



INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



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

Rumen Stefanov

Information Centre for Rare Diseases
and Orphan Drugs, Bulgaria

CEE Summit – PH & Prevention of Birth Defects // 27-30 August 2008 // Budapest, Hungary

www.raredis.org



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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

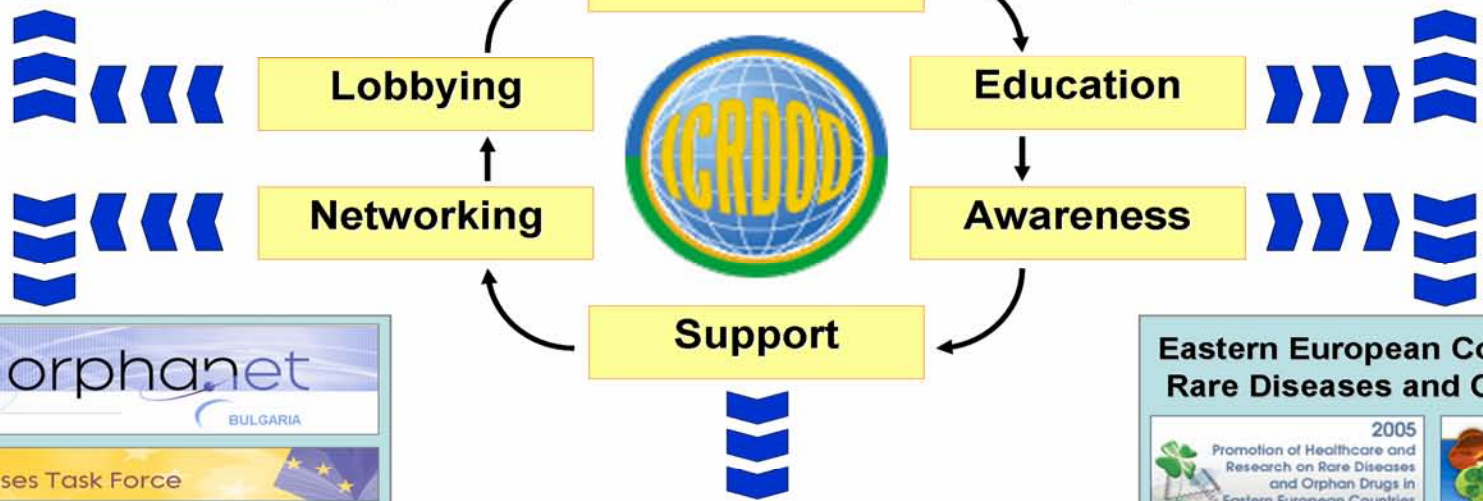
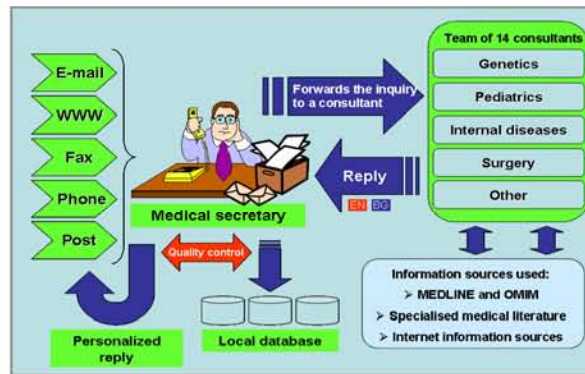


A project of the Bulgarian Association for Promotion of Education and Science (BAPES)

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. Radostav Gaidarska (RD 09-243/03.05.2006) by the workgroup: Assoc. Prof. D-r Rumena Stefanov (chairman), Prof. D-r Paraskeva Stamenova, Prof. D-r Nikolai Tzanov, Prof. D-r Sabina Zaharieva, Prof. D-r Ivailo Tumev, Assoc. Prof. D-r Veneta Bojnova, Assoc. Prof. D-r Mariana Mirojeva, D-r Radica Ticheva, D-r Svetlana Spasova, D-r Simeon Darackiev, Polina Desheva, Galia Stamenova and Vladimir Tonzov.

