



1st National Conference on Angelman
syndrome in Poland - Agenda

**„Between dreams and reality.
On actions to cure
Angelman syndrome.”**

15.02.2025, 9:00 AM

Opening

9.00-9.05 AM Welcome

9.05-9.25 AM **Why are we so determined on the road to cure Angelman syndrome**

dr n. med. Karolina Pospiesznińska-Martysiuk FAST Poland

9.25-9.35 AM **Global Angelman Syndrome Registry (GASR)**

Joanna Węgrzyn FAST Poland

Session 1 Angelman syndrome individuals care

9.35-10.00 AM **The new age of medicine, breakthroughs in neurology. The role of genetic diagnosis in times of personalized medicine**

prof. dr hab. n. med. Maria Mazurkiewicz-Betdzińska

10.00-10.30 AM **Epilepsy in Angelman syndrome**

prof. dr hab. n. med. Justyna Paprocka

10.30-11.00 AM **From newborn to adult, medical and non-medical issues individuals living with Angelman syndrome face over the years**

prof. dr hab. n. med. Barbara Steinborn

11.00-11.30 AM **Coordinated care in rare diseases - the pilot program of coordinated care for individuals living with Angelman syndrome**

prof. dr hab. n. med. Jolanta Wierzba

11.30-11.50 AM **Safe dependant: choking, seizure, accident – what every caregiver should know**

Ratownik Medyczny Tomasz Modrzewski

11.50-12.00 AM Q&A

12.00-12.10 PM Break

Sesja 2 On treatment development

12.10-12.30 PM **What are clinical trials and why do we talk about it so much**

Dariusz Żebrowski - Stowarzyszenie Dobrej Praktyki Badań Klinicznych GCPpl/Fundacja StopDuchenne

12.30-1.10 PM **Update on clinical trials**

prof. dr hab. n. med. Maria Mazurkiewicz-Betdzińska

1.10-1.40 PM **What is still ahead of us – pre-clinical studies**

dr n. med. Łukasz Przysło

1.40-1.55 PM **Not only therapy invention but a real access to it is a success – a cost of living research**

dr hab. n. o zdr. Dariusz Walkowiak

1.55-2.15 PM **What is „quality of life” of caregivers for individuals living with Angelman syndrome**

dr hab. n. hum Jan Domaradzki, prof. UMP

2.15-2.25 PM Q&A

2.30 PM Closing