



INFORMATION CENTRE FOR RARE DISEASES AND ORPHAN DRUGS

ИНФОРМАЦИОНЕН ЦЕНТЪР ЗА РЕДКИ БОЛЕСТИ И ЛЕКАРСТВА СИРАЦИ



# National Plans for Rare Diseases: Bulgarian experience

**Rumen Stefanov**

*ICORD meeting – 23-25 February 2009, Roma, Italy*

**[www.raredis.org](http://www.raredis.org)**



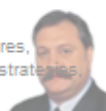
## Ministry of Health

Republic of Bulgaria

Home | Contact | English

### Ministry

leadership structures,  
programmes and strategies,  
Euro



### Regulations

laws, regulations,  
medical standards



### Training

model guidelines  
licenses and other



### Registers

records, licenses  
notices in APK



### Press Center

news, interviews,  
Presentations



### Messages

Конкурс за длъжността  
"старши инспектор" в

### Important information

- » Draft H atstionalna Health Strategy 2008-2013 years
- » Collective agreement in the industry "Health"
- » National Programme for the years 2009-2013 rare diseases

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MINISTER OF HEALTH I  
KINGDOM OF BELGIUM

THE

17.09.2008

**APPROVED**  
**28 Nov 2008**



dynamic  
that Prime  
ambassador of the

»Search

☐ under ☒ throughout the site

Recommendations for bulgarian citizens  
departing for the region, which has spread  
of brucellosis

