Contribution of the Bulgarian Information Centre for Rare Diseases Towards Prevention and Treatment

Rumen Stefanov

Information Centre for Rare Diseases
and Orphan Drugs, Bulgaria

INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ

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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

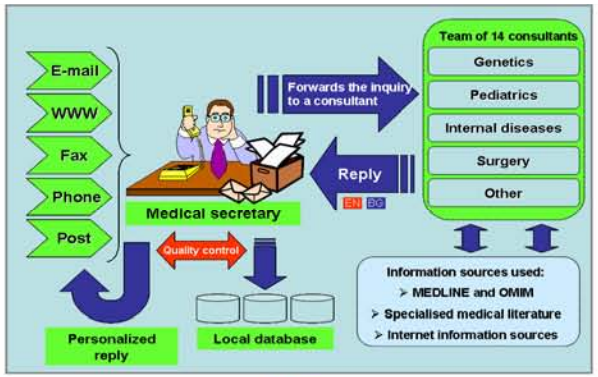
NATIONAL PLAN

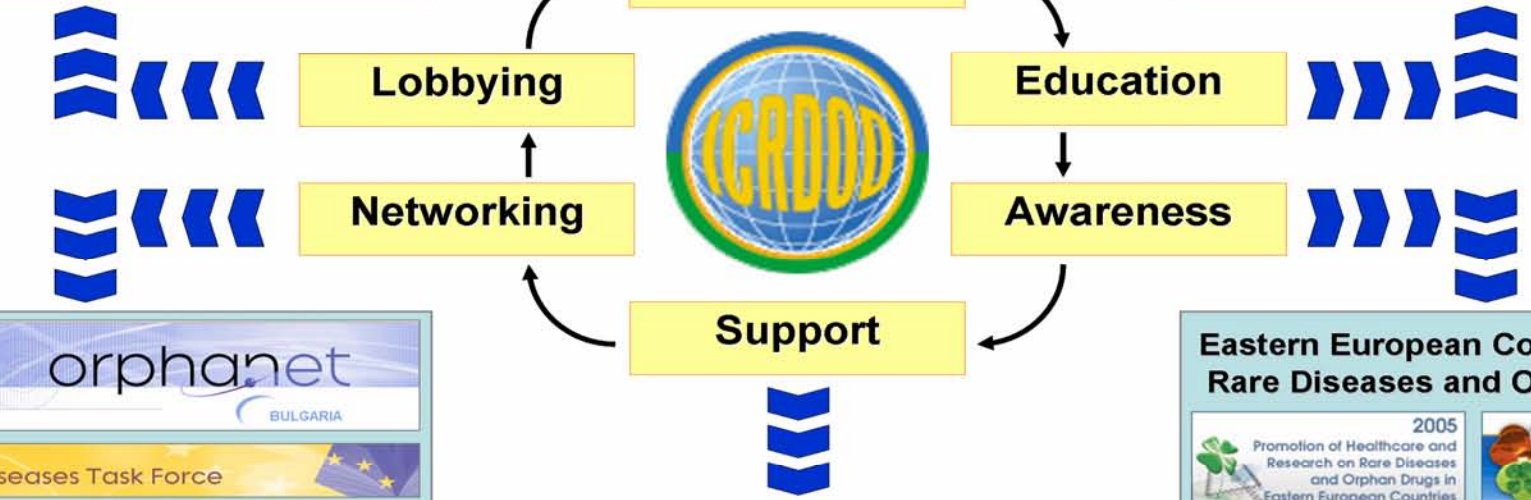
FOR RARE DISEASES

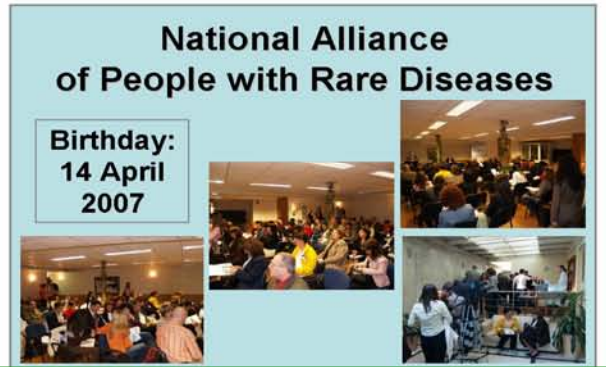
(Project)

