# Table Of Content

4th Eastern European Conference for Rare Diseases and Orphan Drugs "TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES"  

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary</td>
<td>3</td>
</tr>
<tr>
<td>Coordinator, Leader contact and partners</td>
<td>7</td>
</tr>
<tr>
<td>Outputs</td>
<td>8</td>
</tr>
<tr>
<td>D01 - Conference website (EN)</td>
<td>8</td>
</tr>
<tr>
<td>D01 - Conference website abstract (EN)</td>
<td>8</td>
</tr>
<tr>
<td>D02 - Conference poster (EN)</td>
<td>8</td>
</tr>
<tr>
<td>D03 - Conference package (EN)</td>
<td>8</td>
</tr>
<tr>
<td>D04 - Book of conference proceedind sithe CD (EN)</td>
<td>8</td>
</tr>
<tr>
<td>D06 - Final report (EN)</td>
<td>8</td>
</tr>
<tr>
<td>D06 - Media Report (EN)</td>
<td>8</td>
</tr>
<tr>
<td>Final Report (EN)</td>
<td>8</td>
</tr>
<tr>
<td>Final Report - Final Report (EN)</td>
<td>8</td>
</tr>
</tbody>
</table>
**4th Eastern European Conference for Rare Diseases and Orphan Drugs**

"TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES"

**JA2015 - GPSD [705038]**

<table>
<thead>
<tr>
<th>START DATE:</th>
<th>13/06/2009</th>
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<tbody>
<tr>
<td>END DATE:</td>
<td>13/01/2010</td>
</tr>
<tr>
<td>DURATION:</td>
<td>7 month(s)</td>
</tr>
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<td>CURRENT STATUS:</td>
<td>Finalised</td>
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<tr>
<td>PROGRAMME TITLE:</td>
<td>Second Programme of Community action in the Field of Health 2008-2013</td>
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<tr>
<td>PROGRAMME PRIORITY:</td>
<td>-</td>
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<td>CALL:</td>
<td>Promote Health (Hp-2008)</td>
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<tr>
<td>TOPIC:</td>
<td>Action on rare diseases</td>
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<tr>
<td>EC CONTRIBUTION:</td>
<td>28365 EUR</td>
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<td>KEYWORDS:</td>
<td>Rare diseases and disorders</td>
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<td>PORTFOLIO:</td>
<td>Rare diseases</td>
</tr>
</tbody>
</table>
General objectives

The general objective of the conference is to present rare diseases as a common issue of all policies at national/EU level requiring integrated approach by all stakeholders.

Specific objectives:
1. To invite participants from new member states (MS) and other Eastern European countries (EEC) working in different areas of medicine, industry, finance, social policy etc., concerning rare diseases;
2. To invite speakers sharing best practises on integrative approach to rare diseases;
3. To increase public awareness on rare diseases in new MS and EEC and add value to the public health knowledge.

The theme of the 4th EEC RDOD correlates with the second priority area of the Health programme 2008-2013.

Rare diseases are a common issue of all policies at national/EU level and cover variety of aspects: science, medicine, industry, finance, health care policy, social policy.

Different groups of people are involved and good coordination and cooperation between those groups are the guarantee for successful practice in the area of rare diseases which is a challenge of the contemporary United Europe.

Rare diseases are complex and complicated problem requiring timely information, relevant quality of treatment, adequate social policy. An integrative approach toward rare diseases will increase the quality of life of people affected by rare disease, will prolong the healthy life years across their life cycle.

The 4th EEC RDOD is a continued action in the field of rare diseases aimed to improve knowledge, facilitate the access of the EEC to information on these diseases and add value to the public health knowledge. The conference will become an Eastern European unified stage where all stakeholders involved in the area of rare disease will meet and manifest their good will to integrative approach toward the objective of rare diseases.
Expected achievements

Participants from all Europe (MS and non-members) will be invited to attend the 4th EEC RDOD at affordable price and conditions;
- The audience of the conference will include all different groups working in the field of rare diseases: medicine, industry, national and European institutions, authority and media;
- Speakers and lecturers will be among groups of national policy makers, medical and non-medical specialists, industry, patient associations and individual patients. They will present the benefit form the integrative approach to rare diseases;
- Representatives of those groups will give an overview on rare disease by oral presentations, stressing out on the specific aspects and proposing relevant actions in order to bring their views on need for integrative approach to rare diseases;
- The conference outcomes will be disseminated worldwide thus will improve the awareness on rare diseases;
- Directions of successful cooperation between all stakeholders will be produced.

Target audience

Based on the general objective of the conference to present rare diseases as a common issue of all policies at national/EU level requiring integrated approach the aim of the 4th EEC RDOD is to reach stakeholders from the following areas, coming from all EU member states and other EEC (e.g. Croatia, Former Yugoslav Republic of Macedonia, Turkey, Russia, Moldova, Ukraine, etc):
- national and EU governance and policy makers in healthcare, social policy, economy, education, Health Insurance Funds
- research institutions
- patients
- industry
- media

Speakers from EC and countries with experience in rare diseases for instance Italy, France, the Netherlands, UK, Belgium will be invited to share their experience, points of view and proposals in order to reach the general objective of the conference. Conclusions and recommendations will be disseminated in all EU member states and other EEC.

