Activities and Visions of Slovak RD Alliance

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Regional conference of RD, Prague, 2-3 December 2014
Slovak Alliance of Rare Disease (Slovak RD Alliance)

- Non-governmental organisation
civil organisation - established on 12.12.2011

**Mission** – permanently a systematically improve the health and social conditions of life of people with RD and promote their integration into society

**Tools** - How to achieve this?
Associate all patient organizations with RD and mutually cooperate and develop National RD plan in Slovakia

approximately 300,000 people with RD
16 Members of Slovak RD Alliance
Membership in organizations

- EURORDIS
- DITA Task Force
- EUROPLAN
- Working Group for RD – Ministry of Health

Ministerstvo zdravotníctva SR
Professional tasks

Support the work of the NP RD in Slovakia
- Cooperation with representatives
  - EUCERD / Commission Expert Group on RD
  - Working Group for RD – Ministry of Health
  - Interdepartmental comment for RD

Cooperation with experts
- Working with the specialized facilities, especially with University Hospitals, ORPHANET
- Cooperation with professional societies
- Regularly special issue of Acta facultatis (in English)
Projects

- **DITA Task force, EURORDIS**
  Questionnaire of the access to medicines

- **CARE-NMD (Freiburg)**
  Questionnaire about the care for people with Duchenne muscular dystrophy

- **Join action 7**

- **Early diagnosis**
Media coverage

- Media coverage of rare diseases
- www.zriedkave-choroby.sk
- www.sazch.sk
- MINORIT – quarterly newsletter
- TV, Radio, internet
- magazine for medical doctors and pharmacists
- Eurordis photo contest - 2nd place
28 February - Rare Disease Day

Since 2012
organizer of campaign - Slovak RD Alliance

2013 – Theme of the campaign: Rare Disorders without Borders

2014 – Theme of the campaign: Join together for better care
Rare Disease Day in Slovakia

2012
Expert Conference
Introduction to Rare Disease

2013
EUROPLAN Forum of Experts – National strategy/plan

2014
20 February 2014 Press Conference
24 March 2014 Rare Disease Day in National Council of SR
Travelling RD exhibition 2014

8 places – 4 cities
Vision of Slovak RD Alliance

- Determination of Centers of expertise
- Engaging in European reference networks
- Coverage and implementation NP for RD
- Implementation of Rare Diseases into national legislation
- RD patient registers
- Rare Disease Day 2015 campaigne
Thank you for your attention

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