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: Assos. Prof. D-r Rumen Stefanov (chairman), Prof. D-r Paraskeva Stamenova, Prof. D-r Nikolai Tzankov, Prof. D-r Sabina Zaharieva, Prof. D-r Ivailo Tumev, Assos. Prof. D-r Veneta Bojinova, Assos. Prof. D-r Mariana Murdjeva, D-r Radka Tincheva, D-r Svetlana Spasova, D-r Simeon Darakchiev, Polina Dencheva, Galia Stamenova and Vladimir Temov.

The expert group is grateful for the support of D-r Domenica Taruscio (Director of The National Centre for Rare Deseases, Italy), Prof. Segolene Ayme (Leader of Rare Diseases Task Force (RDTF), DG SANCO, EC and ORPHANET), Mr. Yan le Cam (Executive director of EURORDIS), Prof. D-r Petar Tivchev (chairman of the Bulgarian orthopedic-traumatology society), Assos. Prof. D-r Julia Djorgova (chairman of the Bulgarian society of cardiology), Prof. D-r Ivo Dimitrov (Medical University – Plovdiv).







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E-mail

WWW

Fax

Phone

Post

Medical secretary

Forwards the inquiry to a consultant

Reply

EN BG

Team of 14 consultants

- Genetics
- Pediatrics
- Internal diseases
- Surgery
- Other

Quality control

Personalized reply

Local database

Information sources used:

- MEDLINE and OMIM
- Specialised medical literature
- Internet information sources

Information

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Регистрирани потребители

Потребителско име:

Парола:

Влез!

Забравена парола?

Регистрирайте се сега!

Подкрепа от

МИНИСТЕРСТВО НА ЗДРАВЕОПАЗВАНЕТО

Clinical Research Centre for Rare Diseases "Aldo e Cele Dacco'", Mario Negri Institute, Italy

Bulgarian society of Neurology

Напред!

(1) 2 3 4 ... 127 »

Редки Болести : Синдром на Lennox-Gastaut

Пуснато от informer на 2008/7/14 10:10:00 (80 прочитания)

Към нашата база данни е добавено ново рядко заболяване – Синдром на Lennox-Gastaut. Синдромът Lennox-Gastaut (LGS) се характеризира с триадата от полиморфни генерализирани пристъпи (тонични, атонични абсанси или атонични), генерализирани бавни комплекси пика-бавна вълна на ЕЕГ и умствено изоставане. За да получите повече информация натиснете тук и попълнете съответния модул. Описанието е подготвено от нашия консултант по педиатрия -доц. д-р Иван Иванов, дм.

Коментари?

Новини : Промени в екипа на ИЦРБЛС

Пуснато от informer на 2008/6/26 10:00:00 (161 прочитания)

Този месец настъпиха важни промени в екипа на ИЦРБЛС. Г-жа Мариета Игаренска напусна Центъра и ще продължи професионалната си кариера като психолог. Г-н Георги Искров се присъедини към екипа на ИЦРБЛС като технически сътрудник. Успех на Мариета и ползотворна работа на Георги!

Коментари?

Лекарства-сираци : Лечение на аспирационен пневмонит, изискващ интубация и механична вентилация

Пуснато от informer на 2008/6/25 10:10:00 (163 прочитания)

На 10/07/2007 година в списъка на кандидатстващите продукти за статут на лекарства-сираци в ЕС е регистриран нов медикамент под номер 457, чиято активна съставка е ***Лусипултид***. Предназначен е за лечение на **аспирационен пневмонит, изискващ интубация и механична вентилация()**.

Коментари?

