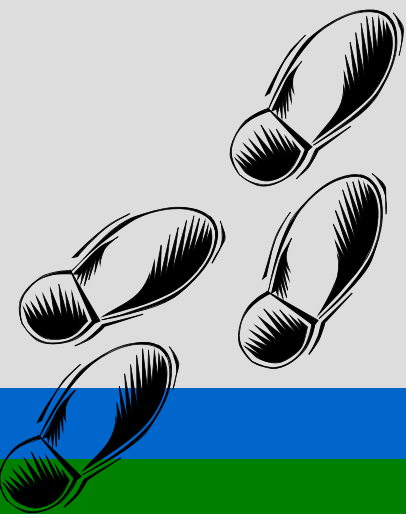




Steps to a national policy on rare diseases: the case of Bulgaria

Rumen Stefanov

Information Centre for Rare Diseases
and Orphan Drugs, Bulgaria





Information Centre for Rare Diseases and Orphan Drugs



Information Centre for Rare Diseases and Orphan Drugs (ICRDOD) is:

- Educational and information service
- In Bulgarian and English languages
- Personalized replies to requests from
 - Patients
 - Families
 - Medical professionals
- Free of charge



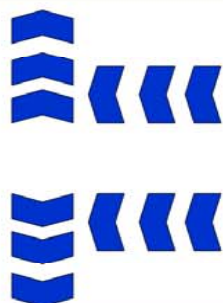
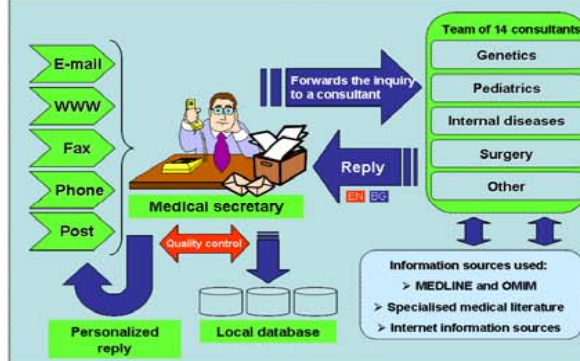
A project of the Bulgarian Association for Promotion of Education and Science (BAPES)



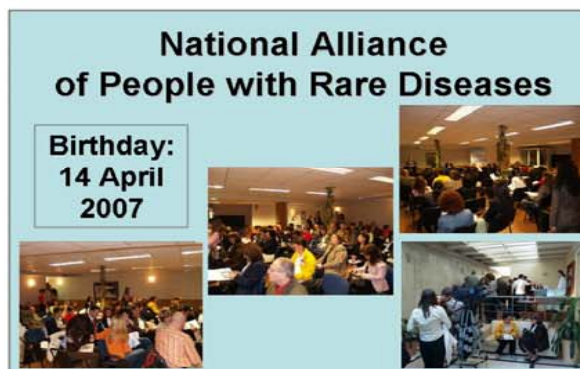
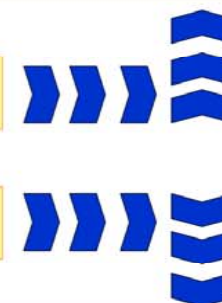
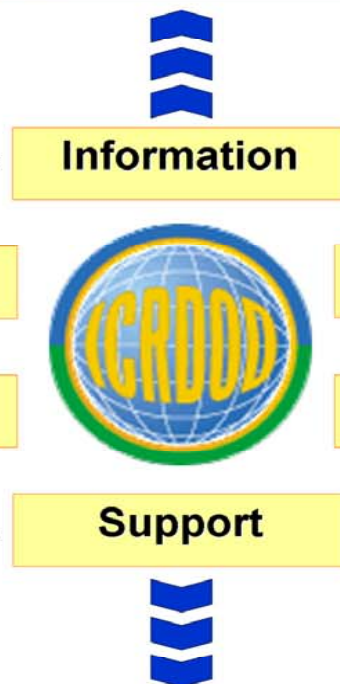
BULGARIAN NATIONAL PLAN FOR RARE DISEASES (Project)

The project "National plan for rare diseases 2007-2011" is written according to an order of the Minister of health - Prof. Radoslav Gaidarski (RD 09-243: 03.05.2006) by the workgroup: Assoc. Prof. Dr. Rumen Stefanov (chairman), Prof. Dr. Paraskeva Stamenova, Prof. Dr. Nikola Tzanakov, Prof. Dr. Sabina Zaharieva, Prof. Dr. Ivailo Tsvetov, Assoc. Prof. Dr. Veneta Bojanova, Assoc. Prof. Dr. Mariana Murdjeva, Dr. Radka Ticheva, Dr. Svetlana Spasova, Dr. Simeon Darichiev, Polina Deatcheva, Galia Stamenova and Vladimir Todorov.

