



# INFORMATION CENTER FOR RARE DISEASES AND ORPHAN DRUGS IN BULGARIA

Jordanova R, Iskrov G, Stefanov R

Information Centre for Rare Diseases and Orphan Drugs – Bulgaria

## Summary

The Information Center for Rare Diseases and Orphan Drugs (ICRDOD) started as a project of the Bulgarian Association for Promotion of Education and Science (BAPES) – a non-government non-profit organisation ([www.raredis.org](http://www.raredis.org)). The center is working simultaneously in 6 main directions- information, education, awareness, support, networking and lobbying. As a result of the work of ICRDOD, the National Plan for Rare Diseases 2009-2013 is a fact from the beginning of this year. At the beginning of May 2009, BAPES started the Rehabilitation center for people with rare diseases "RareDis", thus adding a new direction for ICRDOD's activities and increasing the number of services for people with rare diseases, not only in Bulgaria, but also in the Balkan region. The Information Center for Rare Diseases and Orphan Drugs is a successful model for integrative approach to rare diseases and can be easily adapted and applied in other countries.



## Conclusion

Member State's health policy initiatives for rare diseases must be encouraged by the European commission, should germinate by initiative groups within each country and develop in the suggested directions.