The expert group is grateful for the support of D-r Donatiana Tarancio (Director of The National Centre for Rare Diseases, 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 Tichev (chairman of the Bulgarian orthopedic-traumatology society), Assoc. Prof. D-r Julia Djergova (chairman of the Bulgarian society of cardiology), Prof. D-r Ivo Dimitov (Medical University - Plovdiv).

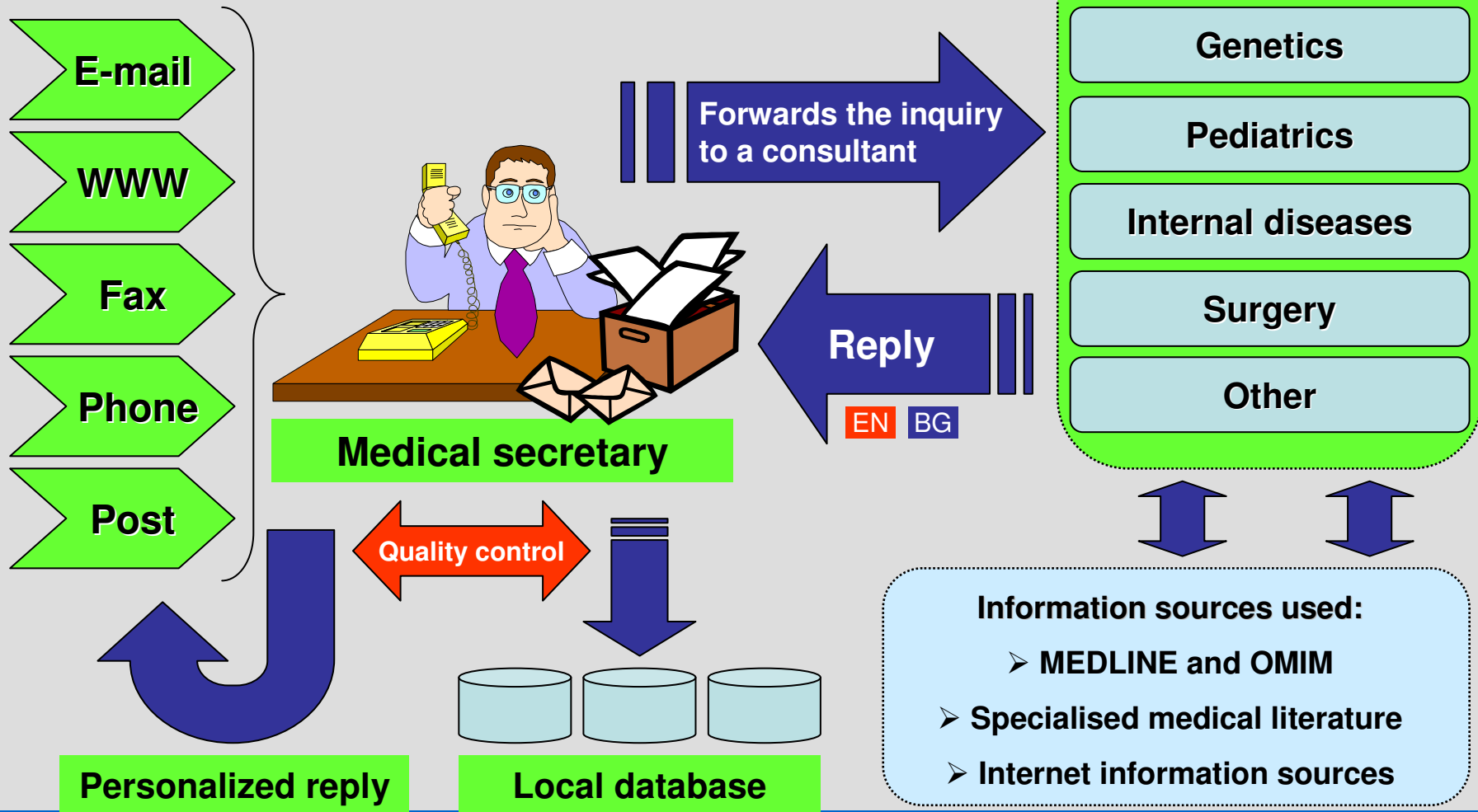


Eastern European Conferences on Rare Diseases and Orphan Drugs

2005 Promotion of Healthcare and Research on Rare Diseases and Orphan Drugs in Eastern European Countries	2006 Fostering Research on Rare Diseases in Eastern European Countries
Rare Diseases: Prevention, Diagnosis, Treatment	
1-2 March 2008	

