



28 August (Friday)

10:20 - 12:40 Broadcast from the Polish Press Agency

- 10:30 - 10:55 Inauguration
 10:55 - 11:00 Short Film by SMA Foundation Poland
 11:00 - 12:40 „The Standard of Care in Spinal Muscular Atrophy vs Patient Needs in Poland”. Panel discussion.
 „SMA – new perspective of life”. Film premiere
 12:40 - 12:50 „Adult living with SMA – Łukasz Kufta”. Reportage
 12:50 - 12:55 Update on the Activities of SMA Foundation Poland
 12:55 - 13:00 Memories of the 2019 Weekend with SMA. Video.

13:00 - 14:30 Session 1

- 13:00 - 13:10 Session Start
 13:10 - 13:40 What's New in Science?
 – **Anna Kordala**, M.A., Department of Physiology, Anatomy and Genetics, University of Oxford,
 13:40 - 14:10 Respiratory Therapy in Emergencies
 – **Prof. Dr Andrew Bush**, Professor of Paediatrics and Paediatric Respiriology, National Heart and Lung Institute, and Consultant Paediatric Chest Physician, Royal Brompton Harefield NHS Foundation Trust
 14:10 - 14:40 Clinical tools to aid the nutritional evaluation of SMAI
 – **Dr Ramona de Amicis**, International Center for the Assessment of Nutritional Status, Department of Food, Enviromental and Nutritional Sciences, University of Milan
 – **Andrea Foppiani**, Department of Food Enviromental and Nutritional Sciences, University of Milan,
 14:40 - 14:50 Wrap-up
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29 August (Saturday)

10:00 - 11:40 Session 2

- 10:00 - 10:10 Introduction
 10:10 - 10:40 Standards Based Orthopaedic Care – **dr Tomasz Potaczek**, University Hospital of Orthopaedics and Rehabilitation in Zakopane
 10:40 - 11:10 Is There a Link between Scoliosis and Hip Mobility in People with SMA?
 – **dr Agnieszka Stępień**, President, Stowarzyszenie Fizjoterapia Polska, Lecturer, Department of Rehabilitation, University of Physical Education in Warsaw
 11:10 - 11:40 Scoliosis in the Era of SMA Treatments – **dr Albert Fujak**, Klinika Ortopedyczna Uniwersytetu Erlangen-Nuerenberg, Malteser Waldkrankenhaus St. Marien GmbH
 11:40 - 11:50 Construction, Conservation and Adaptation of a Wheelchair
 – **Emil Stefaniak**, Active Rehabilitation Instructor, Foundation for Active Rehabilitation
 – **Dawid Feder**, Active Rehabilitation Instructor, Foundation for Active Rehabilitation
 11:50 - 12:00 **Adult with SMA: Angelika Chrankiewicz-Gadek**” Reportage

12:00 - 13:40 Session 3

- 12:00 - 12:10 Introduction
- 12:10 - 12:40 The Standard of Care in Anaesthesiology – **dr Zbigniew Szkulmowski**, kierownik Ośrodka Wentylacji Domowej w Bydgoszczy, przewodniczący Sekcji Wentylacji domowej w Polskim Towarzystwie Anestezjologii i Intensywnej Terapii
- 12:40 - 13:10 Non-invasive Ventilation in Rehabilitation – **dr Anna Pyszora**, Katedra Opieki Paliatywnej Collegium Medicum, Uniwersytet Mikołaja Kopernika w Toruniu
- 13:10 - 13:40 Including a SMA Patient in Non-invasive Ventilation Programme – **mgr inż. Paweł Jędrzejewski**, kierownik krajowy ds. Organizacji Medycznej, Pallmed
- 13:40 - 14:10 Cough Assist and Its Use – **Ivana Sundov**, Bjeska
- 14: 10 - 14:20 „Adult with SMA: Agata Rocznik”. Reportage

14:20 - 16:30 Session 4

- 14:20 - 14:30 Introduction
- 14:30 - 15:00 Immunisation in SMA – **lek. med. Renata Laudan**, paediatrician
- 15:00 - 15:30 Childbirth School for Women with SMA – **Adam Komar**, President, Fundacja Potrafię Pomóc, Founder, Wrocław Childbirth School for People with Disability
- 15:30 - 16:00 Disability Recognition and Benefits for Disabled People and Their Carers – **Ewa Szymczuk**, Social Adviser, Centrum Integracja, Warsaw

- 16:00 - 16:30 Travelling in Poland Without Barriers – **Monika Sztajerowska**, founder of the website „Wakacje bez barier” (Holidays without barriers), Author of *Wakacje bez barier (Holidays without Barriers)*
- 16:30 - 16:40 Wrap-up **ONLINE ACCESS**

<https://konferencja2020.fsma.pl>

<http://centrumprasowe.pap.pl/cp/pl/index/>

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