Reti europee ed internazionali per la ricerca scientifica per le malattie rare

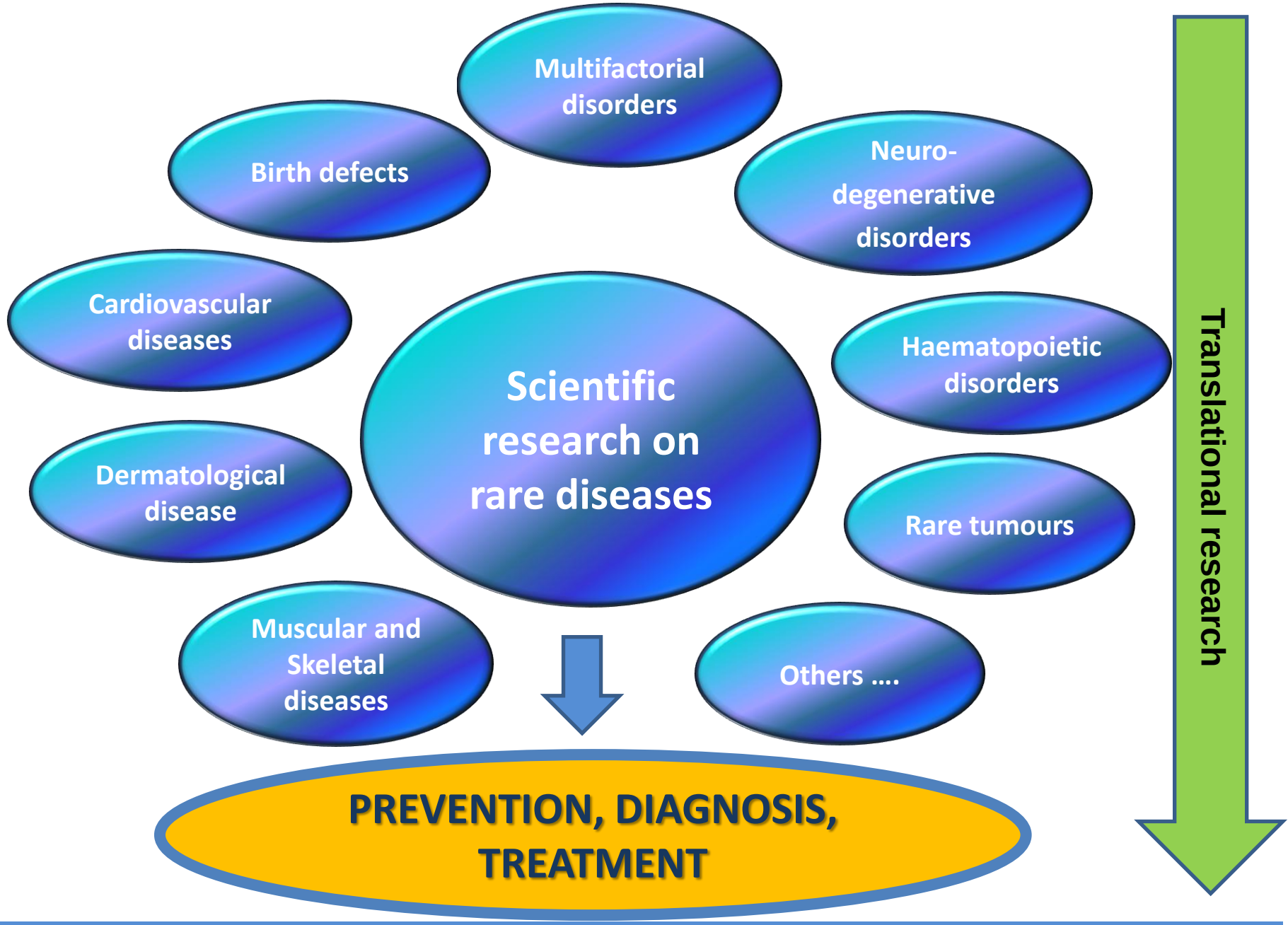
Domenica Taruscio

Direttore
Centro Nazionale Malattie Rare
Istituto Superiore di Sanità
Roma

RICERCA, INNOVAZIONE E COMPETITIVITÀ:
QUALI VANTAGGI PER IL PAESE E PER I PAZIENTI?

Associazione Culturale "G. Dossetti", Fondazione "Gianni Benzi"

CAMERA DEI DEPUTATI
Palazzo Marini - Roma


Multifactorial disorders
Birth defects
Neuro-degenerative disorders
Cardiovascular diseases
Scientific research on rare diseases
Haematopoietic disorders
Dermatological disease
Rare tumours
Muscular and Skeletal diseases
Others ....
PREVENTION, DIAGNOSIS, TREATMENT
Translational research

MAIN FACTORS INFLUENCING SCIENTIFIC RESEARCH ON RARE DISEASES

- **Presence of registries and biobanks**

  biological samples and clinical information sharing
- **International collaboration**: *trans-national call*
- Dedicated **funds**
- Presence of **Patient's associations**

