

Table Of Content

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS	2
Summary	3
Coordinator, Leader contact and partners	6
Outputs	7
D13 - E-Newsletter (EN)	7
D01 - Final activity report OPERA (EN)	7
D03 - Database Eurordis membership and other patient organisations (EN)	7
D04 - 1 Workshop Rare ! Together of disease Specific European Networks (EN)	7
D07 - Draft Q&A document to Establishing and developing a European rare Disease Federation (EN)	7
D08 - Summer school 2009 (EN)	7
D09 - Drup development Pedagogic kil (EN)	7
D11 - Participation in EMEA committees and working parties: COMP, PDCO, PCWP (EN) ...	7
D12-01 - Video contest- Eurordis website (EN)	7
D12-02 - Video Contest on RDDay website (EN)	7
D14-01-01 - Logo & Banner	7
D14-01-02 - Rare Disease Day poster (EN)	7
D14-01-03 - Poster (EN)	7
D14-01-04 - Information pack (EN)	7
D14-01-05 - Website (EN)	7
D14-01-06 - EU Media Review (EN)	7
D14-02 - Rare Disease Day Book (EN)	7
D15 - Online Patient Community Portal-Pilot Phase (EN)	7
D16 - Eurordis Website Version 4 (EN)	7
D2-01 - CNA Workshop (EN)	7
D2-02 - CNA Workshop (EN)	7
D5-01 - Respite Care Services (EN)	7
D5-02 - Therapeutic Recreation Programmes (EN)	7
D6-01 - European Helplines Network 1 (EN)	7
D6-02 - European Helplines Network 2 (EN)	7
D6-03 - European Helplines Network 3 (EN)	7
D6-04 - European Helplines Network 4 (EN)	7
D6-05 - European Helplines Network 5 (EN)	7
D6-06 - European Helplines Network 6 (EN)	7
D6-07 - European Helplines Network 7 (EN)	7
D6-08 - European Helplines Network 8 (EN)	7
D6-09 - European Helplines Network 9 (EN)	7
Final report	7

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS

JA2015 - GPSD [705038]

START DATE: 01/01/2009

END DATE: 01/01/2010

DURATION: 12 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: Second Programme of Community action in the Field of Health 2008-2013

PROGRAMME PRIORITY: -

CALL: Promote Health (Hp-2008)

TOPIC: Action on rare diseases

EC CONTRIBUTION: 473075 EUR

KEYWORDS: Accessibility, Health system, Patients rights, Rare diseases and disorders

PORTFOLIO: Rare diseases

Mission and vision of the operating grant holder

The European Organisation for Rare Diseases, EURORDIS, is a patient-driven alliance of patient organisations and individuals active in the field of rare diseases.

EURORDIS' mission is:

- To build a strong pan-European community of patient organisations and people living with rare diseases;
- To be their voice at the European level; and – directly or indirectly – to fight against the impact of rare diseases on their lives.

To this end, EURORDIS undertakes activities on behalf of its members, notably in favour of:

- Empowering rare disease patient groups;
- Advocating rare diseases as a public health issue;
- Raising public rare disease awareness, and also that of national and international institutions;
- Improving access to information, treatment, care, and support for people living with rare diseases;
- Encouraging good practices in relation to these;
- Promoting scientific and clinical rare disease research;
- Developing rare disease treatments and orphan drugs;
- Improving quality of life through patient support, social, welfare, and educational services.

Strategic objectives and specific activities

1. Membership and networking
 - 1.1. European Workshops of National Alliances of Rare Diseases
 - 1.2. Capacity Building of European Rare Disease Specific Networks
 - 1.3. Priority recruitment of members in new and future EU Member States
2. Services to patients
 - 2.1. European Network of Help Lines for Rare Diseases
 - 2.2. European Network of Therapeutic Recreation Programmes for Rare Diseases
 - 2.3. European Network of Respite Care Services for Rare Diseases
 - 2.4. Integration at School
3. Therapeutic Development
 - 3.1. Task Forces of patient representatives and volunteers
 - 3.2. Capacity building: Summer School
 - 3.3. A Charter for Clinical Trials
 - 3.4. Compiled documents on marketed Orphan Medicinal Products
4. Communication
 - 4.1. Rare Disease Day 2009
 - 4.2. A Rare Disease Day Book on Access to Care based on EurordisCare 2&3 surveys
 - 4.3. Eurordis web site development: new version

Expected outcomes

1. Involvement of patient organisations in the development of national plans and strategies for rare diseases in more Member States through information exchange and networking:

- Dissemination of information on national plans (via newsletter and web site...)
- 2 workshops of the Council of National Alliances, representatives of National Alliances will exchange information on the initiatives taken at member states level, the selected priorities, and the involvement of patient representatives in the definition of national plans for rare diseases;
- Support to the organisation of 10 National Conferences on rare diseases to ensure that the development of National Plans is promoted and the Commission's Communication on RD is presented will be offered via the participation to the EuroPlan project. Each Conference will be organised in close co-operation between national authorities and existing national RD alliances, EURORDIS participation in organising committees of National Conferences, intervention of EURORDIS at Conferences (supported by the EuroPlan project).