National Alliance of People with Rare Diseases

Birthday: 14 April 2007





Изберете език



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Новини

Статии

Форуми

Полезни връзки

За нас

Връзка с нас

RSS новини

Регистрирани потребители

Потребителско име:

Парола:

Влез!

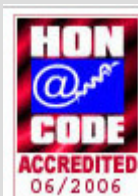
Забравена парола?

Регистрирайте се сега!

Подкрепа от



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



ICRDOD is in compliance with the HONcode

Search bar with dropdown menu showing '5' and a 'Напред!' button.

(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 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 Исков 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 **аспираторен 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, рецидивирани инфекции, леко нарушено кръвосъсирване и неврологични проблеми. Лекува се с трансплантация на костен мозък, което подобрява хематологичните и имунологични дефицити, но неврологичните проблеми персистерат. 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](#).



Търсене

Търсене

Детайлно търсене

Нашите Конференции

2008 RARE DISEASES – PREVENTION, DIAGNOSIS, TREATMENT

2007 First National Conference of People with Rare Diseases

2006 Fostering Research on Rare Diseases in Eastern European Countries

2005 Promotion of Healthcare and Research on Rare Diseases and Orphan Drugs in Eastern European Countries

Анкета

Кой сте вие?

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

Гласувай!

Резултати

Последни новини



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

www.conf2005.raredis.org

Promotion of Healthcare and Research on Rare Diseases and Orphan Drugs in Eastern European Countries

results, facts, speakers, media, conference webcast

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- ▶ Morning Session
- ▶ Afternoon Session
- ▶ Photo Gallery
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Sponsor

MORNING SESSION

Speaker	Presentation	Broadband	Dial-up
 Dr. Nikola Sabev Ministry of Health, Bulgaria	National health policy and rare diseases Download PDF [77 KB]	Video HQ [31.5 MB]	Video LQ [10.5 MB]
 Mrs. Melanie Carr European Medicines Agency (EMA)	Orphan drugs addressing patients' needs across Europe Download PDF [117 KB]	Video HQ [16.6 MB]	Video LQ [5.5 MB]
 Mrs. Christel Nourissier European Organisation for Rare Diseases (EURORDIS)	The role of patient associations for improving the quality of life of people with rare diseases Download PDF [142 KB]	Video HQ [26.2 MB]	Video LQ [8.7 MB]
 Speaker	Towards an optimal framework for rare disease therapies in Europe	Video HQ [27.3 MB]	Video LQ [9.1 MB]

With the support and partnership of the Ministry of Health of Bulgaria

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ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



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



Main sponsor:



Sponsors:



- 184 participants
- 21 countries
- 16 speakers
- 30 presentations
- 98 posters

www.conf2006.raredis.org



INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



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



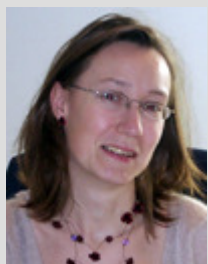
Prof. Ségolène AYME
ORPHANET, RDTF



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

www.conf2006.raredis.org

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INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



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:





INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



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





INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



Inauguration of the new office of ICRDOD

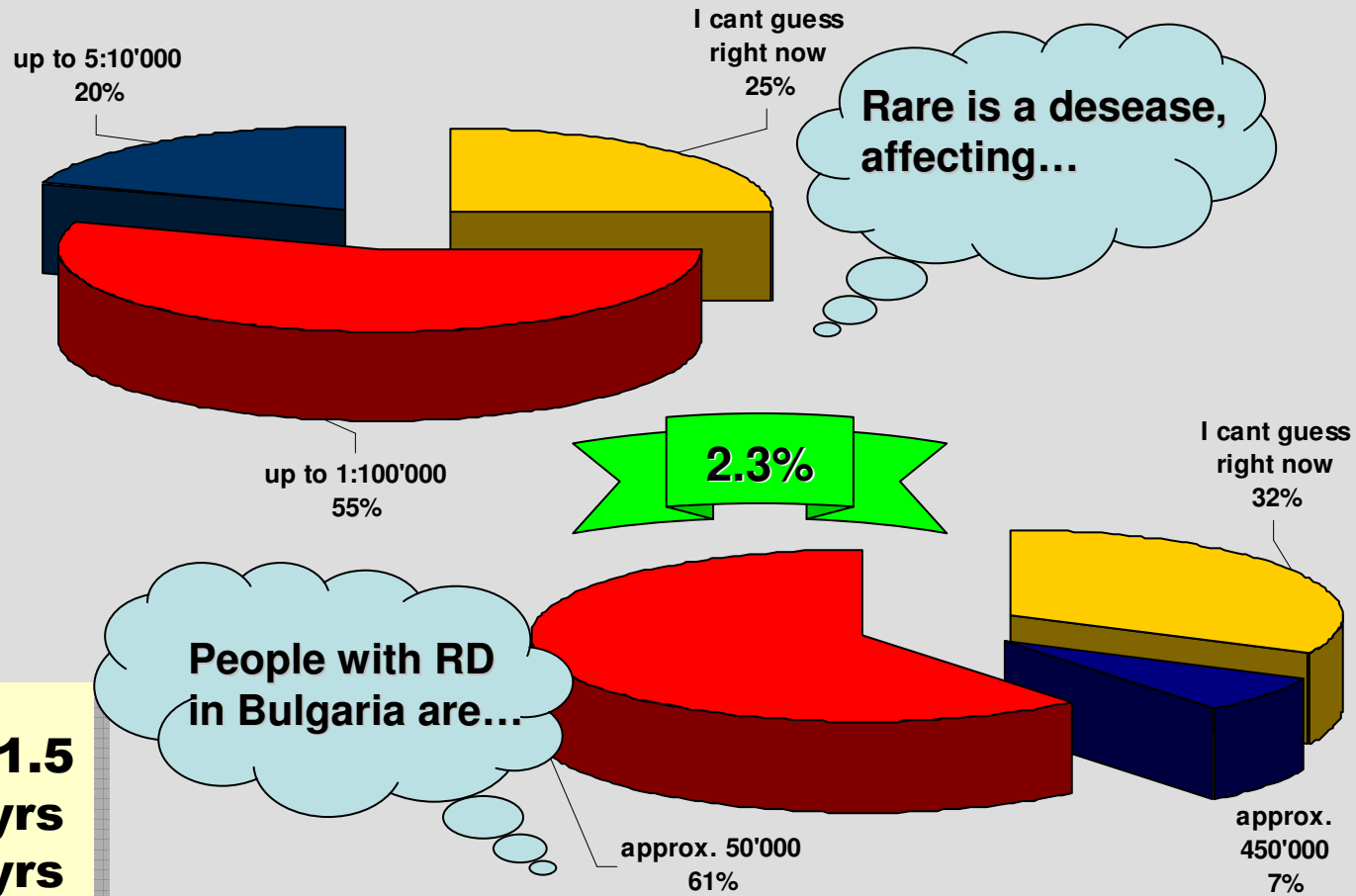




Current level of GP's awareness on RD

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





INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



National Alliance of People with Rare Diseases – 14 April 2007



Support

www.raredis.org



orphanet

Languages: Français | **English** | Español | Deutsch | Italiano | Portuges

orphanet The European Portal for Rare Diseases and Orphan Drugs

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RARE DISEASES | ORPHAN DRUGS | CLINICS | CLINICAL LABORATORIES | RESEARCH ACTIVITIES | SUPPORT GROUPS | PROFESSIONAL DIRECTORY | EDUCATION TOOLS

SEARCH: Disease Name Type a disease → OK

OTHER SEARCH: > Orphan Drugs > Support Groups > Research activities > Clinics > Clinical laboratories

Orphanet Today: Diseases: 4276, Clinics: 2228, Laboratories: 3433, Support groups: 1381, Professionals: 7919, Daily visitors: 20000

Improve the quality of medical care for Rare Diseases. Provide adapted services to the rare diseases community.