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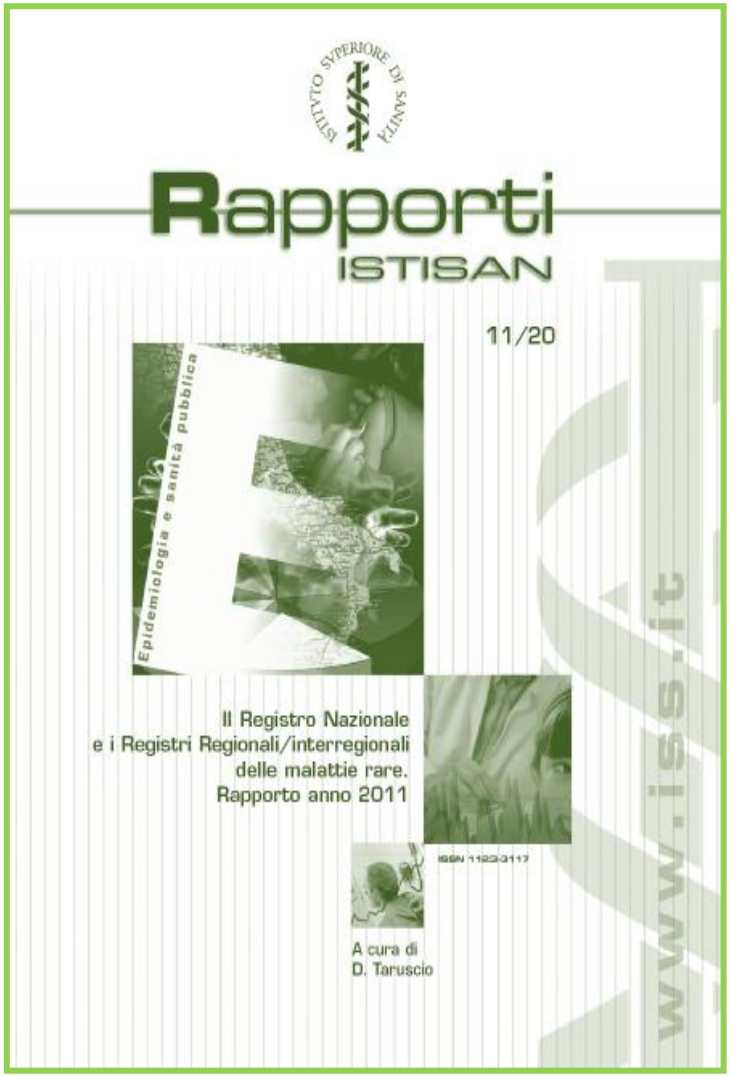
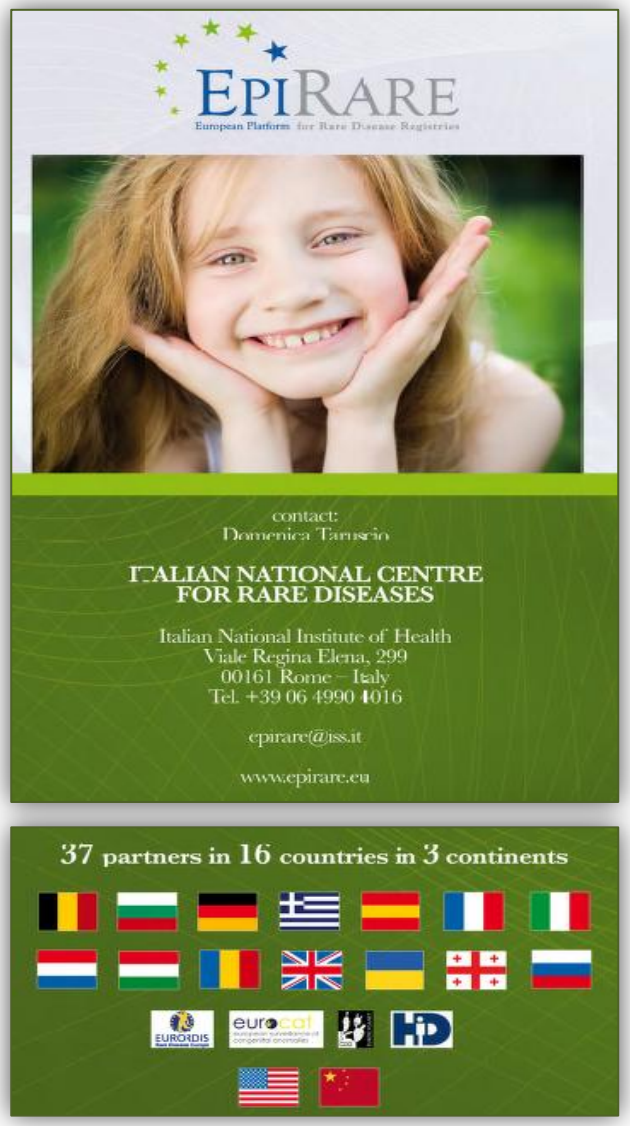
FLUSSO EPIDEMIOLOGICO: DAL LIVELLO REGIONALE A QUELLO NAZIONALE

REGISTRO NAZIONALE MALATTIE RARE

PRESIDI CENTRI → **REGISTRI REGIONALI E INTERREGIONALI** → **DATA SET (OGNI 6 MESI)**



www.iss.it/cnmr



www.epirare.eu

EPIRARE
European Platform for Rare Disease Registries

A three year project co-founded by the European Commission within the framework of the EU program of Community Action in the field of Public Heath

Home | The project | Workpackages | Partners | Join us | The EPIRARE Survey | Deliverables & meetings | News | Contact

News

Public Health Genomics II
Three Conferences
April 17-20, 2012
Radisson Blu, Rome
site • program

The Epirare Project

The interest of researchers in the establishment of disease registries, is shown by the increasing number of RD registers in EU Member States as national or local initiatives mainly located at universities (Orphanet, 2009). Applications for funding RD networks, promoting data sharing and collaboration among researchers, are also submitted regularly to the European Commission.

The need for shared quality data collections for different health and healthcare purposes and the awareness of difficulties posed by their maintenance is witnessed by a number of recent documents (EPPOSI, 2009; Pharmaceutical Forum Reports, 2008).

The recent adoption of the Council Recommendation on RDs, which recommends the development of registers and databases for epidemiological purposes, is expected to result in a burst of initiatives for RD registration.
While a wide population base is especially needed for epidemiological and clinical research in RDs, the Regulation on personal data protection creates important challenges to EU data collection and exchange, requiring a legitimate purpose

Rome
first Epirare
meeting

11 - 12 July
2011
ISS

The meeting was held on July, 11-12 2011 in Rome (Italy) - Sanità – Viale Regina Elena, 299

- Agenda
- Participants
- Accomodations
- Proceedings
- Meeting Secretariat
- How to get to the meeting site

www.epirare.eu

2 International Workshop
RARE DISEASE AND
ORPHAN DRUG REGISTRIES

7- 9 October, 2013

Istituto Superiore di Sanità
Rome (Italy)

www.epirare.eu

International Summer School

RARE DISEASE AND ORPHAN DRUG REGISTRIES

organized by

NATIONAL CENTRE FOR RARE DISEASES

ITALIAN NATIONAL INSTITUTE OF HEALTH

Rome (Italy)

16-20 SEPTEMBER 2013

MAIN FACTORS INFLUENCING SCIENTIFIC RESEARCH ON RARE DISEASES

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  biological samples and clinical information sharing
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The Council Recommendation on European Action in the field of rare diseases

Adopted by the EU Council in 2009

Recommended Member States to adopt National Plans strategies for rare diseases, before the end of 2013.