2. Increased outreach and involvement of rare disease patient organisations in EU health policy definition:

- Frequent consultation with members (represented by the board of Directors, or Eurordis European Public Affairs Committee, or directly with the entire membership) done by email or during workshops and meetings gives the floor to patients and their representatives to express their opinion on key public health debates such as the quality of care, patient safety, European Reference Networks for rare diseases, genetic counselling, cross-boarder care ...
- Innovative methods inspired by DG Research supported project ECSITE will provide further opportunities of consultation and involvement of patients in EU health policy definition (supported by the Polka project).

3. Enlargement and reinforcement of the rare disease networks, and development of tools to exchange information and best practices:

- More member organisations in more countries will join and participate in Eurordis activities. A new database of patient organisations and members will be created, with information on patient representatives involved in each activity. More dissemination of information and feedback from members.
- New Web 2.0 facilities will improve web based communication. Web 2.0 corresponds to enriched interface solutions and technical tools to facilitate Internet surfing and ergonomics. It also corresponds to information sharing and dissemination within communities;
- Support to emerging National Alliances and to the European Network of National Alliances
- Support to emerging Disease Specific Networks (Rare! Together project)
- The recently created network of Help Lines for rare diseases should be strengthened, with more members and best practices to share and to disseminate throughout Europe.

4. Increased outreach and capacity building of rare disease patient representatives

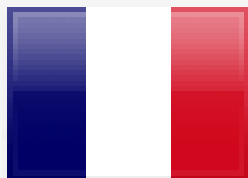
into medicines regulatory activities of the EMEA:

- Better understanding by patient representatives of the EU policy and regulatory decision making process, and capacity building of patient representatives to fulfil the tasks as provided for by the EU legislation on pharmaceutical products;
- At the end of 2009, more patients' representatives in rare diseases should play a role at the national or European level in regulatory affairs, drug development, product information, pharmacovigilance and risk communication.

5. Improved knowledge via public awareness on rare diseases, improved access to information for patient representatives, patients and their families, as well as enhanced patient to patient exchange of information on their disease through social networking and new online tools.

The Rare Disease Day 2009 will be an opportunity to increase awareness on rare diseases in Europe and communicate on all relevant initiatives from the European institutions and member states.

COORDINATOR



European Organisation for Rare Diseases (European Organisation for Rare Diseases)

Plateforme Maladies Rares - 102 rue Didot
75014 Paris

France

PARTNERS

No partners related to the current project

D13 - E-Newsletter (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

[http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d13_en_p
s.pdf](http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d13_en_p
s.pdf)

D01 - Final activity report OPERA (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

[http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d1_en_is.
pdf](http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d1_en_is.
pdf)

D03 - Database Eurordis membership and other patient organisations (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

[http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d3_en_ps
.pdf](http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d3_en_ps
.pdf)

D04 - 1 Workshop Rare ! Together of disease Specific European Networks (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

[http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d4_en_ps
.pdf](http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d4_en_ps
.pdf)

D07 - Draft Q&A document to Establishing and developing a European rare Disease Federation

(EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d7_oth_en_ps.pdf

D08 - Summer school 2009 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d8_oth_en_ps.pdf

D09 - Drug development Pedagogic kil (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d9_oth_en_ps.pdf

D11 - Participation in EMEA committees and working parties: COMP, PDCO, PCWP (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d11_oth_en_ps.pdf

D12-01 - Video contest- Eurordis website (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d12-01_oth_en_ps.pdf

D12-02 - Video Contest on RDDay website (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d12-02_oth_en_ps.pdf

D14-01-01 - Logo & Banner

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-01-01_en_ps.pdf

D14-01-02 - Rare Disease Day poster (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-01-02_pos-01_en_ps.pdf

D14-01-03 - Poster (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-01-03_pos-02_en_ps.pdf

D14-01-04 - Information pack (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-01-04_en_ps.pdf

D14-01-05 - Website (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-01-05_en_ps.pdf

D14-01-06 - EU Media Review (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-01-06_en_ps.pdf

D14-02 - Rare Disease Day Book (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d14-02_en_ps.pdf

D15 - Online Patient Community Portal-Pilot Phase (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d15_en_ps.pdf

D16 - Eurordis Website Version 4 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d16_en_ps.pdf

D2-01 - CNA Workshop (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d2-01_en_is.pdf

D2-02 - CNA Workshop (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d2-02_en_is.pdf

D5-01 - Respite Care Services (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d5-01_en_is.pdf

D5-02 - Therapeutic Recreation Programmes (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d5-02_en_is.pdf

D6-01 - European Helplines Network 1 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-01_en_is.PDF

D6-02 - European Helplines Network 2 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-02_en_is.PDF

D6-03 - European Helplines Network 3 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-03_en_is.PDF

D6-04 - European Helplines Network 4 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-04_en_is.PDF

D6-05 - European Helplines Network 5 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-05_en_is.PDF

D6-06 - European Helplines Network 6 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-06_en_is.PDF

D6-07 - European Helplines Network 7 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-07_en_is.PDF

D6-08 - European Helplines Network 8 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-08_en_is.PDF

D6-09 - European Helplines Network 9 (EN)

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d6-09_en_is.PDF

Final report

European Organisation for Rare Diseases

OPERATING GRANT FOR RARE DISEASE ASSOCIATIONS (OPERA)

Published on: 01/01/2009

http://azorina.cc.cec.eu.int:8082/publications/20083278/20083278_d1_en_is_1.pdf