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Services for professionals: > Classifications of rare diseases, > Diagnostic assistance, > Professional encyclopaedia, > The Orphanet Journal of Rare Diseases, > Emergency Guidelines, > Powerpoint presentations, > Newsletters, > Register your activity, > OrphanXchange

Services for patients: > Information about a disease, > Patient encyclopaedia, > Clinics, > Participate in clinical trials, > Clinical studies now recruiting, > Support Groups, > Contact other patients/families, > Training sessions, > Glossary, > Newsletters

NEWS / EVENTS: 7th EPPDSI Workshop on Partnering for Rare Disease Therapy Development, Madrid 26-27 October 2008; NEW: European Commission Inventory of Incentive Measures for Orphan Medicinal Products; NEW: EURORDIS Position Paper on Embryonic Stem Cell Research & Therapy

Services for support groups: > Register your support group, > Website assistance, creation/hosting, > Newsletters

Services for industry: > OrphanXchange, > Orphan Drugs, > Clinical trials, > Newsletters, > Register your clinical trial

MEDIA: > Newsletters, > Press releases, > Events / conferences, > About Orphanet

THE ORPHANET JOURNAL OF RARE DISEASES: > Access the journal, > Submit a paper

ORPHANET IN COUNTRIES: Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republik, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lebanon, Lithuania, Luxembourg, Malta, Morocco, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovakia

Partner access: Orphanet | Rare Diseases | Orphan Drugs | Clinics | Clinical Laboratories | Research projects | Clinical trials | Support Groups

Networking



European Project for Rare Diseases National Plans Development (EUROPLAN)



[ves 63 projects](#)

Calls

- > Call for Proposals 2007
- > Call for Tenders
- > Info Day 2007

Links

- > European Commission Public Health
- > Health-EU Portal
- > European Commission
- > Europa Portal
- > EU Agencies

Call for Proposals 2007 Programme of Community Action in the field of Public Health (2003-2008)

Commission approves 63 projects

On 8 November 2007 the European Commission approved Community co-financing for 63 projects in the field of public health, according to the amended annual work plan for 2007.

In addition, the Commission established a reserve list of eleven projects, which could receive Community co-financing within the limits of further available appropriations.

Here you consult the approved [list of the projects awarded with grants](#) and the [reserve list](#). Please note that the order in which the projects are listed in the reserve list constitutes the order of priority.

The Public Health Executive Agency has assessed the evaluation process of the 2007 call for proposals. Now, you can check the [summary](#) of the report, the full report will be published by the end of November 2007.

Details of the exclusion, selection and award criteria can be found in the document "[General principles and criteria](#) for the selection and funding of actions under the "Public Health" Programme".

- Call for proposals 2007 [en](#) [pdf](#)
- Work Plan 2007 [bg](#) [es](#) [cs](#) [da](#) [de](#) [et](#) [el](#) [en](#) [fr](#) [it](#) [lv](#) [lt](#) [hu](#) [nl](#) [pl](#) [pt](#) [ro](#) [sk](#) [sl](#) [fi](#) [sv](#) [pdf](#)

What's New

- > Commission approves 63 projects
- > New Programme adopted

Special Topics

- > Call for Proposals
- > Projects abstracts
- > List of funded projects

Documents

- > Info Day IT issues video
- > Call FAQ
- > NFP List
- > Info Day presentations
- > Call 2006: evaluation

Networking

www.raredis.org

- 17 countries
- 3 years
- 1.1 M euro



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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



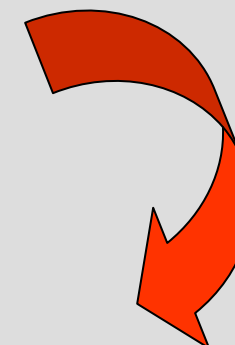


News : National program for rare diseases

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, timely diagnostics, adequate treatment and rehabilitation for rare diseases.



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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.