AREAS OF THE RECOMMENDATIONS

Area 1. Plans and strategies in the field of rare diseases
Area 2. Adequate definition and codification of rare diseases
Area 3. Research on rare diseases
Area 4. Centers of expertise and European reference networks for rare diseases
Area 5. Gathering the expertise on rare diseases at European level
Area 6. Empowerment of patient organizations
Area 7. Sustainability

EUROPLAN

EUROPLAN

European Project for Rare Diseases National Plans Development

Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health

2012-2015

Home | The project | Partners | Events | National Plans | Ongoing Activities | Documents | Members area | Contact

EUROPLAN 2012-2015

provides technical and scientific
support to Countries
in order to develop and implement
National Plans and Strategies
for Rare Diseases

News

RARE DISEASE AND ORPHAN DRUG REGISTRIES
International Workshop
8-9 October 2012
ISS - Rome, Italy
Website - Agenda

The Czech government adopted on August 28/2012 in its Decree 633
The Czech National Plan for Rare Diseases 2012-2014
[see the document]

It's available the DRAFT (english version) of the
Strategy of The Netherlands in the field of Rare Diseases
[see the document]

EUROPLAN 2012-2015

a three-year project, embedded in the EUCERD Joint Action as Work Package 4, it is coordinated by the Italian National Institute of Health - Italian National Centre for Rare Diseases.

Its main goal is to establish an international and interactive network of stakeholders (mainly policy makers) to speed up the elaboration and the implementation of Rare Diseases National Plans/Strategies, through scientific and technical assistance, Workshops and the active

www.europlanproject.eu

http://www.e-rare.eu/

ERA-Net for Research Programmes on Rare Diseases

Search

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- EXTRANET

NEWSLETTER SUBSCRIPTION

contact@e-rare.eu

Joint Transnational Call 2013 Preannouncement

On the 7th of December 2012 it is expected that E-Rare opens its 5th Joint Transnational Call for Research Projects on Rare Diseases (JTC 2013). We are proud to announce that this year six new funding agencies are joining the call. The following countries have announced their participation....

Results of Joint Transnational Call 2012

Joint Transnational Call 2013 Preannouncement

E-Rare Ethics Workshop

Related European Initiatives

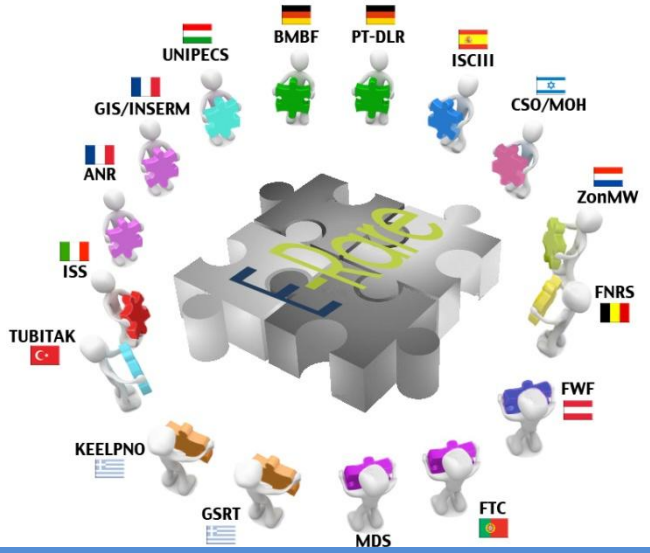
Reports & Publications

For Researchers

"E-Rare"
European Research Area – Network for Research Programmes on Rare Diseases

The E-Rare Consortium

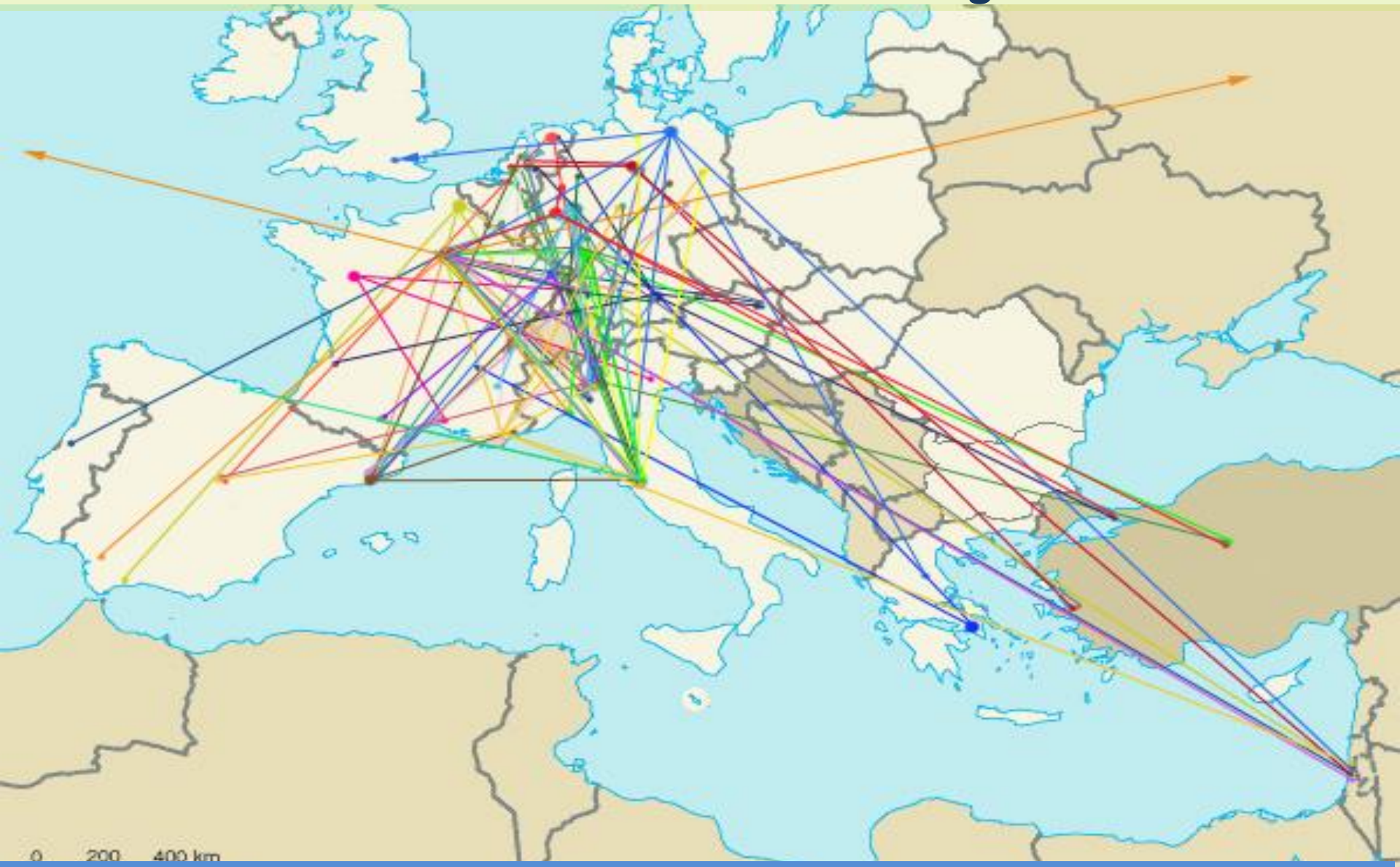
17 Partners (public bodies, ministries and research funding organizations) from 13 Countries