The expert group is grateful for the support of Dr. Domenico Tarnicio (Director of The National Centre for Rare Diseases, Italy), Prof. Segolene Ayme (Leader of Rare Diseases Task Force (RDIF), DG SANCO, EC and ORPHANET), Mr. Yau le Cam (Executive director of EURORDIS), Prof. Dr. Peter Tsvetov (chairman of the Bulgarian orthopedic-traumatology society), Assoc. Prof. Dr. Julia Doyrova (chairman of the Bulgarian society of cardiology), Prof. Dr. Ivo Dimitrov (Medical University - Plovdiv).



Lobbying
Networking





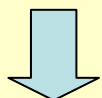
Do we need a policy on rare diseases?

	Common diseases	Rare diseases
Awareness Information	Diabetes, hepatitis, hypertension, stroke...	Ackerman syndrome, Sclerosing bone dysplasia - mental retardation
Patients	Many patients with 1 disease	Many diseases with 1 patient
Prevention	Priority for GPs Many disease specific programs	Folic acid ? Prenatal screening ?
Diagnosis	Quick, many lab tests, Primary/secondary healthcare	Expensive tests (if available) Delay, High level of expertise
Treatment	Many drugs for 1 disease	No treatment / too expensive
Follow up	1 disease – 1-2 specialists	1 disease – team of specialists

