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International Conference VISEGRAD COUNTRIES CONTRIBUTION TO EUROPEAN REFERENCE NETWORK ON RARE NEUROLOGICAL DISEASES 23rd of April 2016

Hotel Golden Tulip, Warsaw, Poland

ORGANIZER

POLISH HUNTINGTON'S DISEASE ASSOCIATION

PARTNERS

P.J. Safarik University, Kosice, Slovakia

Huntington's Disease Association of Czech Republic, Prague, Czech Republic Szeged University, Szeged, Hungary, Semmelweis University, Budapest, Hungary Institute of Psychiatry and Neurology, Warsaw, Poland

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23rd of April 2016 (Saturday)

- 08:00 09:00 PARTICIPANTS REGISTRATION
- 09:00 09:20 DANUTA LIS, JERZY T. MARCINKOWSKI OPENING
- 09:20 10:00 EUROPEAN REFERENCE NETWORK ON RARE NEUROLOGICAL DISEASES PROJECT INTRODUCTION BY JEAN-MARC BURGUNDER PARTICIPANTS INTRODUCTION

SESSION OF VISEGRAD COUNTRIES PARTICIPANTS

- 10:00 10:10 DANIEL ZIELONKA, POLAND
 - INTRODUCTION AND AIM OF THE CONFERENCE
- 10:10 11:50 EXCHANGE OF INFORMATION ON CURRENT PRACTICES AND RESEARCH IN RARE NEUROLOGICAL DISORDERS IN EUROPE – INTRODUCTION OF ALL PARTICIPANTS AND PRESENTATION OF THEIR FIELDS OF INTERESTS – PARTICIPANTS ONE BY ONE PRESENT HER/HIS IDEA OF THE NETWORK.

11:50 - 12:00 COFFEE BREAK

EUROPEAN/GLOBAL CONTEXT

12:00 - 12:30 Bernhard Landwehrmeyer, Germany

HUNTINGTON'S DISEASE AND OBSERVATIONAL STUDIES

- 12:30 1 2:50 Adrian Danek and Bernhard Landwehrmeyer, Germany Experience from Neuroacantocytosis – bulding the network and IT platform
- 12:50 13:00 **JEAN-MARC BURGUNDER, SWITZERLAND** EUROPEAN REFERENCE NETWORKS ON RARE NEUROLOGICAL DISORDERS COLLABORATION OPPORTUNITIES FOR THE VISEGRAD COUNTRIES
- 13:00 14:00 **DISCUSSION MODERATED BY JEAN-MARC BURGUNDER, SWITZERLAND** EUROPEAN REFERENCE NETWORKS ON RARE NEUROLOGICAL DISORDERS IDENTIFICATION OF KEY COLLABORATIVE PROJECTS, NEXT STEPS, ROADMAP AND RESPONSIBILITIES FOR FUTURE COLLABORATION
- 14:00 15:00 LUNCH

- 15:00 15:30 RAFAŁ PŁOSKI, POLAND NEW GENERATION SEQUENCING AS A DIAGNOSTIC TOOL FOR NETWORK
 15:30 - 16:30 DISCUSSION MODERATED BY DANIEL ZIELONKA, POLAND ASSESSING THE GAPS AND CHALLENGES FOR PATIENTS IN VISEGRAD COUNTRIES
 16:30 - 16:50 COFFEE BREAK
 16:50 - 18:00 DISCUSSION MODERATED BY DANIEL ZIELONKA, POLAND SPLIT OF TASKS FOR PARTICIPANTS
 18:00 - 19:00 DANUTA LIS, DANIEL ZIELONKA, POLAND SUMMARY OF THE MEETING AND FAREWELL
- 19:00 DINNER



