



37<sup>th</sup> Annual General Meeting  
27th – 30th September 2007, Warszawa, POLAND

**First Day - Thursday 27th September 2007**

*Arrival of Delegates/Transport from airport*

16.00 – 17.00 Registration

17.30 – 19.00 *Executive Committee Meeting*

19.00 – 21.00 Welcome party  
Speeches by: President of EAMDA : Boris Šuštaršič  
Chair Muscular Dystrophy Organisation Poland  
Snacks and drinks

**Second Day – Friday 28th September 2007**

**EAMDA ANNUAL GENERAL MEETING and preconference workshops**

07.30 – 08.45 Breakfast

**37<sup>th</sup> Annual General Meeting EAMDA 2007**

09.00 – 11.00 EAMDA Annual General Meeting – members only

11.00 – 11.30 Coffee Break

11.30 - 13.00 Preconference workshop part 1. – members only  
*The role of patient organisations in the roadmap to therapy and better standards of care. After a short introduction by Peter Streng the participants will pinpoint barriers in working groups.*

13.00 – 14.30 LUNCH

14.30 – 16.30 Preconference workshop part 2. - members only  
*Priorisation of barriers. How to overcome these barriers and what is the role of a patient organization? Ria Broekgaarden.*

17.30 – 19.30 Visit WARSAWA Centre, „The Old Town“

20.00 Traditional Polish DINNER



37<sup>th</sup> Annual General Meeting  
27th – 30th September 2007, Warszawa, POLAND

**Third Day – Saturday 29th September 2007**

**EAMDA ANNUAL CONFERENCE**

07.30 – 08.45 Breakfast

09.00 – 09.30 Official Opening /welcome speeches  
- president EAMDA  
- chair of the Polish MDA  
- representative of Polish Ministry of Health/City of Warsaw  
- Professor Dr Hausmanova

**09.30 -11.00 Session 1: DMD, state of the art in care and cure**

*„Clinical trials, overview of progress and bottlenecks“*  
Prof Dr. K. Busby, University of Newcastle

*„Exon skipping, overview of current developments“*,  
Dr Judith van Deutekom, Prosensa

*"Standards of care in DMD, best practise in Poland"*  
Dr Barbara Ryniewicz

*"Early prevention of cardiomyopathy"*  
Dr Michal Marchel

*„Standards of palliative care in DMD“*  
Dr Andrzej Opuchlik

„Ask the expert“ Questions & Answers by speakers and audience

**11.00 – 11.30 Coffee break**

**11.30 – 13.00 Session 2: Spinal Muscular Atrophy, state of the art in care and cure**

*„Clinical trials in SMA, overview of bottlenecks and progress“*  
speaker to be confirmed

*"Standards of care current best practise in Poland"*  
Dr Maria Jedrzejowska

*„Harmonisation of standards of care and implication for patients“*  
Prof Dr. K. Busby, University of Newcastle

*„Gait in Spinal Muscular Atrophy“*,  
Dr Ales Praznikar

„Ask the expert“ Questions & Answers by speakers and audience

**13.00 – 14.15 LUNCH**



37<sup>th</sup> Annual General Meeting  
27th – 30th September 2007, Warsaw, POLAND

**13.00 – 14.15 LUNCH**

**14.30 – 15.30 Session 3      Therapy development & Science**

*“Report Bottleneck meeting Paris, January 2007”*

Dr Serge Braun / AFM

*“TREAT NMD, where do we stand”*

Prof Dr. K. Busby, University of Newcastle

*“The importance of the classification of NMD”*

Dr H. Lochmuller

*“Stem cell therapy – do’s and don’ts –“*

Dr Serge Braun / AFM

**15.30 – 16.00 Coffee break**

16.00 – 17.00 General Discussion with a forum of all speakers, chaired by Ria Broekgaarden, VSN

17.00 - 17.15 Wrap up by Peter Streng, EAMDA

Official Closing by the President

20.00 - DINNER for Speakers and EAMDA delegates