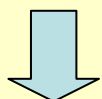


Current level of GP's awareness on RD

5106 GPs

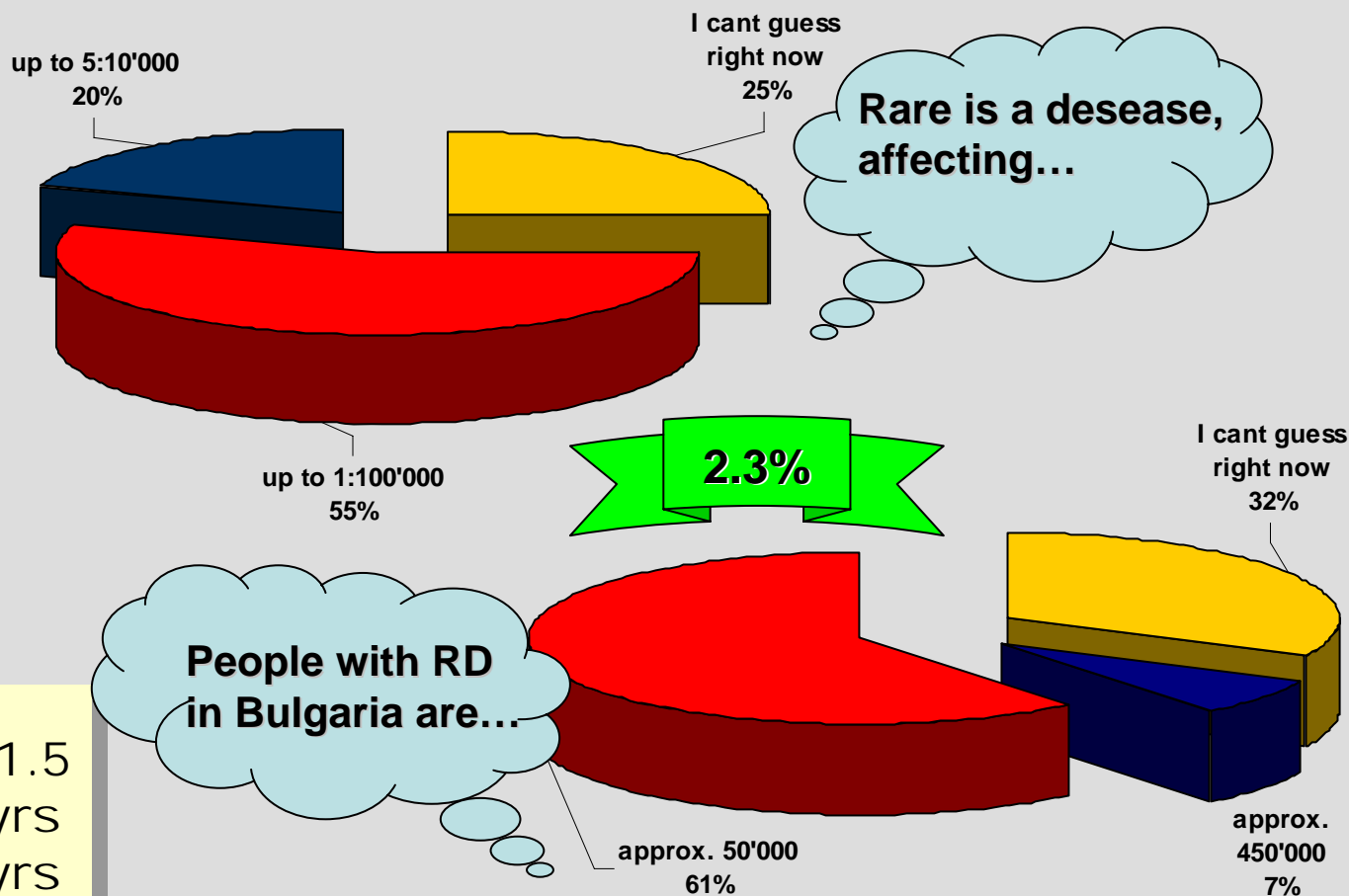


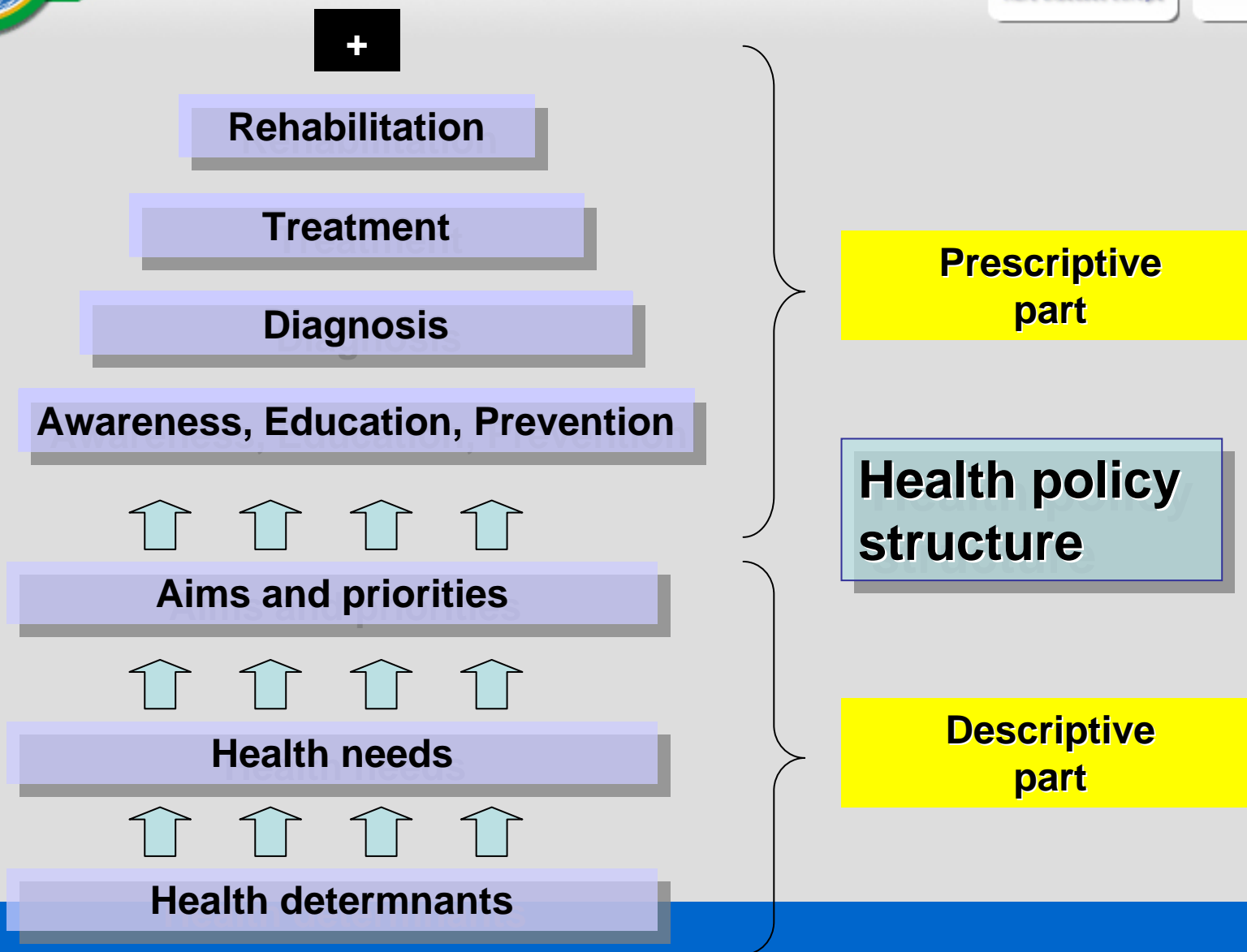
1993 (39%)
random sample

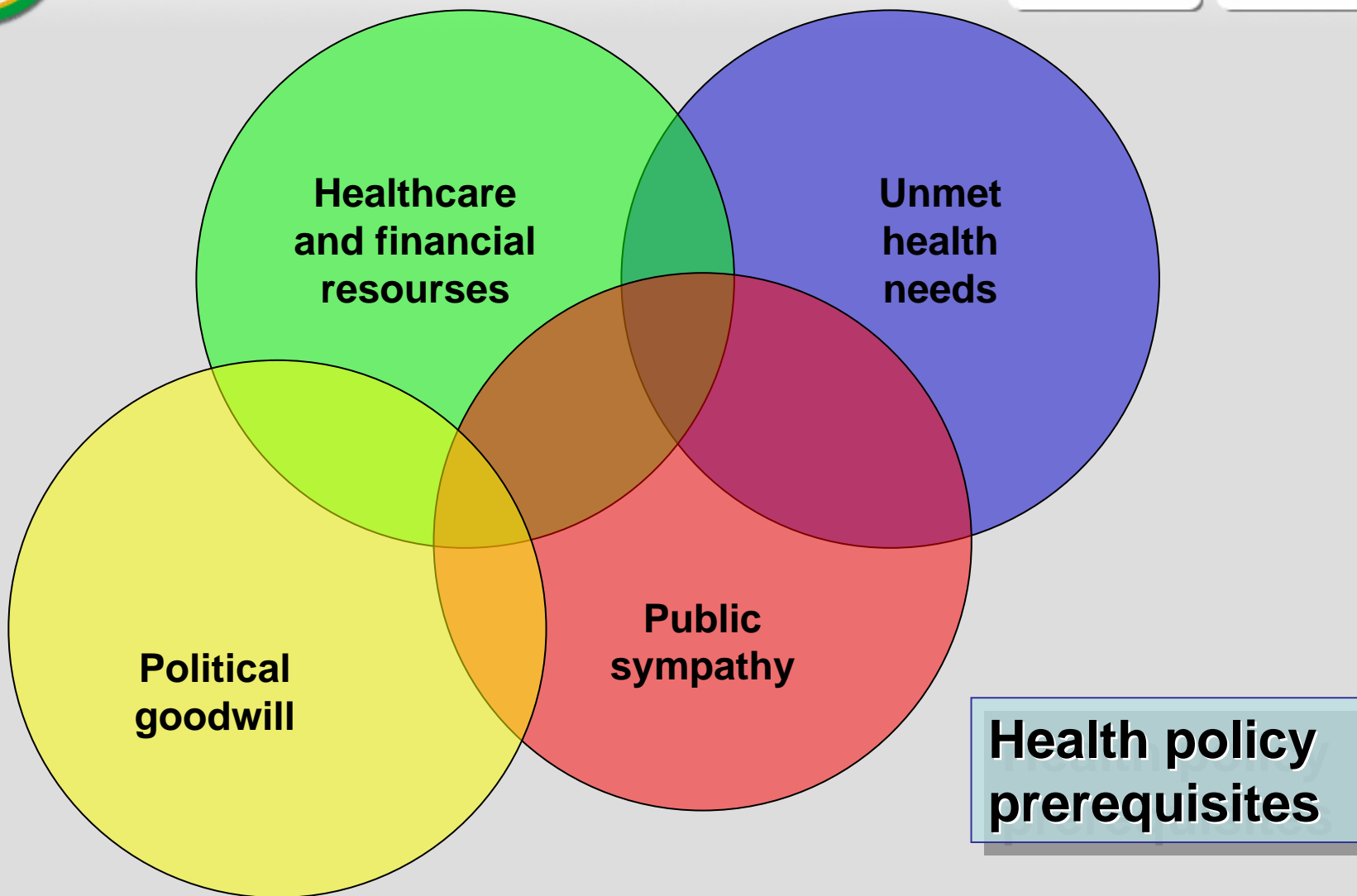


1007 (51%)
participated

Sex ratio M/F = 1:1.5
Mean age = 45.9 yrs
Practice = 19.2 yrs











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News : National program for rare diseases

Posted by rumen on 2004/11/11 23:52:00 (1192 reads)



Today, the **Bulgarian Association for Promotion of Education and Science (BAPES)** deposited at the **Bulgarian Ministry of Health** an official proposal for establishment of **National program for rare diseases and orphan drugs** (Reg. No. 15-00-151/11.11.2004).

There are 6 specific items, explained in the proposal:

1. To add rare diseases in the National Health Strategy of Bulgaria.
2. To prepare a National program for rare diseases and orphan drugs.
3. To adapt and accept regulations, based on the existing EU practice.
4. To establish and update a list of rare diseases.
5. To involve the regional centers of healthcare for providing health information and education about rare diseases and orphan drugs.