PubMed : Синдром на Chediak-Higashi

Пуснато от informer на 2008/6/20 10:10:00 (216 прочитания)

PubMed, порталът за биомедицинска и научна литература индексира интересна статия на тема **Синдром на Chediak-Higashi** (Curr Opin Hematol. 2008 Jan;15(1):22-9.). Автори са Kaplan J De Domenico I Ward DM *и др.*, от Department of Pathology, University of Utah School of Medicine, Salt Lake City, Utah, USA. Синдромът на Chediak-Higashi е рядко автозомно рецесивно заболяване, описано преди повече от 50 години. Характеризира се с хипопигментация, рецидивиращи инфекции, леко нарушено кръвосъсирване и неврологични проблеми. Лекува се с трансплантация на костен мозък, което подобрява хематологичните и имунологични дефицити, но неврологичните проблеми персистират. Клиничните изследвания са открили мутации в CHS1/LYST гена. Видът на мутацията определя тежестта на заболяването. Изучаването на тези мутации ще обясни как CHS1/LYST генът влияе на хематологичните, имунните и неврологичните процеси. За да прочетете пълното резюме на статията, натиснете тук.

PubMed

Търсене

Търсене

Детайлно търсене

Нашите Конференции

Анкета

Кой сте вие?

- A patient
- A parent or relative
- A medical professional
- A medical student
- Other

Гласувай!

Резултати

Последни новини

HON@ CODE ACCREDITED 06/2006

ICRDOD is in compliance with the HONcode

Education

www.raredis.org

First Eastern European Conference on Rare Diseases and Orphan Drugs – 27 May 2005

www.conf2005.raredis.org

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Second Eastern European Conference on Rare Diseases and Orphan Drugs – 8-9 Sept 2006

- 184 participants
- 21 countries

- 16 speakers
- 30 presentations
- 98 posters

Main sponsor:

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www.conf2006.raredis.org

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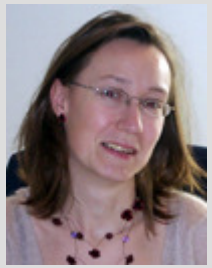
Second Eastern European Conference on Rare Diseases and Orphan Drugs – 8-9 Sept 2006

Prof. Ségolène AYME
ORPHANET, RDTF

Dr. Marlene E. HAFFNER
Office of Orphan Products Development, FDA, USA

Prof. Josep Torrent-Farnell
Committee for Orphan Medicinal Products, EMEA



Dr. Catherine BERENS
DG Research - RTD-F2, European commission

Mrs. Christel NOURISSIER
EURORDIS

Dr. Domenica TARUSCIO
National Centre for Rare Diseases, Italy

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Third Eastern European Conference on Rare Diseases and Orphan Drugs – 1-2 March 2008

Category	n	Proportion
Doctors	106	55%
Government	12	6%
Industry	11	6%
Patients	23	12%
Students	40	21%
Total	192	100%

Main sponsor: **Sponsor:**

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Third Eastern European Conference on Rare Diseases and Orphan Drugs – 1-2 March 2008

