



Information Centre for Rare Diseases and Orphan Drugs in Bulgaria

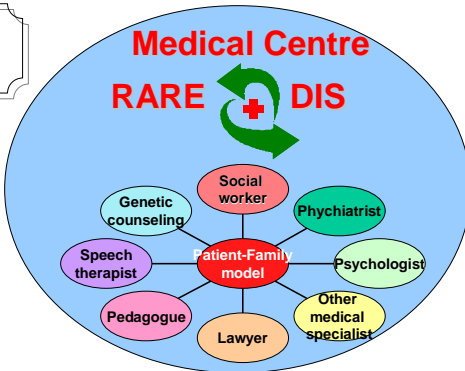
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Information Centre for Rare Diseases and Orphan Drugs, Bulgaria

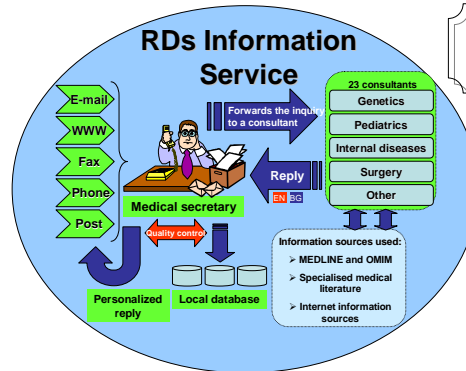
Summary

The Information Centre for Rare Diseases and Orphan Drugs (ICRDOD) is a project and activity of the Bulgarian Association for Promotion of Education and Science (BAPES). It is a free educational and information service in Bulgarian and English languages, providing personalized replies to requests from patients, families and medical professionals. It started working in 6 main directions – information, education, awareness, support, networking and lobbying. This combination helped ICRDOD to start producing its own RDs information by initiating and maintaining RDs registries, the statistics of which are available online. In May 2009, the Rehabilitation and training centre for people with rare diseases "RareDis" started its work, 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. We present our Centre for rare diseases as a successful model for truly integrative rare disease approach that can be adapted and applied also in other countries.

2009



2004



2008

RDs Prevalence & Registries

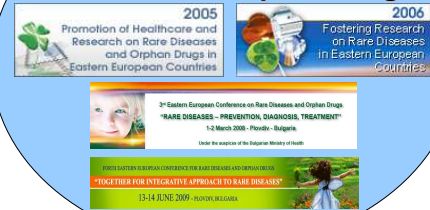
- National Registry of Thalassaemia Major Patients in Bulgaria
- Pilot Epidemiological Study of Chronic Myeloid Leukaemia in Bulgaria
- List of Orphan Drugs officially available in Bulgaria



ICRDOD Website Homepage

2005

Eastern European Conferences on Rare Diseases and Orphan Drugs



Patient Empowerment

- Directory of RDs patient associations in Bulgaria
- Raising RDs awareness activities coverage



2007

Europartnerships



2006

Conclusion

Almost all RDs initiatives in Eastern Europe started as information service and step by step they developed and enlarged into the suggested above 6 directions. Thus, completing the full cycle of the integrative approach to RDs.