6. Collaboration for improving the Information Centre for Rare Diseases and Orphan Drugs and its portal www.raredis.org.

We will keep you informed about the decision of the Ministry of Health and all subsequent activities.

Previous article - Next article



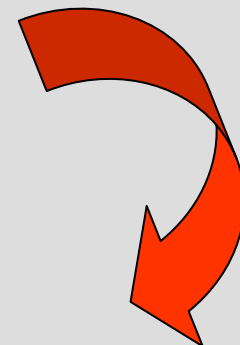


NEWS : National program for rare diseases

Posted by informer on 2006/2/23 2:10:00 (859 reads)



On 9th of February 2006 the ICRDOD deposited at the Bulgarian Ministry of Health a proposal for establishment of a **National Program for Rare Diseases and Orphan Drugs** in Bulgaria. The proposal is stressing on the importance to place in the full glare of publicity the problems of the patients with rare diseases, as well as theirs doctors. The initiative is supported by leading European organizations like RDTE and ORPHANET, EURORDIS, CNMR, as well as key opinion leaders from Bulgaria like Prof. J. Jorgova, Chairman of the Bulgarian Society of Cardiology, Prof. Dr. P. Stamenova, Chairman of the Bulgarian Society of Neurology, and Prof. P. Tivchev, President of Bulgarian Orthopedic-Traumatology Society. We will keep you informed with the progression of this initiative.



NEWS : National Program for Rare Diseases

Posted by informer on 2006/12/5 22:10:00 (372 reads)



On 24th of November 2006, a **project of National Program for Rare Diseases 2007-2011** in Bulgaria was deposited at the Bulgarian Ministry of Health (Ref. № 96-P-46) by an expert group. The aim of the program is to create a unified national health policy, providing the Bulgarian citizens with prevention, tamely diagnostics, adequate treatment and rehabilitation for rare diseases.



Finally ...

1 policy → 2 programs

**National program
for diagnosis, prevention
and control of treatment
of hereditary diseases,
predispositions and
inborn anomalies
2009 - 2013**

**National program
for rare diseases
2009 - 2013**





“National program for rare diseases 2009-2013”

The aim of the program is to create an **adequate institutional framework and mechanisms**, ensuring timely prevention, diagnosis, optimal treatment and rehabilitation of patients with rare diseases in Bulgaria.

Priorities:

1. Epidemiological data surveillance
2. Training of medical students and doctors
3. Boosting research on rare diseases
4. National awareness campaigns
5. Support of patient associations
6. Collaboration with other EU member states

