paweł Kowalczyk</i>
10:50–11:10	Nerve vagus stimulator in TSC <i>Katarzyna Kotulska-Jóźwiak</i>
11:10–11:30	Epilepsy in TSC: the role of dietary therapy <i>Elizabeth Thiele</i>
11:30–11:50	Drug resistant epilepsy in TSC — case studies (Cenobamate) <i>Sergiusz Jóźwiak</i>
11:50–12:10	Vigabatrin and visual field constriction: condemned but not guilty <i>Robert C. Sergott</i>
12:10–12:30	Discussion
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12:30-13:30 **Lunch and poster session**

13:30-14:15 **Special session: Medications on the Horizon**

Steffen Fetzner (LivaNova)

Lisa Moore-Ramdin (Jazz Pharmaceuticals)

Kim Lindfield (Biogen)

14:15-14:30 **Coffee break**

14:30-16:10 **Session V
NF-1**

Chairs: Eric Legius, Joanna Narbutt

14:30-14:50 NF-1 diagnosis and surveillance
Eric Legius

14:50-15:10 Treatment of skin lesions in NF-1
Joanna Narbutt

15:10-15:30 Malignant tumors in NF-1
Tomasz Świtaj

15:30-15:50 Mosaicism — diagnostic challenge in NF-1 and schwannomatosis
Magdalena Koczkowska

15:50-16:10 Discussion

16:10-16:40 **Coffee break**

16:40-18:20 **Session VI
SWS and other rare neurocutaneous conditions**

Chair: Jeffrey Loeb, Sergiusz Józwiak

16:40-17:00 Epilepsy in Sturge-Weber Syndrome
Rima Nabbut

17:00–17:20	Developing novel prevention and treatment strategies in SWS <i>Jeffrey Loeb</i>
17:20–17:40	Von Hippel-Lindau-disease. Lowering of cancer risk and all cause mortality by optimization of blood As and Se levels in females with hereditary predisposition to cancers <i>Jan Lubiński</i>
17:40–18:00	White and brown spots — differential diagnosis in neurocutaneous disorders <i>Robert Schwartz</i>
18:00–18:20	Discussion

Saturday, 23 May 2026

CONFERENCE ROOM

08:00–10:00	Session VII Diagnostic challenges in neurocutaneous disorders <i>Chairs: Justyna Paprocka, Robert Śmigiel</i>
08:00–08:20	Neurocutaneous disorders in the era of large-scale genomic studies <i>Robert Śmigiel</i>
08:20–08:40	Ophthalmological manifestations of neurocutaneous disorders <i>Joanna Jędrzejczak-Młodziejewska</i>
08:40–09:00	Transition from childhood to adulthood <i>Ilona Kopyta</i>
09:00–09:20	New insights into the biology and therapy of mTORopathies from experimental models <i>Jacek Jaworski</i>

09:20-09:40 Autism spectrum disorders in neurocutaneous diseases: bridging
neurology and behaviour
Justyna Paprocka

09:40-10:00 Discussion

10:00-10:20 **Coffee break**

10:20-11:50 **Session VIII**
Best poster presentations and closing session
Chairs: Sergiusz Józwiak, Piotr Skrzypczyk, Agnieszka Madej-Pilarczyk