Objectives:

- to **harmonise** and **develop synergies** between national research programmes on rare diseases
- to **develop common research policy** on rare diseases
- to **implement transnational research** funding activities (Joint Calls)

E-RARE
international collaboration to share knowledge and information



IN FOCUS NEWS

BIOMEDICAL RESEARCH

Rare-disease project has global ambitions

Consortium aims for hundreds of new therapies by 2020.

BY ALISON ABBOTT

Prader–Willi syndrome. Fabry renal disease. Spinocerebellar ataxia. Few people have heard of these and the other 'rare diseases', some of which affect only hundreds of patients worldwide. Drug companies searching for the next blockbuster pay them little attention. But the diseases are usually incurable — and there are thousands of them.

This week, the US National Institutes of Health (NIH) and the European Commission launch a joint assault on these conditions, whose small numbers of patients make it difficult to test new treatments and develop diagnostic methods. The International Rare Disease Research Consortium being formed under the auspices of the two bodies has the ambitious goal of developing a diagnostic tool for every known rare disease by 2020, along with new therapies to treat 200 of them. "The number of individuals with a particular rare disease is so small that we need to be able to pool information from patients in as many countries as possible," says Ruxandra Draghia-Akli, the commission's director of health research.

At the launch meeting in Bethesda, Maryland, on 6–8 April, prospective partners will map out research strategies to identify diagnostic biomarkers, design clinical trials and coordinate genome sequencing in these diseases. Nearly all the rare diseases, of which there are an estimated 6,000–8,000, are the result of small genetic changes.

The meeting will also discuss the governance of the project, which is most likely to be modelled on the pioneering Human Genome Project. As such, the consortium is open to research agencies and organizations from all over the world. Representatives from countries including Canada, Japan and some individual European nations are all attending the meeting, and may join the consortium. Those wishing to participate will have to pledge a minimum financial contribution, which has not yet been agreed, and share all relevant data. Indeed, the project will have to overcome numerous obstacles to information sharing, such as the fact that physicians in different countries often use entirely different words to describe the same disease.

Draghia-Akli points out that the project could yield major benefits for the emerging field of personalized medicine — another political priority for the NIH and the commission — which also faces the challenge of small populations of patients.

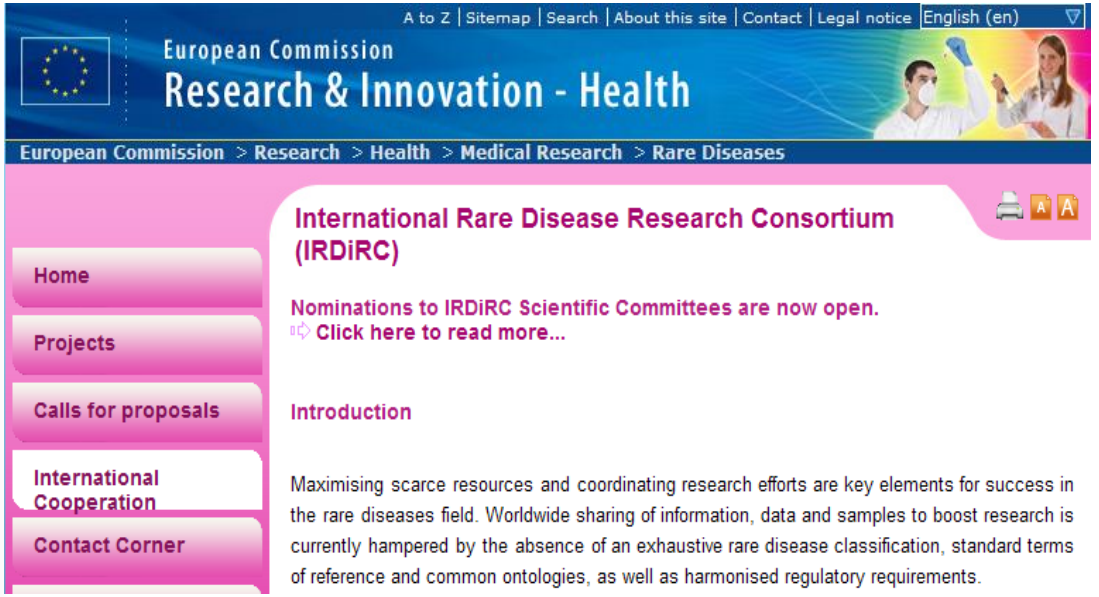
"We need to be able to pool information from patients in as many countries as possible."

Regulatory agencies such as the US Food and Drug Administration and the European Medicines Agency rely on large, randomized and controlled clinical trials when deciding whether to approve new medicines, and one of the aims of the consortium will be to develop alternative clinical-trial methods for diseases that affect few people.

