



# Programme

**Thursday, 21 May 2026**

## CONFERENCE ROOM

12:00-12:15

### **Opening addresses**

*Sergiusz Józwiak, Paolo Curatolo*

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12:15-13:55

### **Session I Tuberous sclerosis**

*Chairs: Paolo Curatolo, Sergiusz Józwiak*

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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

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13:55-14:25

**Coffee break**

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14:25-15:25

**Jazz Pharmaceuticals Sponsored Symposium**

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15:25–17:45

**Session II**  
**Epilepsy in TSC**

*Prowadzący: Lieven Lagae, Katarzyna Kotulska-Jóźwiak*

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15:25–15:45

Epilepsy in TSC — natural course, impact of early treatment

*Paolo Curatolo*

15:45–16:05

Treatment of Lennox-Gastaut syndrome in TSC

*Lieven Lagae*

16:05–16:25

Postnatal preventive trials of epilepsy treatment

*Sergiusz Jóźwiak*

16:25–16:45

Is prenatal treatment of epilepsy possible?

*Darcy Krueger*

16:45–17:05

The Changing Trajectory of TSC in the Post-mTORi Era: Long-term Outcomes from Hong Kong

*William Ching-Yuen Chu, Wai Lan Yeung, Godfrey Chi Fung Chan*

17:05–17:25

Is it really a drug-resistant? — case studies

17:25–17:45

Discussion

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19:30–22:00

**Refreshments**

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**Friday, 22 May 2026**

**CONFERENCE ROOM**

08:00–10:00

**Session III**  
**Tumors in TSC**

*Chairs: Alicja Dębska-Ślizień, Wojciech Młynarski*

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08:00-08:20	SEGA Diagnosis and Management — 23 years of mTOR inhibitor therapy <i>David Franz</i>
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	<b>Coffee break</b>
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10:30-12:30	<b>Session IV</b> <b>Treatment of Drug resistant epilepsy in TSC</b> <i>Chairs: Elizabeth Thiele</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>Katarzyna Kotulska-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	<b>Lunch and poster session</b>
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13:30-14:15	<b>Special session: Medications on the Horizon</b>
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14:15-14:30	<b>Coffee break</b>
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14:30-16:10	<b>Session V</b> <b>NF-1</b> <i>Chairs: Eric Legius, Joanna Narbutt</i>
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14:30-14:50	NF-1 diagnosis and surveillance <i>Eric Legius</i>
14:50-15:10	Treatment of skin lesions in NF-1 <i>Joanna Narbutt</i>
15:10-15:30	Malignant tumors in NF-1 <i>Tomasz Świtaj</i>
15:30-15:50	Mosaicism — diagnostic challenge in NF-1 and schwannomatosis <i>Magdalena Koczkowska</i>
15:50-16:10	Discussion
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16:10-16:40	<b>Coffee break</b>
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16:40-18:20	<b>Session VI</b> <b>SWS and other rare neurocutaneous conditions</b> <i>Chair: Jeffrey Loeb, Sergiusz Józwiak</i>
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16:40-17:00	Epilepsy in Sturge-Weber Syndrome <i>Rima Nabbout</i>

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

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## Saturday, 23 May 2026

### CONFERENCE ROOM

08:00–10:00	<b>Session VII</b> <b>Diagnostic challenges in neurocutaneous disorders</b> <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

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

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

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