Project

www.raredis.org

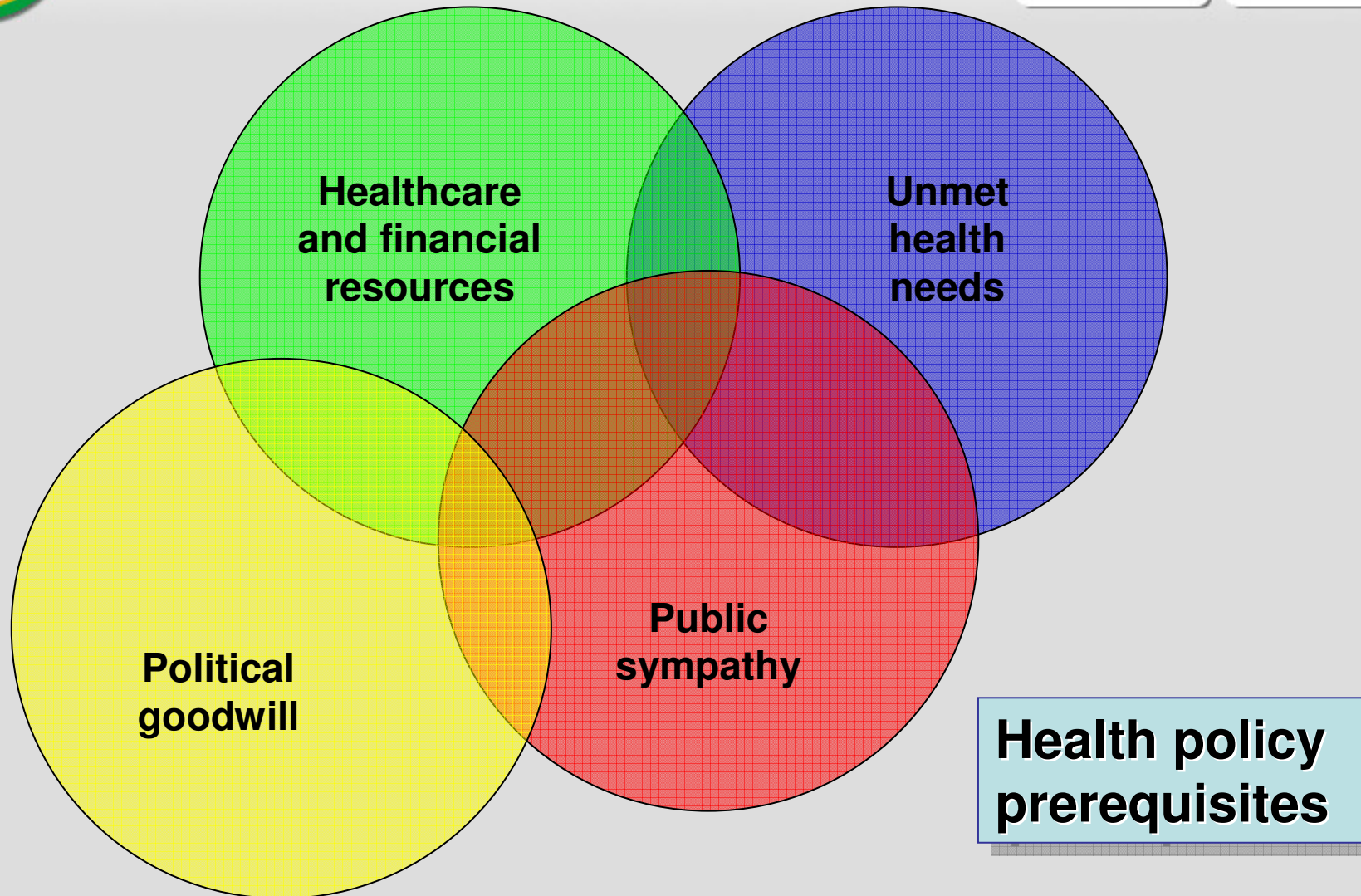


National program for rare diseases 2009-2013 (genetic, birth defects and non-inherited diseases)

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





4th Eastern European Conference for Rare Diseases and Orphan Drugs

**"TOGETHER FOR INTEGRATIVE APPROACH
TO RARE DISEASES"**

25-26 April 2009

**Plovdiv
Bulgaria**

