



A PROJECT OF THE BULGARIAN ASSOCIATION FOR PROMOTION OF EDUCATION AND SCIENCE
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Dear Sir / Madam,

With this e-mail we would like to express our strong support to the initiative of the European Commission regarding **European Action in the Field of Rare Diseases**.

We are a team members of the “*Information Centre for Rare Diseases and Orphan Drugs*” (ICRDOD) (www.raredis.org) - the first and unique Eastern European educational and information centre, dedicated to patients, associations and medical professionals, interested in rare diseases and orphan drugs. ICRDOD is a main project of the **Bulgarian Association for Promotion of Education and Science (BAPES)** is a non-government non-profit organization, registered under the Bulgarian law on legal persons with non-profit purposes in 2003:

- Providing **free of charge information** about rare diseases, specialized clinics, laboratories in Europe, contact details of medical specialists that are experts in rare diseases.
- Running a **multilingual Internet site** about rare diseases and orphan drugs (www.raredis.org) with news, educational topics for patients, doctors and associations, discussion forums, etc.;
- Organization of numbers of **workshops and conferences** focusing on different aspects of rare diseases.
- Support to the establishment of national Alliance of People with Rare diseases (NAPRD).
- Members of BAPES are among the initiators of the **National Program for Rare Diseases 2007-2011**. The aim of the program is to create a unified national health policy, providing the Bulgarian citizens with prevention, timely diagnostics, adequate treatment and rehabilitation for rare diseases.

Acting in the field of rare diseases we are well acquainted with the different aspects of life of people who suffer in rare disease. To make them life better – this should be a matter of a consensual effort: by the governments, by the ministers, by the political bodies, the society, the affected people themselves.

In this fast growing and developing world, where the nature is so destroyed and polluted ... no one is “immunized” against rare disease. So the all efforts are not only healing, but even more important - toward preventing being affected by rare disease.

We strongly support the activity of the EC and we are convinced there in the importance to stimulate the MS to develop national plans.

We wish success in this very important action of the EC and are ready for close and beneficial cooperation with partners all over the Europe.

On the behalf of the ICRDOD’s team members,

Marieta Igarenska

Project Coordinator

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