These methods are becoming ever more important now that genome analysis is helping to break down common diseases into ever smaller subclasses. "Soon there will be no disease called breast cancer," says Draghia-Akli. Instead, the catch-all term will be replaced by "a large number of rare diseases, each of which causes malignant growth in breast tissue and requires individual treatment", she says.

The commission will launch a €100-million (US$140-million) call for research proposals in July, which will support the consortium's scientific goals by focusing heavily on developing appropriate clinical trials. ■

Nature **472**, 17 (2011)



International Rare Disease Research Consortium (IRDiRC)

Ambitious goals

- Maximising scarce resources and coordinating research efforts
- Worldwide sharing of information, data and samples to boost research

IRDiRC will team up researchers and funding agencies to achieve two main objectives by the year 2020, namely to deliver **200 new therapies for rare diseases** and **diagnostic tools** for most rare diseases.

http://ec.europa.eu/research/health/medical-research/rare-diseases/irdirc_en.html

European Commission
Research & Innovation - Health

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International Rare Diseases Research Consortium (IRDiRC)

In the Spotlight

Watch the videos "In search of IRDIRC" and "IRDIRC, teaming up for research".

First International Rare Diseases Research Consortium Conference, Dublin, Ireland, 16-17/04/2013.

Introduction

Maximising scarce resources and coordinating research efforts are key elements for success in the rare diseases field. Worldwide sharing of information, data and samples to boost research is currently hampered by the absence of an exhaustive rare disease classification, standard terms of reference and common ontologies, as well as harmonised regulatory requirements.

The International Rare Diseases Research Consortium (IRDiRC) **was launched in April 2011** to foster international collaboration in rare diseases research. IRDiRC will team up researchers and organisations investing in rare diseases research in order to achieve two main objectives, namely to deliver **200 new therapies for rare diseases and means to diagnose most rare diseases by the year 2020.**

For any questions or queries with regard to IRDiRC, please use the following e-mail address: RTD-IRDIRC [at] ec.europa.eu

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International Cooperation
Committed members
Become a member
How will it work?
Governance
Current state of play
Documents
Contact Corner
e-library

Committed members

The European Commission (EC) and the US National Institutes of Health (NIH) initiated the discussions that led to the launch of IRDiRC. Since the launch, the interest to participate has been growing rapidly. For a current list of committed members. please see the list below

Country	Organisation
Australia	Western Australian Department of Health
Canada	Canadian Institutes for Health Research
Canada	Genome Canada
Italy	Italian National Institute of Health
Italy	Telethon Foundation
European Union	European Commission
France	French Association against Myopathies
France	French National Research Agency
France	Lysogene
Germany	Federal Ministry of Education and research
the Netherlands	The Netherlands Organisation for Health Research and Development

HEALTH.2012.2.4.4 **RARE DISEASES**

HEALTH.2012.2.1.1-1 (A-C) – **OMICS** FOR RARE DISEASES
HEALTH.2013.4.2-3: **New methodologies** for small clinical trials
HEALTH.2013.1.2-1. Development of **imaging technologies** for therapeutic interventions in rare diseases

RD-CONNECT

An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research

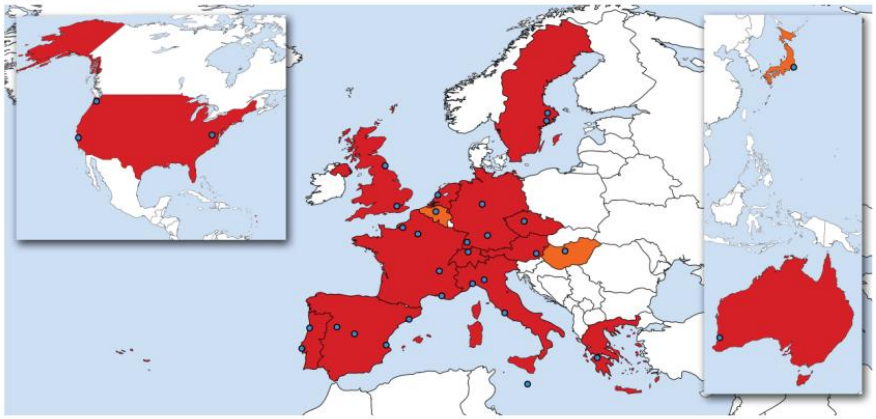
Proposal submitted under:

FP7 HEALTH.2012.2.1.1-1-C:

"Databases, biobanks and clinical bio-informatics hub for rare diseases"

Coordinator: Hanns Lochmüller

Global partner distribution



Workpackage leaders

http://www.rd-connect.eu

RARE-Bestpractices

Funded by the European Union within the Seventh Framework Programme (**FP7/2007-2013, CALL HEALTH.2012.2.4.4-3**: Best practice and knowledge sharing in the clinical management of rare diseases" (Coordinated Action))

Starting date of the project is the **1st of January 2013**.

The main goal of the project is the development of a networking platform

i) **exploiting the collection, evaluation and dissemination of existing best practices** on rare diseases;
ii) **developing an agreed methodology** for the elaboration of guidelines on rare diseases, with a view to ensuring scientific quality and effective sustainable governance;
iii) **setting up educational activities** targeted to stakeholders to share expertise and knowledge and to contribute to the sustainability of the networking platform.