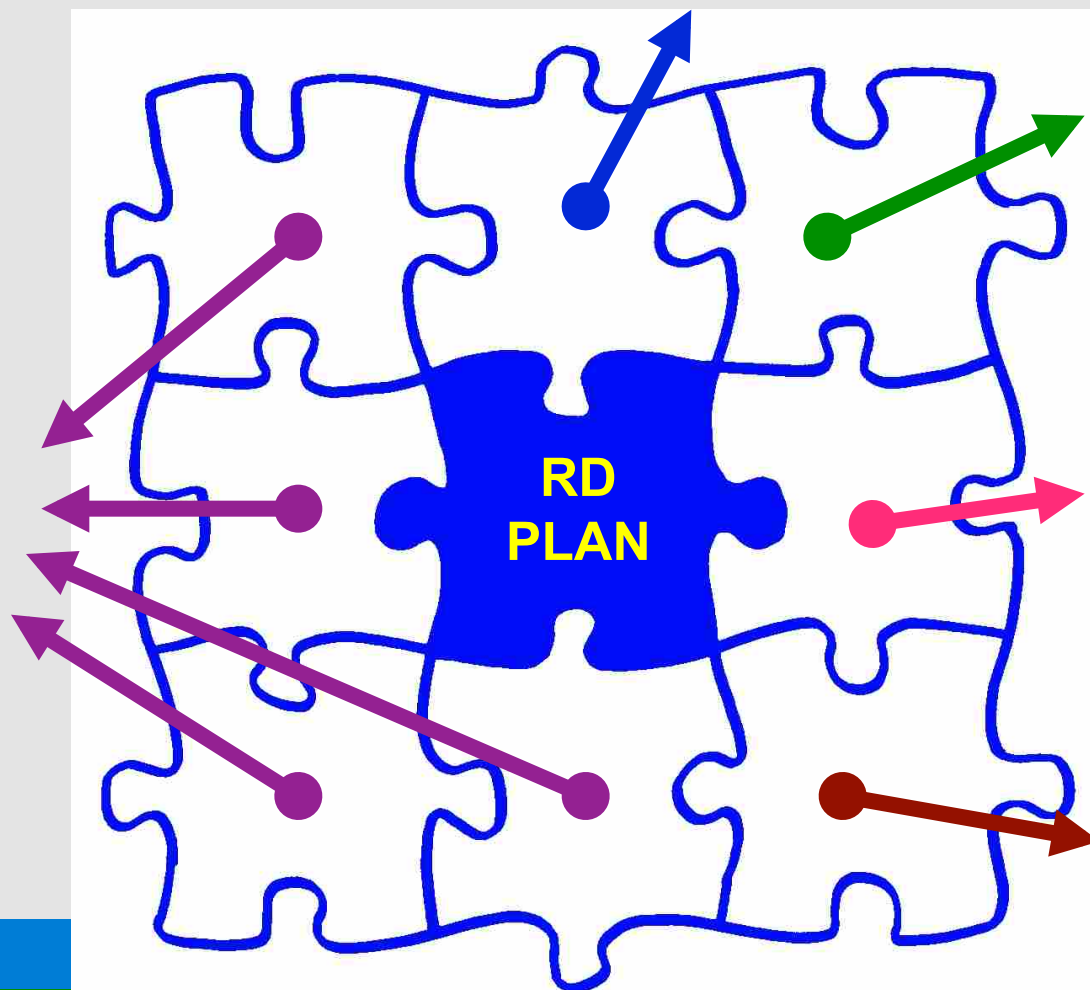
Anticorruption

Procurement and ads

National consultants

# LESSONS LEARNT

EU good practices  
and support



Strong patient  
organizations  
or alliance

2

Medical  
community  
support

1

Public support  
and sympathy

3

Political  
goodwill

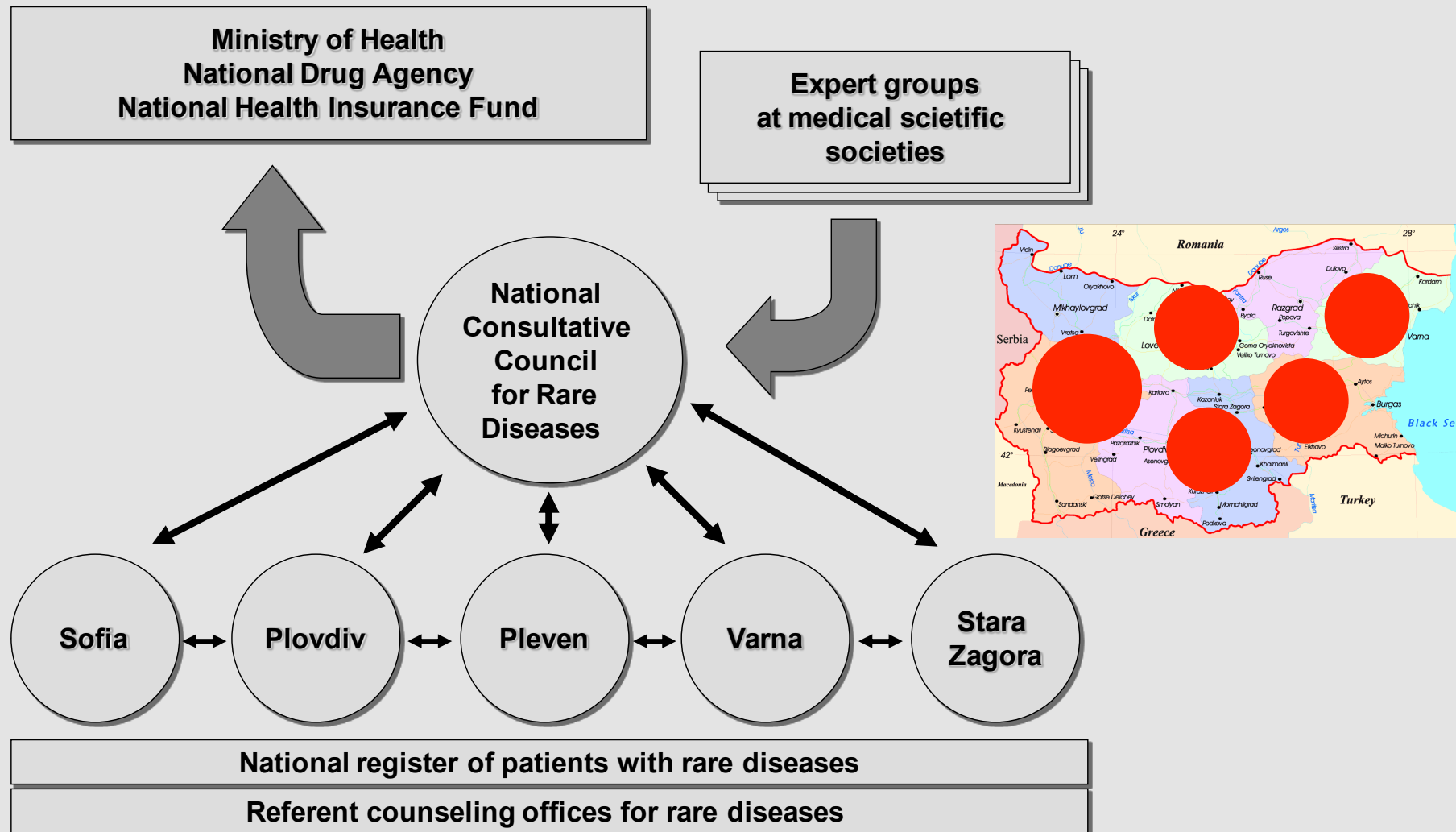
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# National program for rare diseases 2009-2013 (genetic, birth defects and non-inherited diseases)

- 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.







## Key Activities for 2009

- ✓ National Consultative Council for Rare Diseases
- ☐ Expert groups on rare diseases by medical specialties
- ☐ Improving genetic infrastructure, equipment and supplies
- ☐ Improving prenatal and neonatal screening
- ☐ Network of reference centers for rare diseases
- ☐ Public awareness
- ☐ Integrative approach

# 4th Eastern European Conference for Rare Diseases and Orphan Drugs

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

**13-14 June 2009**

**Plovdiv  
Bulgaria**