www.raredis.org

Inauguration of the new office of ICRDOD

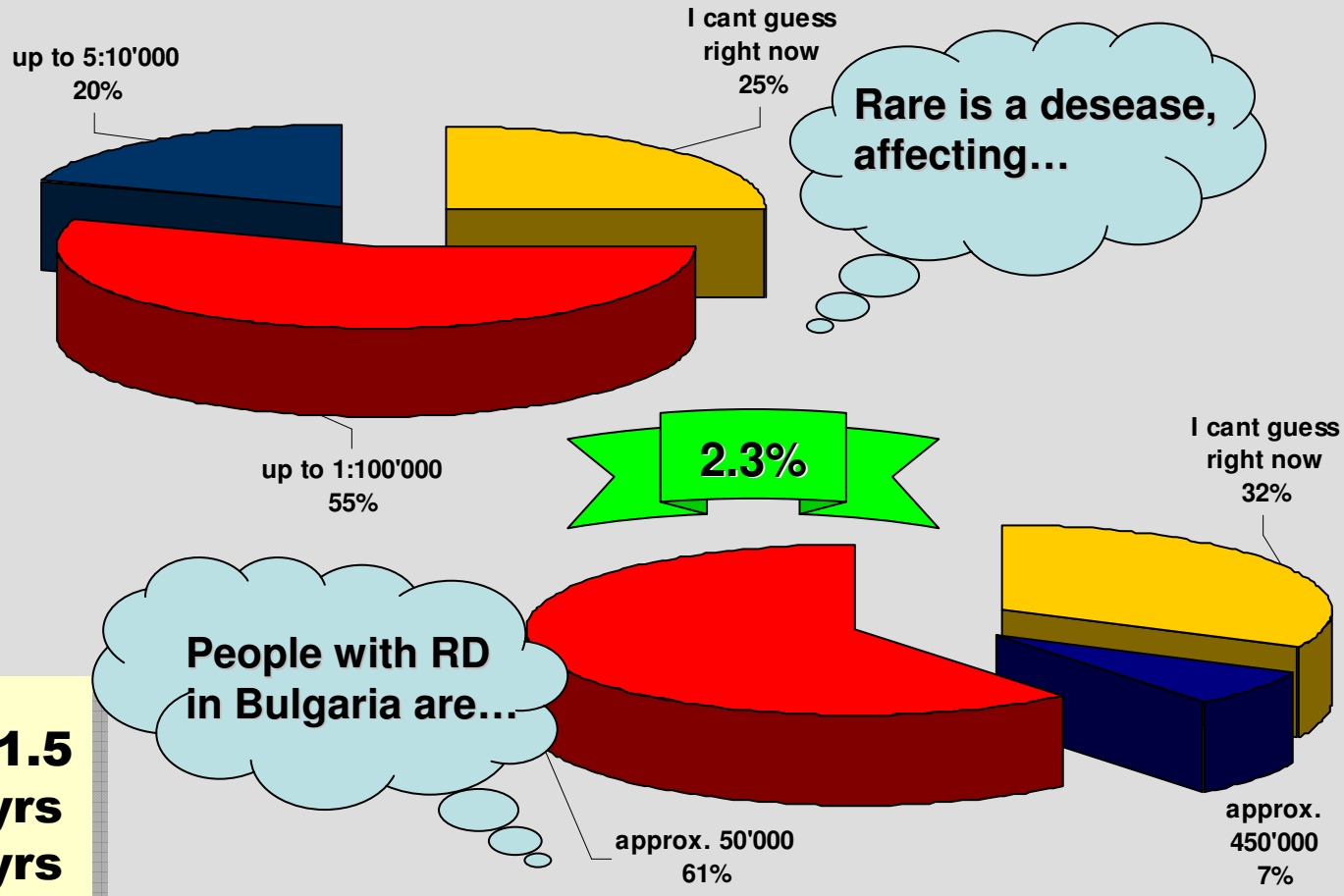
Current level of GP's awareness on RD

5106 GPs

1993 (39%) random sample

1007 (51%) participated

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



National Alliance of People with Rare Diseases – 14 April 2007











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Networking

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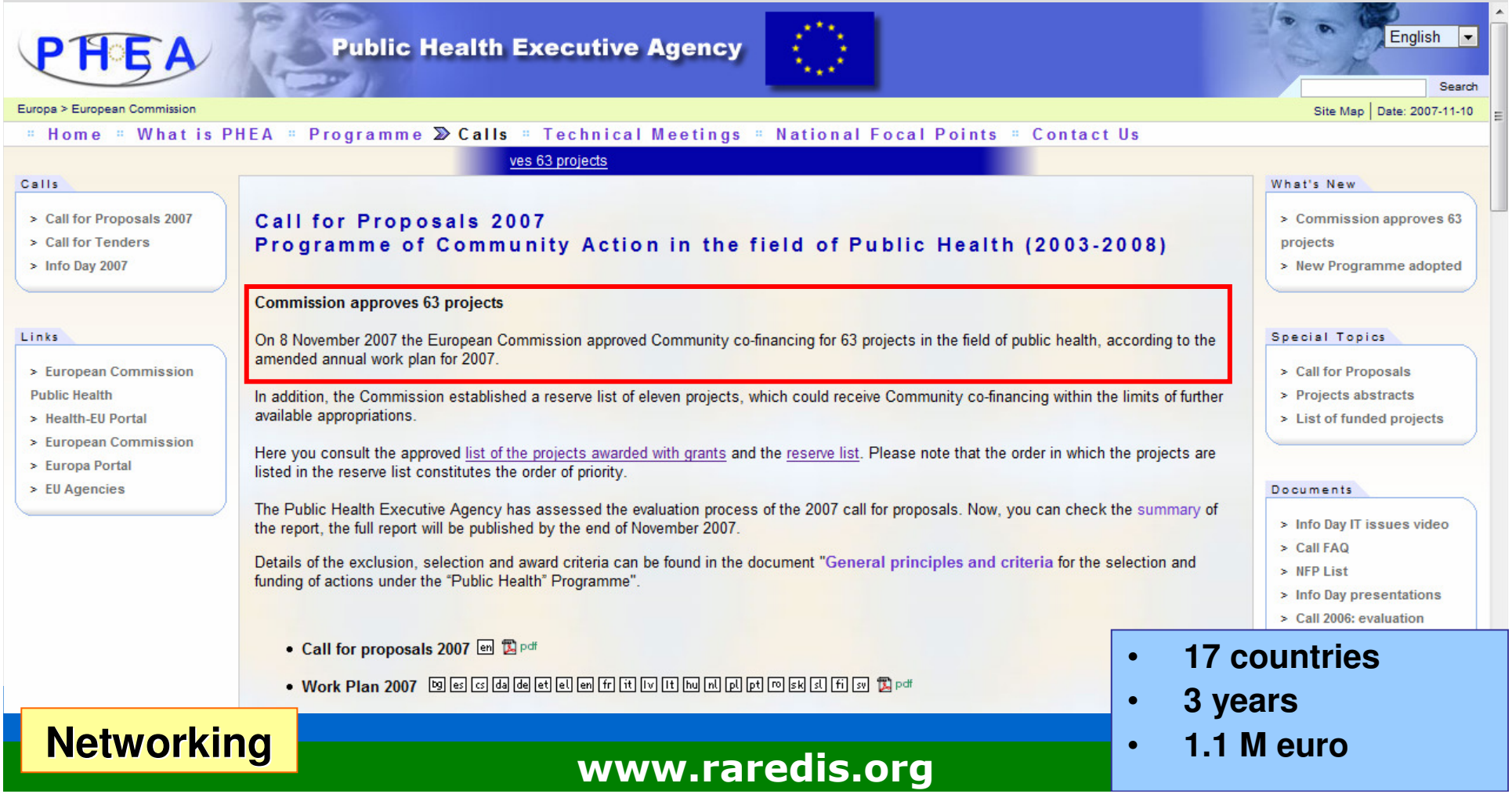
European Project for Rare Diseases National Plans Development (EUROPLAN)



Networking

www.raredis.org

- **17 countries**
- **3 years**
- **1.1 M euro**

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informer

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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

Lobbying

www.raredis.org

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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 RDTF 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.