Venue

Italian National Institute of Health
Aula Marotta
Viale Regina Elena, 299
Rome (Italy)

Course Director

Domenica Taruscio
Director
Italian National Centre for Rare Diseases
Italian National Institute of Health
Viale Regina Elena, 299
Rome (Italy)

Tutors

Graziella Filippini - *Fondazione Istituto Neurologico C. Besta Milano, Italian Cochrane Centre*
Robin Harbour - *Healthcare Improvement Scotland*
Michele Hilton Boon - *Healthcare Improvement Scotland*
Jörg Meerpohl - *Institute of Medical Biometry and Medical Informatics - University of Freiburg, German Cochrane Centre, GRADE Working Group*
Paola Laricchiuta, Cristina Morciano, Domenica Taruscio – *Italian National Centre for Rare Diseases* **–** *Italian National Institute of Health*

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Cristina Morciano
Email: cristina.morciano@iss.it
Tel. 0039 06 49904422

For more information visit the website
www.iss.it/cnmr

ISTITUTO SUPERIORE DI SANITÀ

Summer School
Clinical practice guidelines
on rare diseases

July 9-11, 2012

Italian National Institute of Health
Viale Regina Elena, 299
Rome (Italy)

Organised by the
Italian National Centre for Rare Diseases
Italian National Institute of Health

CentroNazionaleMalattieRare
CNMR

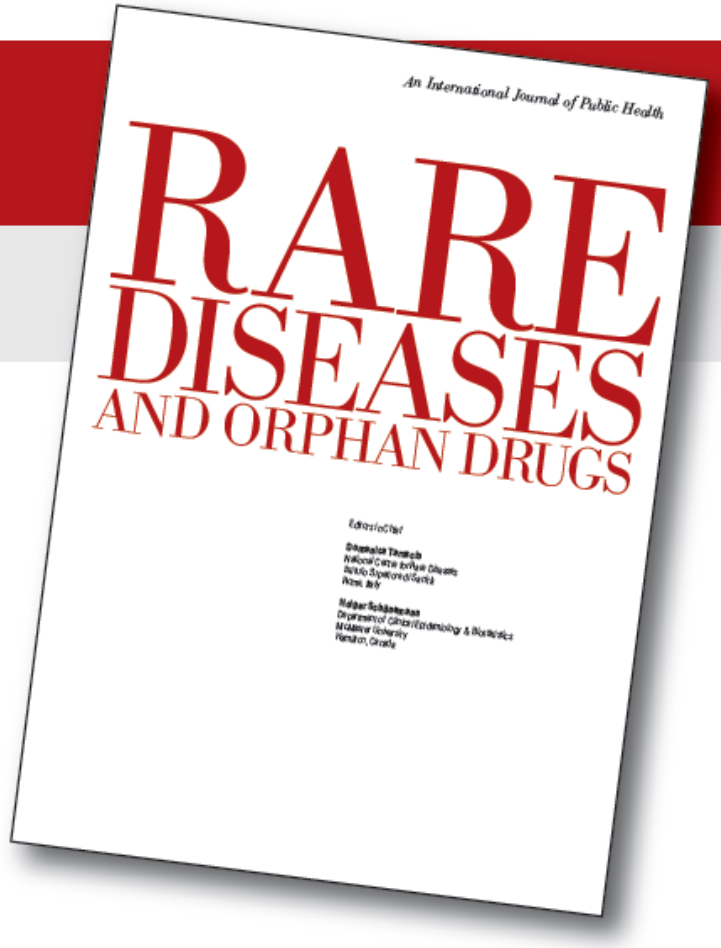
Next event: July 2013

Announcing a new journal

RARE DISEASES AND ORPHAN DRUGS

An International Journal of Public Health

Coming in 2013



Editors in Chief

Domenica Taruscio
National Center for Rare Diseases
Istituto Superiore di Sanità
Rome, Italy

Holger Schünemann
Department of Clinical Epidemiology & Biostatistics
McMaster University
Hamilton, Canada

RARE DISEASES AND ORPHAN DRUGS (RARE)

www.rarejournal.org

RARE DISEASES AND ORPHAN DRUGS (RARE)
is a new international open access, online, peer-reviewed journal published three times per year.

Selected example of topics covered by the journal are given below:

- Health policies on rare diseases and orphan drugs
- Rare disease epidemiology and registries
- Clinical research and methodology
- Rare disease best practices
- Practice guidelines
- Comparative effectiveness research
- Socio-economical analysis
- Primary prevention, risk factors and screening
- Health promotion
- Quality assurance (genetic testing, etc)
- Legal and ethical issues
- Narrative medicine
- Patients' needs and health-related quality of life

Rare Diseases and Orphan Drugs is published by the National Centre for Rare Diseases of the Istituto Superiore di Sanità (Italy), in the framework of the Project RARE-Bestpractices.

www.rarejournal.org

RARE-Bestpractices project is funded by the European Commission's 7th Framework Programme. Grant Agreement n.305690

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Who we are | What we do | Membership | Library | Contact Us | Donate

EURORDIS
Rare Diseases Europe

The Voice of Rare Disease Patients in Europe

About rare diseases | About orphan drugs | Living with a rare disease | Rare Disease Policy | Services to Patients | Get Involved | Training Resources | News & Events

Home

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Rare Disease Day

Rare Disease Day: The 2013 Campaign is launched!

- 100 days to Rare Disease Day!
- First Joint European and North American Declaration on Registries
- ECRD 2012 Brussels Report now available
- Participate in EURORDIS' survey on registries

Who we are

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 537 rare disease patient organisations in 49 countries.

Read our mission statement

What are you looking for:

Social Networks

FACEBOOK

Featured Patient Organisation

CDG: Two stories, one shared hope

Featured Events

3rd Annual World Orphan Drug Congress Europe,

Members' Corner

Next EURORDIS Membership Meeting

Search Site CONTACT US DONATE NO

NORD
National Organization for Rare Disorders

Alone we are rare. Together we are strong.

For Patients & Families | For Patient Organizations | For Medical Professionals | For Industry | Rare Disease Information | Advocacy | About NORD | News & Events

1 2

News and Events | News for Patients | News for Patient Organizations | News for Medical Professionals | News for Industry

NORD/DIA Conference in a Single Word: Collaboration

Conference on Rare Diseases and Orphan Products drew together nearly 500 patient

Send Your Message to Congress Today

Join NORD in urging members of Congree to find a better solution than sequestration. More >

WHAT IS NORD?

The National Organization for Rare Disorders is dedicated to helping the nearly 30 million Americans with rare diseases, and the organizations that serve them, through programs of education, advocacy, research, and patient services. More >

I WANT TO:

- Find a patient organization >
- Get help with medication costs >
- Build a patient organization >
- Give in honor of someone >
- Write my Congressman >

The RARE DISEASE DATABASE

Search NORD's Database for reports on more than 1,200 diseases. **Search Now>**

GET OUR LATEST E-NEWS

CORD Canadian Organization for Rare Disorders

CORD is Canada's national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. » More info

Current Events

ADVOCARE
CONSUMER ADVOCARE NETWORK

Patient Experts in Health Technology Conference
Join other patient advocates who are taking an active role in assuring that Canadian patients have sustainable access to optimal health technologies, including drugs, diagnostics, combination therapies and health services.

