

# Opportunities for awareness raising campaigns

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# Overview of the Intervention

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- Why organize an awareness raising campaign?
- Awareness raising campaigns and the political agenda;
- Overview of policies on Rare Diseases:
  - European Union;
  - Romania.
- Opportunities for action:
  - Romania;
  - European Union.
- Themes for discussion.

# Why organize an awareness raising campaign?

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- Rare Diseases policies are designed to help patients:
  - *“The purpose of public health care in Romania is promoting health, preventing diseases and improving the quality of life” (Art. 1, Law on Health Reform no. 95/2006)”*
- Politicians do not know about Rare Diseases (RD) in general, and Primary Immunodeficiencies (PID) in particular;
- They also need to see that there is social support for PIDs;
- Society needs to be informed about PIDs.

*Politicians are in charge of adopting policies and the budget to implement them!*

# Awareness raising campaigns need to be linked to the Political Agenda (1)

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- A successful campaign results in a win-win situation for campaigners and politicians;
- Need to link campaign's objectives with policy makers' agendas;
- Activities to be developed depend on the topic and political environment:
  - The topic is on policy makers' agenda already;
  - The topic is known and out of the political agenda;
  - The topic is unknown and out of the political agenda.

# Overview of key EU Developments (1)

Rare Diseases: an EU priority since the late 1990s

1999

- EU Regulation on Orphan Medicinal Products

2002

- Blood Directive

2007

- 7<sup>th</sup> Framework Programme for Research and Technological Development

2008

- Commission Communication on Rare Diseases

2009

- Council Recommendation on an Action in the field of RD

2011

- EU Directive on Patient's rights in cross-border healthcare

## Overview of key EU Developments (2)

Rare diseases: a Member States priority since 2009

2005

- Some Member States started developing plans to support patients with RD (France in 2005, Portugal and Greece in 2008)

2009

- Member States were requested by the Council of Ministers to develop their strategies/plans for rare diseases by 2013

2009 - 2013

- Member States working on national plans/strategies for RD

End 2013

- European Commission to evaluate national measures



# European Union – PID-related activities

**2002**

1<sup>st</sup> European Day for  
PIDs in the European  
Parliament

**2004**

Workshop on PIDs in  
the European  
Parliament

**2006**

Conference on PIDs  
sponsored by the  
European Commission

**2008**

Debate in the European  
Parliament on rare  
diseases of plasma  
cells, including PIDs

**2008**

Thematic Briefs of  
European policies on  
PIDs

**2008/2009**

Consensus document on  
plasma cells rare  
diseases, including PIDs

**2011**

Expert  
recommendations for  
better management of  
PID, chaired by MEP

**2012/2013**

Development of policies  
affecting PIDs





# Overview of policies for RD - Romania

**2000**

1<sup>st</sup> national programme  
for the treatment of  
RDs (haemophilia &  
thalassemia)

**2008**

Draft national rare  
diseases plan

**2008**

1<sup>st</sup> Rare Disease Day  
in Romania

**2011**

Introduction of PIDs in  
the national treatment  
programme for rare  
diseases

**2011**

Introduction of  
screening for PID in  
the national child  
diagnostics sub-  
programme

**2013**

1<sup>st</sup> PID Awareness  
Week in Romania

**2013**

Protocol  
MoH/RONARD to work  
on a national plan for  
rare diseases



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# Analysis of current situation

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- RDs are on the political agenda at both the European, as well as the Romanian level;
- European and national politicians are committed to develop policies to address RDs.

Good moment to start an awareness campaign on PIDs! ...

... but where do we start?

# Opportunities for Action – Romania (1)

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## National Plan for Rare Diseases

- 2013 is the year when a plan has to be adopted;
- Committee for drafting the plan expected to be appointed this autumn;
- Ministry of Health partnered with RONARD to develop a plan.

## What can we do?

- Create working relationship with policy makers involved in its drafting;
- Develop working relationship with other RD organisations;
- Launch of awareness raising campaign

# Opportunities for Action – Romania (2)

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## Healthcare Reform

- Government committed to reform;
- Basic health care pack not yet configured;
- National programmes expected to stay the same, but not guaranteed;
- Clear need for improved funding
  - in 2012, 34 PID patients receiving treatment out of 300, and 1,865 newborn screening tests for PID carried out in 2012;
- So far, RDs in general and PIDs specifically have not been a discussion topic (basic pack or national programmes);
- Evaluation report by NICE International challenges value of funding RDs in Romania;
- 2013 is when decisions are expected.

## What can we do?

- Political branding;
- Link topic with current political priorities;
- Create working relationship with policy makers involved in its drafting;
- Find champions to support PIDs;
- Create working relationship with other RD organisations.

# Opportunities for Action – European Union

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- Report of the European Commission on national plans/strategies on Rare Diseases (end of 2013);
  - Overview of the situation in the 28 EU Member States;
  - Opportunity to compare Romania with the rest of the EU;
  - Identifying possible objectives and targets.
- Development of European Reference Networks (2013 – 2014);
  - Opportunity to engage with decision-makers and experts
- European Day for Rare Diseases (28 February 2014);
- World Primary Immunodeficiencies Week (April 2014);
- European Elections (22-25 May 2014)
  - Opportunity to engage MEP candidates.

## Conclusions

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- Awareness on RD facilitates the development of campaigns on PIDs at a European and national level;
- Romania is just developing its policy on RDs creating opportunities for promoting PIDs;
- Activities at a European level are a good example that can be replicated at a national/local level.

# Themes for Debate

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- What are our objectives? What are we trying to achieve?
  - *E.g.: facilitate access to treatment for all PID patients;*
- What do we need to achieve our objectives?
  - *E.g.: Political support to help introduce PIDs in the political debate;*
- What would be our first steps to achieve these objectives?
  - *E.g.: Contact local politicians;*
- Who can help us?
  - *E.g.: other patients organisations, medical community, etc.*



Thank you!

Vă mulțumesc pentru atenție!



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## Diagram – Organisation of the Romanian RD System