Lobbying

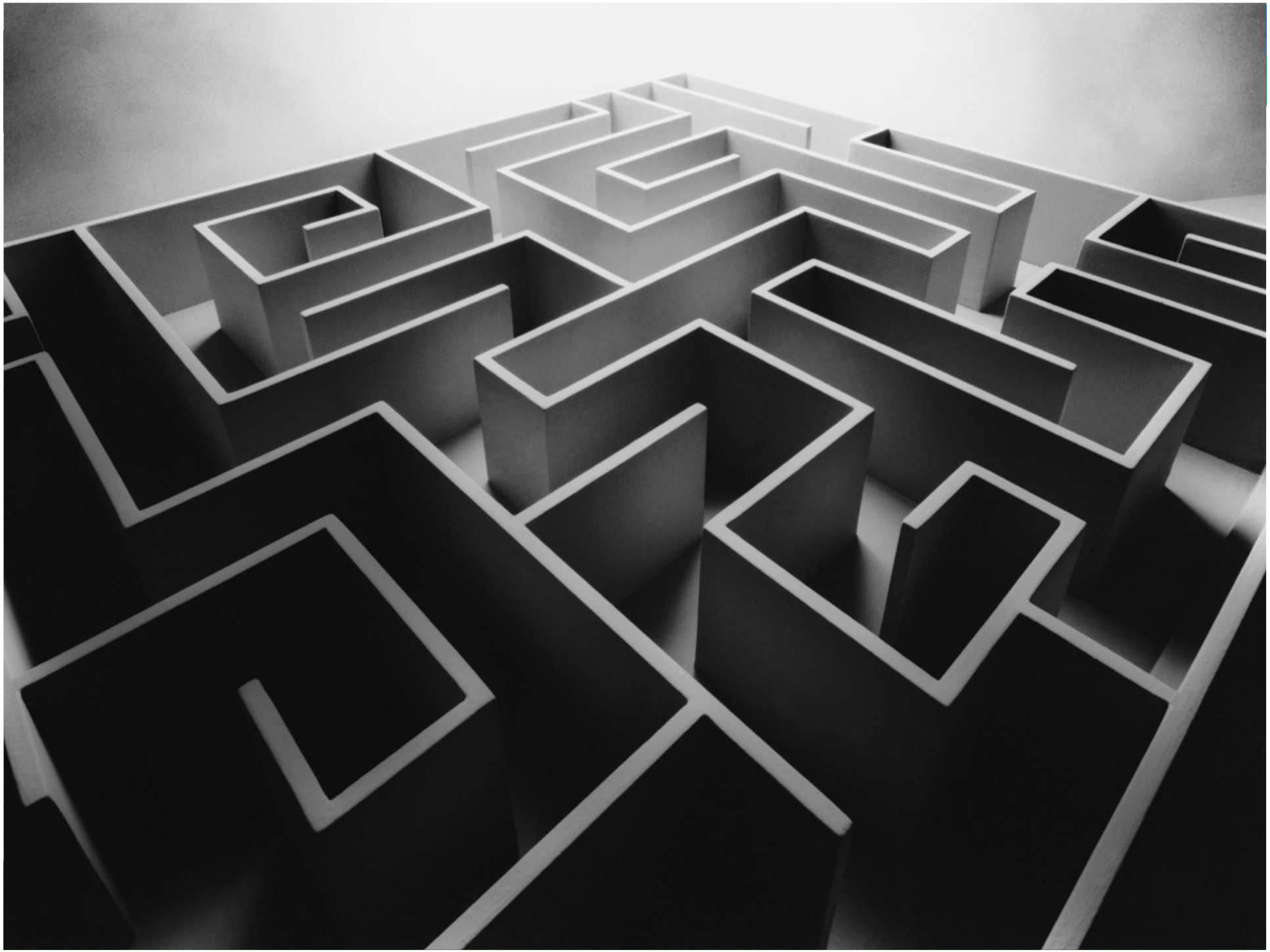
National program for rare diseases 2009-2013 (genetic, birth defects and non-inherited diseases)