Date: Nov 25, 2012 (Patient Advocates)

Canadian Organization for Rare Disorders Welcomes Announcement of Orphan Drug Framework
TORONTO, Oct. 3, 2012 - The Canadian Organization for Rare Disorders, on behalf of the 2.8 million Canadians with rare disorders, welcomes Health Minister Aglukkaq's announcement of the "first ever Canadian framework to increase access to new treatments and information" and the launch of Orphanet-Canada. » View press release

All I see is Hope - One woman's Story of Overcoming the Odds. CORD Board Member, Maureen Smith's struggle with her own rare disorder and how medications have drastically improved her life. Click here to watch her story.

EURORDIS
Rare Diseases Europe

The Voice of Rare Disease Patients in Europe

NORD
National Organization for Rare Disorders

CORD
Canadian Organization for Rare Disorders

EURORDIS
Rare Diseases Europe

EURORDIS-NORD-CORD release a Joint Declaration for Rare Disease Patient Registries

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- First Joint European and North American Declaration on Registries
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FACEBOOK

EURORDIS - European Rare Diseases Organisation on Facebook

Like

3,312 people like **EURORDIS - European Rare Diseases Organisation.**

Featured Patient Organisation

CDG: Two stories, one shared hope

Liliana and MP were born 27 years apart. Their stories show us the progress and development achieved in nearly 30 years.

Featured Events

3rd Annual World Orphan Drug Congress Europe, 29-30 November, Geneva

EURORDIS member patient organisations are eligible for free guest attendance.

Members' Corner

Next EURORDIS Membership Meeting

Save the date. The next EURORDIS Membership Meeting will take place in Dubrovnik, May 30 to June 1st.

ICORD
International Conference on Rare Diseases & Orphan Drugs

- **Welcome to ICORD!**
- Preamble
- Aims
- ICORD Position statement
- Society & Membership
- Board
- Conferences
- Secretariat
- Bank Information

Events

- ICORD 2013 China
- Past Events

Welcome to ICORD!

International Conferences for Rare Diseases and Orphan Drugs

- **ICORD launches a Declaration for policy and action plans for rare diseases – The "*ICORD Yukiwariso Declaration*" (PDF)**
  - *Go to web page*
- **Full reports from the 7th ICORD meeting in Tokyo 4-6 February, 2012 are now available for download in English and Japanese**
  - *Go to web page*
- ***Presentation slides* from the 7th ICORD meeting in Tokyo 2012 are available on the website**
  - *Go to web page*

The 8th ICORD meeting will be held in Shanghai, China in 2013.

Mission

The ICORD mission is to improve the welfare of patients with rare diseases and their families world-wide through better knowledge, research, care, information, education and awareness.

ICORD is an International Society for all individuals active in rare diseases and/or orphan drugs, including health care, research, academic, industry, patient organizations, regulatory authorities, health authorities, and public policy

http://icord.se

About ISS

Www.iss.it

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Mission

The Istituto Superiore di Sanità (ISS) is the leading technical and scientific public body of the Italian National Health Service. Its activities include research, control, training and consultation in the interest of public health protection.

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Training and Scientific Meetings

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Getting to ISS bay air and train

Committees

Committee for Equal Opportunities

Ethical Committee

ISS Staff

This section is linked to the ISS people bibliographic database. Only people who

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The Documentation Service

Intellectual Property Portfolio

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According to the ISS Presidential
of January 24, 2003 concerning th
Organization of the Institute and
personnel ("Regolamento recante
per l'organizzazione strutturale e l
disciplina del rapporto di lavoro de
dipendenti dell'Istituto superiore d
sanità"):

Technical-Scientific Services

Central Directorates

National Centres

Departments

Community Reference Laboratories

Reference Laboratory for Parasites

Reference Laboratory for Escherichia-coli

Reference Laboratory for Chemical Elements in Food of Animal Origin

Centro Nazionale Malattie Rare

www.iss.it/cnmr

Responsabile: Domenica Taruscio

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Le malattie rare

Cosa sono le malattie rare?
Malattie che colpiscono 1 ogni 2000 abitanti

Malattie rare esentate in Italia
Elenco ordinato delle patologie e ricerca on line

Ho una malattia rara? Cosa fare? Guida all'esenzione
Dal sospetto di malattia ai centri di diagnosi e cura

Il disabile e i suoi diritti
Una guida concreta per orientarsi tra agevolazioni, detrazioni, sconti fiscali e altre opportunità

Le malattie rare e l'Europa

Le informazioni e le iniziative della Commissione Europea.

Ulteriori informazioni sul portale ad esse dedicato.

Rete Nazionale e centri di diagnosi e cura

Il sito per **cercare i centri di diagnosi e cura** e **conoscere la Rete Nazionale**

Associazioni di pazienti

Visita il sito per conoscere i

CentroNazionaleMalattieRare

CNMR

In rilievo

23 Novembre 2012
Public consultation on the implementation of European Reference Networks (ERN)

Announcing a new journal
RARE DISEASES AND ORPHAN DRUGS
An International Journal of Public Health
Coming in 2013

16-20 September 2013
International Summer School "Rare Disease and orphan drug registries"

5 novembre 2012
FOCUS Convegno: "PREVENZIONE PRIMARIA DELLE MALFORMAZIONI CONGENITE"

Tematiche

- Acido folico e folati prima della gravidanza
- Farmaci Orfani
- Linee Guida
- Medicina Narrativa
- Progetti europei
- Test genetici

Registri

Registro Nazionale Farmaci Orfani

Registro Nazionale Malattie Rare

Registri Malformazioni Congenite

Il sito dedicato al concorso Il Volo di Pegaso

"Il Volo di Pègaso - Raccontare le malattie rare: parole e immagini", il concorso artistico letterario nato per garantire spazi espressivi e visibilità alle persone con malattie rare.

