

The POLKA Project

a new approach to empowerment



Workshop 3

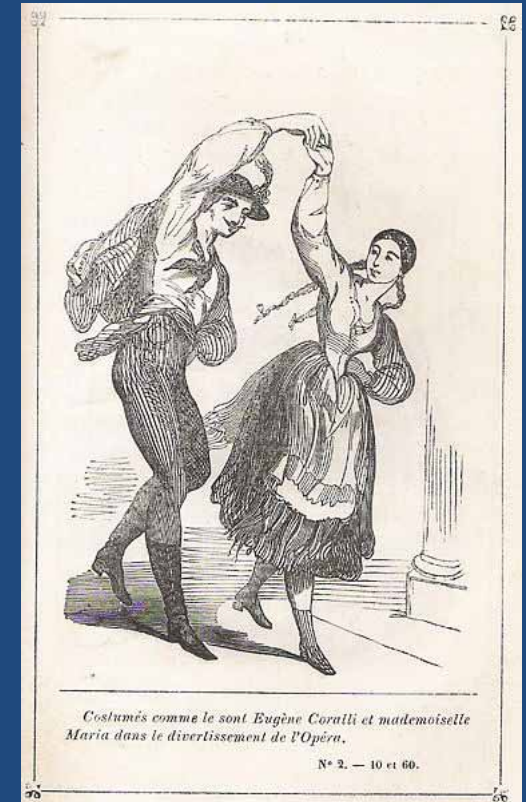
Patients ' Consensus on Preferred Policy Scenarii for Rare Diseases



What is polka?

“The polka is a lively Central European dance and also a genre of dance music familiar throughout Europe and the Americas. It originated in the middle of the 19th century in the Czech lands and is still a common genre in Swedish, Lithuanian, Czech, Polish, German, Hungarian, Austrian, Russian, Slovenian and Slovakian folk music....

The name comes from the Czech word *půlka* – literally, "little half" – a reference to the short half-steps featuring in the dance.” (Wikipedia.org)



What is the Polka project? - I

- Patients consensus on Preferred Policy Scenarii for Rare Diseases
- 3 years project, started September 2008
- Budget: 1 million €, funded by the European Commission and co-funders (CSL Behring, Sigma Tau and Novartis)
- Organised in 6 work packages

What is the Polka project -II

- Pillar 1: To empower patients and collect patients' opinions on selected topics
- Pillar 2: To guide the implementation of the policy on European Reference Networks and National Centres of Expertise
- Pillar 3: To organise the 5th European Conference on Rare Diseases (ECRD) 2010 and more

Management of the Polka Project

- Eurordis is the main beneficiary
- 4 associated beneficiaries
 - Eurordis, RDD, FDR, NCCG-NHS
- 2 collaborating partners
 - MPA (Sweden), DSCOD (Netherlands)
- and subcontractors

- Steering Committee

Pillar 1: Empowering of patients and more

- Deliberative Patients Debates
- Train and prepare patients to
 - Participate in discussions and advocacy
 - Involvement on national and international level
 - Collect patients opinions on selected topics

Consensual or not?

Topics

- Process of selection
 - Consultation
 - Steering Committee
- Criteria for selection
 - Controversial, but consensus possible
 - Relevant to rare patients
 - Can contribute to policy making
 - Can form "clusters" of relevance

Selected topics

Cluster one: Access to treatment and orphan drugs:

- Centres of expertise
- Cross Border Healthcare
- Is there any upper limit on what we should spend on a single patient? – The case of orphan drugs

Cluster two: Genetic issues

- Diagnosis, information to the patient, genetic counselling
- Neonatal screening
- Stem cell research
- Pre-implantation genetic diagnosis

How is it done?

- Experts will prepare
- Play Decide method
- Delphi-like method
- Sessions in public places (??)

Success depending on...

- It takes two to tango, but many to Polka!



credits

A project by:

Eurordis: Yann Le Cam

Rare Disorders Denmark: Lene Jensen

Fundació Doctor Robert: Prof Josep Torrent i Farnell

National Commissioning Group NHS UK: Dr Edmund Jessop

Collaborating partners:

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Project co financed by the EU Public Health Programme 2008-13

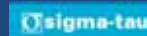


With the financial support of:

CSL Behring

Sigma Tau

Novartis



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