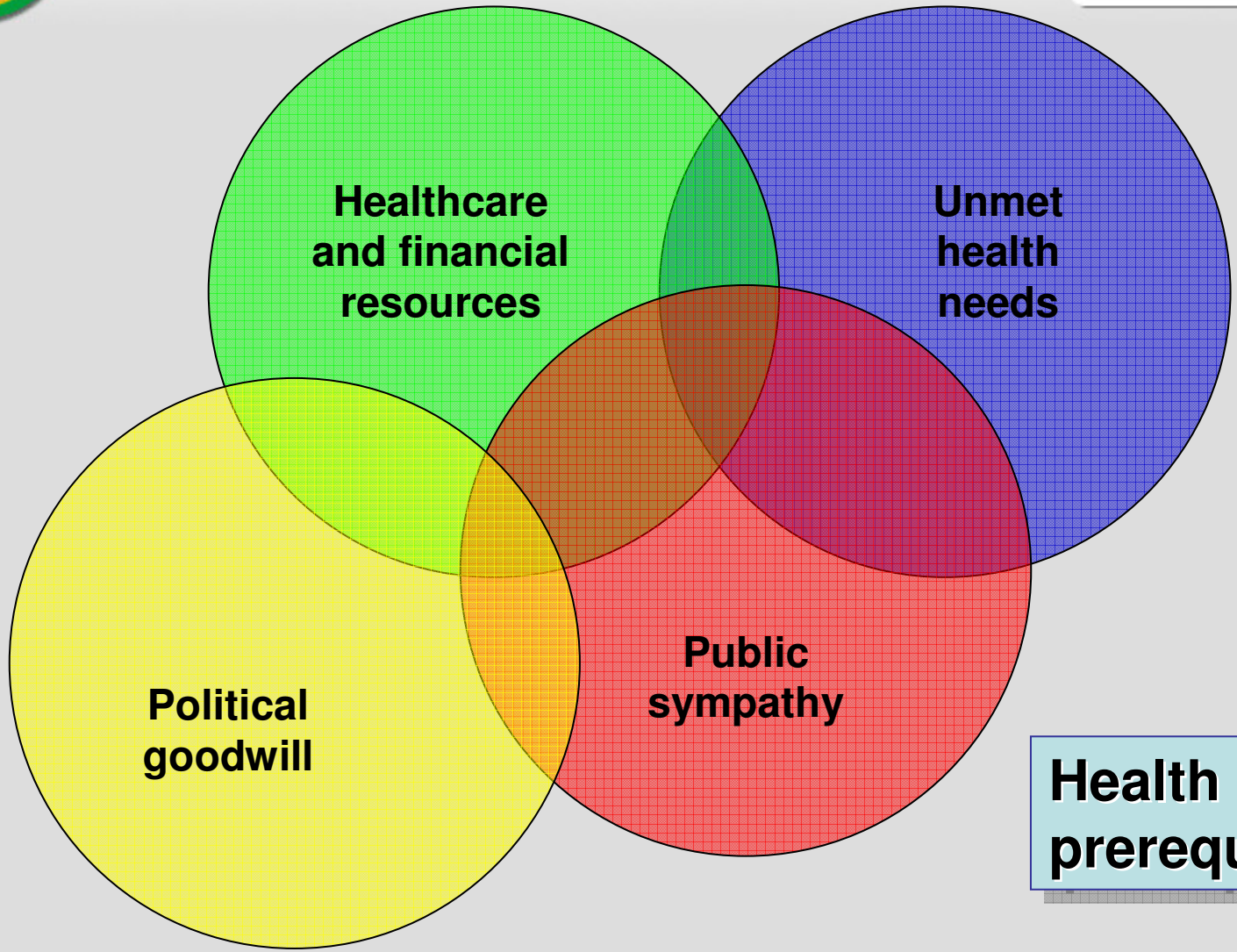
The aim of the program is to create an **adequate institutional framework and mechanisms**, ensuring timely prevention, diagnosis, optimal treatment and rehabilitation of patients with rare diseases (genetic, birth defects and non-inherited diseases) in Bulgaria.

National program for rare diseases 2009-2013 (genetic, birth defects and non-inherited diseases)

Priorities:

1. Epidemiological data surveillance
2. **Improving and expanding neonatal screening programs**
3. **Improving prevention and diagnostic services for rare diseases with genetic origin**
4. Integrative approach and social integration
5. Training of medical students and doctors
6. Boosting research on rare diseases
7. National awareness campaigns
8. Support of patient associations
9. Collaboration with other EU member states





Health policy prerequisites

4th Eastern European Conference for Rare Diseases and Orphan Drugs

"TOGETHER FOR INTEGRATIVE APPROACH TO RARE DISEASES"

25-26 April 2009

Plovdiv

Bulgaria