Notiziario CNMR e altre pubblicazioni

Il Notiziario del CNMR (Supplemento al Notiziario ISS), i notiziari ISS e i

IRDiRC

SEVENTH FRAMEWORK PROGRAMME

CentroNazionaleMalattieRare
CNMR

ICORD
International Conference on Rare Diseases & Orphan Drugs

E-Rare

NATIONAL REGISTRIES
RARE DISEASES
ORPHAN DRUGS

NATIONAL NETWORK ON
RARE DISEASES

ORPHAN DRUGS

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

ITALIAN NETWORK
FOLIC ACID

efsa
European Food Safety Authority

www.iss.it/cnmr

PATIENTS' ASSOCIATIONS

Public health activities

Research activities

Educational activities

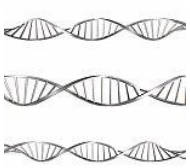
RESEARCH

ISTITUTO SUPERIORE DI SANITÀ

NATIONAL INSTITUTES OF HEALTH

EDUCATION

GENETIC TESTS



NARRATIVE MEDICINE

PROGETTI
EUROPEI

European Union Committee of Experts on Rare Diseases

EURO PLAN

E-Rare

EPIRARE

GUIDELINES

EUROPLAN

European Project for Rare Diseases National Plans Development

Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health

2012-2015

EUROPLAN 2012-2015

provides technical and scientific
support to Countries
in order to develop and implement
National Plans and Strategies
for Rare Diseases

EUROPLAN WORKSHOP

INCEPTION WORKSHOP ON NATIONAL PLANNING FOR RARE DISEASES

ROME
10-11 September 2012

EUROPLAN 2012-2015

a three-year project, embedded in the EUCERD Joint Action as Work Package 4, it is coordinated by the Italian National Institute of Health - Italian National Centre for Rare Diseases.

Its main goal is to establish an international and interactive network of stakeholders (mainly policy makers) to speed up the elaboration and the implementation of Rare Diseases National Plans/Strategies, through scientific and technical assistance, Workshops and the active participation of patients Groups (EURORDIS and National Alliances) [read more]

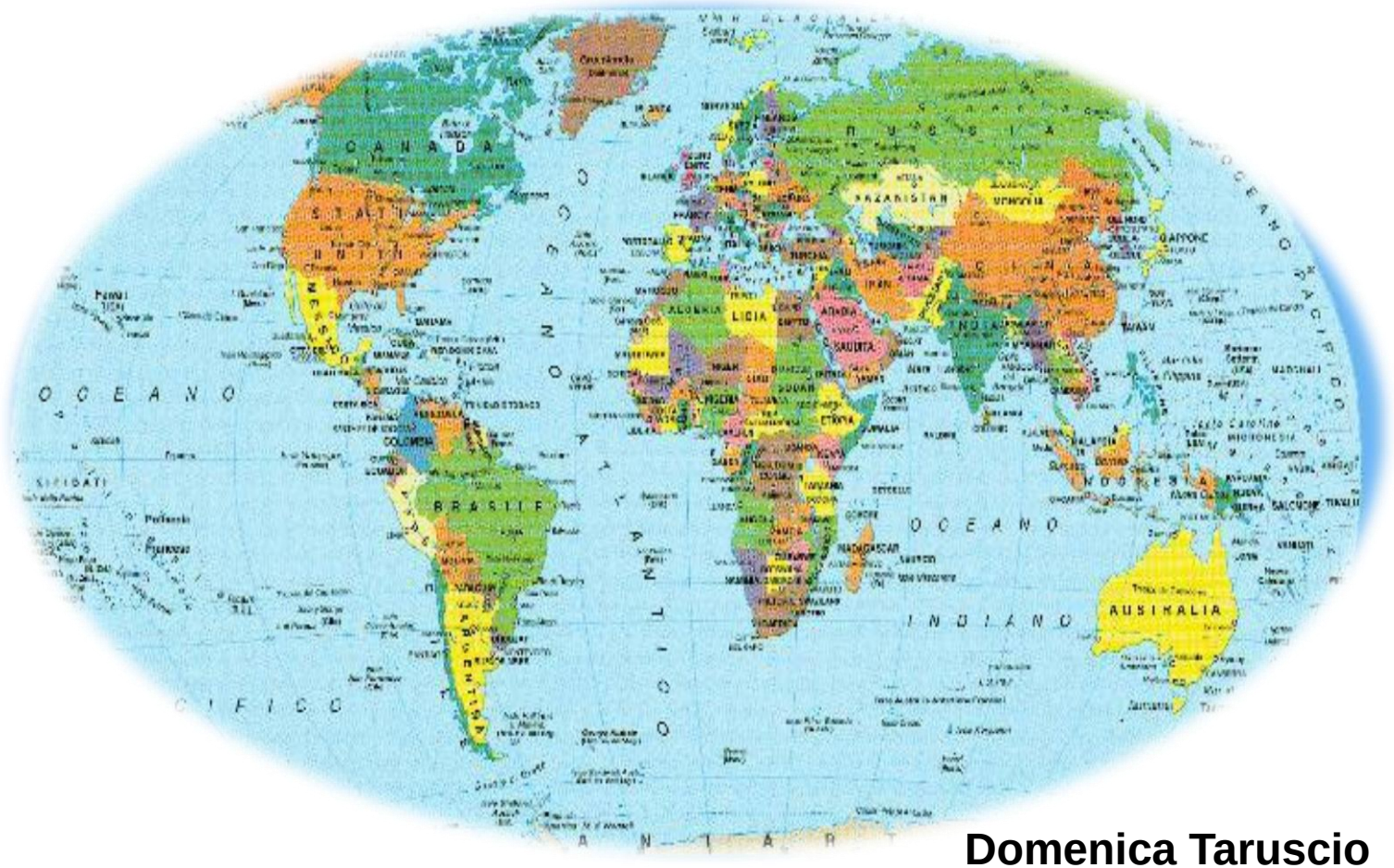
News

RARE DISEASE AND ORPHAN DRUG REGISTRIES
International Workshop
8-9 October 2012
ISS - Rome, Italy
Website - Agenda

The Czech government adopted on August 28/2012 in its Decree 633
The Czech National Plan for Rare Diseases 2012-2014
[see the document]

It's available the DRAFT (english version) of the
Strategy of The Netherlands in the field of Rare Diseases
[see the document]

www.europlanproject.eu



MANY THANKS FOR YOUR ATTENTION

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