

Program of the International Conference on TSC and other neurocutaneous disorders

May 21, 2026 (Thursday)

12.00-12.15 S.Jozwiak, P.Curatolo Opening addresses

12.15-14.30 Session I Tuberous sclerosis

Chairs: Paolo Curatolo, Sergiusz Jozwiak

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

David Kwiatkowski –Genetics and Pathogenesis of TSC

Anna Jansen – TSC-associated neuropsychiatric disorders: screen-act-repeat

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

Discussion

14.30-15.00 Coffee break

15.00-16.00 JAZZ Session

16.15 -18.35 Session Epilepsy in TSC

Chairs: Lieven Lagae, Katarzyna Kotulska

Paolo Curatolo – Epilepsy in TSC - natural course, impact of early treatment

Lieven Lagae – Treatment of Lennox-Gastaut syndrome in TSC

Sergiusz Jozwiak- Postnatal preventive trials of epilepsy treatment

Darcy Krueger – Is prenatal treatment of epilepsy possible?

William Ching-Yuen Chu, Wai Lan Yeung, Godfrey Chi Fung Chan - The Changing Trajectory of TSC in the Post-mTORI Era: Long-term Outcomes from Hong Kong

Bełdzińska – Is it really a drug-resistant? Case studies.

Discussion

20.00 Welcome reception

May 22, 2026 (Friday)

8.00-10.00 Session Tumors in TSC

Chairs: Alicja Dębska-Słizień, Wojciech Młynarski

David Franz – SEGA Diagnosis and Management - 23 years of mTOR inhibitor therapy

John Bisler - Pathogenesis and management of kidney lesions in TSC

Piotr Skrzypczyk – Diagnostic challenges of renal cell carcinoma in TSC

Maria Respondek- Liberska - Cardiac tumors in TSC – an update.

Elzbieta Radzikowska – Lymphangioleyomyomatosis – sirolimus and other treatment options

Discussion

10.00-10.30 Coffee break

10.30- 12.30 Session : Treatment of Drug resistant epilepsy in TSC

Chairs: Justyna Paprocka, Elisabeth Thiele, Maria Mazurkiewicz-Bełdzińska

Paweł Kowalczyk – Epilepsy surgery in TSC

Katarzyna Kotulska – Nerve vagus stimulator in TSC

Elisabeth Thiele Epilepsy in TSC: the role of dietary therapy

Katarzyna Kotulska - Drug resistant epilepsy in TSC – case studies (Cenobamate)

Discussion

12.30-13.30 Lunch and poster session

13.30-14.30 Best poster presentations

14.45-16.45 Session : NF1

Chair: Eric Legius

Eric Legius – NF-1 Diagnosis and surveillance .

Joanna Narbutt – Treatment of skin lesions in NF-1

Tomasz Świtaj - Malignant tumors in NF-1

Magdalena Koczkowska - Mosaicism – diagnostic challenge in NF-1 and schwannomatosis

Discussion

16.45-17.15 Coffee break

17.15-19.00 Session: SWS and other rare neurocutaneous conditions

Chair: Jeffrey Loeb,

Rima Nabbout – Epilepsy in Sturge-Weber-

Jeffrey Loeb - Developing novel prevention and treatment strategies in SWS

Jan Lubiński – 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

Robert Schwartz - White and brown spots- differential diagnosis in neurocutaneous disorders wyslalem

Discussion

20.00 Gala dinner

May 23, 2026 (Saturday)

8.00-10.00 Diagnostic challenges in neurocutaneous disorders

Chairs: Steve Roach , Robert Smigiel

Robert Śmigiel - Neurocutaneous disorders in the era of large-scale genomic studies

Jedrzejczak Joanna - Ophtalmological manifestations of neurocutaneous disorders
Ilona Kopyta- Transition from childhood to adulthood
Interesting case presentations
Discussion

10.00-10.30 Coffee break

10.30-12.30 Session: Pharma presentations and closing remarks.