Personal invitations to eminent experts in rare diseases at EU level (Rare Disease Task Force members, COMP/EMEA members, DG SANCO experts, leaders of EU funded projects on rare diseases such as ORPHANET, etc.) will be send in order to establish the conference scientific committee. Such a scientific committee will broaden the European dimension of the conference by bringing their top level of expertise to participants.
Conference programme

First day (13 June 2009)

08:00-10:00 REGISTRATION
10:00-10.30 OPENING CEREMONY
Expected official guests: Mrs. Zorka Parvanova - First Lady of Bulgaria, Dr. Evgeniy Zhelev - Minister of Health, Members of the Parliament
10:30-12:30 SESSION 1
Policy on rare diseases
Moderators: Rumen Stefanov, Stephanie Donahoe, Domenica Taruscio
Presentation duration: 20 minutes
Catherine Berens (DG Research)
Stephanie Donahoe (FDA/USA)
Domenica Taruscio (EUROPLAN)
Christel Nourissier (EUORDIS)
Karin Blumer (Joint EBE-EuropaBio Rare Diseases & Orphan Medicinal Products Task Force)
Rumen Stefanov (BAPES)
12:30-13:00 Press Conference
12:30-13:30 Lunch Break
13:30-17:00 SESSION 2
Sharing best practices on integrative approach on rare diseases in different countries
Moderators: Domenica Taruscio, Catherine Berens, Sonja van Weely, Iva Stoeva
Presentation duration: 10 minutes
Participating countries: Armenia, Bulgaria, Croatia, Czech Republic, Greece, Hungary, Italy, Macedonia, The Netherlands, Poland, Romania, Russia, Serbia, Slovenia, Turkey, UK.
17:00-19:00 PARALLEL WORKSHOPS:
Workshop 1 - Central and Eastern European (CEE) activities (part 1)
Moderators: Iva Stoeva, Natasa Bijelic, Borut Peterlin
Workshop 2 - Integrative management of rare diseases
Moderators: Domenica Taruscio, Ivan Ivanov, Elisaveta Naumova, Edmund Jessop
Workshop 3 - Access to orphan drugs in CEE countries
Moderators: Stephanie Donahoe, Rumen Stefanov, Tsveta Milanova
Workshop 4 - Rare tumors
Moderators: Asen Dudov, Aydin Dortok
20:00 GALA DINNER FOR ALL THE PARTICIPANTS

Second day (14 June 2009)

09:00-10:00 POSTER SESSION
Moderators: Rumen Stefanov, Domenica Taruscio, Marianna Murdjeva, Sonja van Weely
10:00-12.30 SESSION 3
Models of integrative approach in different rare diseases
Moderators: Valeria Kaleva, Sanka Vejvalkova, Alexey Sokolov
Thalassemia - Vasili Berdoukas (Greece), Valeria Kaleva (Bulgaria)
Neuro muscular diseases - Ysbrand Poortman (WANDA)
Prader Willy syndrome - Uros Hladnik (Italy)
Lesch-Nyhan syndrome - Uros Hladnik (Italy)
Chronic myeloid leukemia - Stafan Goranov (Bulgaria), Vesselina Goranova (Bulgaria)
Epidermolysis bullosa - Edmund Jessop (UK), Ivelina Yordanova (Bulgaria)
Primary immunodeficiencies - Elisaveta Naumova (Bulgaria)
10:00-12.30 PARALLEL WORKSHOP:
Workshop 5 - Central and Eastern European (CEE) activities (part 2)
Moderators: Grzegorz Wegrzyn, Ysbrand Poortman, Radostina Simeonova, Celine Lewis
12:30-13:00 CLOSING REMARKS AND TAKE-HOME MESSAGES
### COORDINATOR

Bulgarian Association for Promotion of Education and Science  
(Bulgarian Association for Promotion of Education and Science)  
Bratya Sveshtarovi n°4  
4017 Plovdiv  
Bulgaria

### PARTNERS

No partners related to the current project
D01 - Conference website (EN)
Bulgarian Association for Promotion of Education and Science
4th Eastern European Conference for Rare Diseases and Orphan Drugs
"TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES" (4th EEC RDOD)
Published on: 13/06/2009
http://conf2009.raredis.org/

D01 - Conference website abstract (EN)
Bulgarian Association for Promotion of Education and Science
4th Eastern European Conference for Rare Diseases and Orphan Drugs
"TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES" (4th EEC RDOD)
Published on: 13/06/2009
http://azorina.cc.cec.eu.int:8082/publications/20084253/20084253_d01-00_en_ps.pdf

D02 - Conference poster (EN)
Bulgarian Association for Promotion of Education and Science
4th Eastern European Conference for Rare Diseases and Orphan Drugs
"TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES" (4th EEC RDOD)
Published on: 13/06/2009
http://azorina.cc.cec.eu.int:8082/publications/20084253/20084253_d02-00_pos_en_ps.pdf

D03 - Conference package (EN)
Bulgarian Association for Promotion of Education and Science
4th Eastern European Conference for Rare Diseases and Orphan Drugs
"TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES" (4th EEC RDOD)
Published on: 13/06/2009
http://azorina.cc.cec.eu.int:8082/publications/20084253/20084253_d03-00_en_ps.pdf