



Instituto de Salud Carlos III

Investigación en Enfermedades Raras

JORNADA
Actualización de Recursos de Atención en Enfermedades Raras
Burgos 24 de junio de 2014



JORNADA
 Burgos, 24 de Junio de 2014

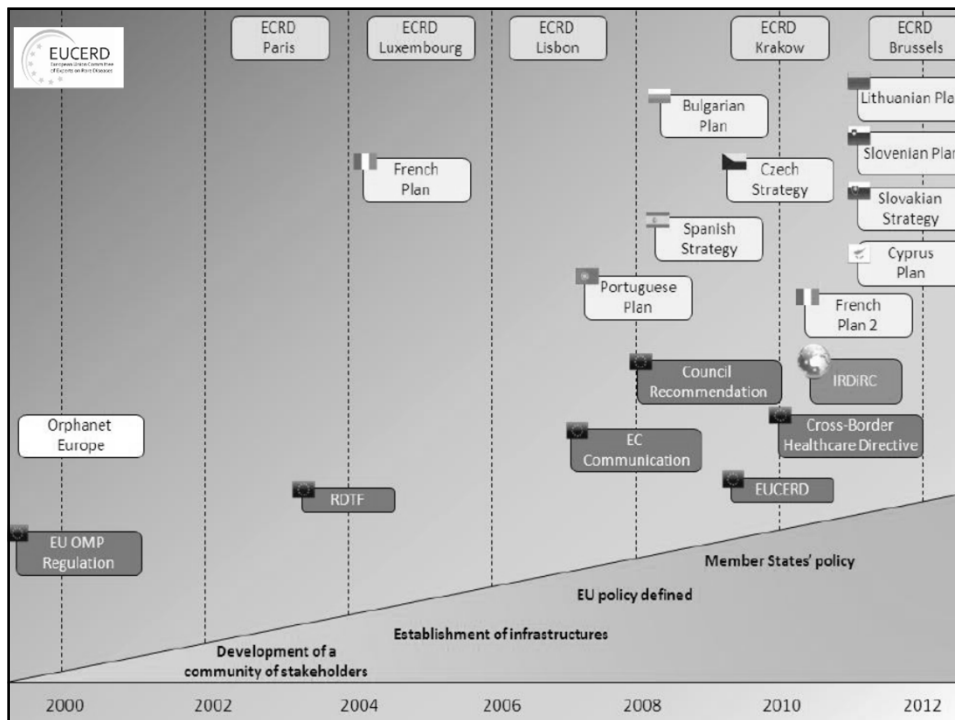
Actualización de **Recursos de Atención en Enfermedades Raras**


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 CENTRO DE REFERENCIA ESTATAL DE ATENCIÓN A PERSONAS CON ENFERMEDADES Raras Y SUS FAMILIAS
 Bernardino Obregón, 24 - 09001 Burgos

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www.creer enfermedadesraras.es

Manuel Posada
Director
Instituto de Investigación en Enfermedades Raras






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European Strategic Framework

- **Communication
from the Commission**

- **Council
recommendations**




COMMISSION OF THE EUROPEAN COMMUNITIES

Brussels, 11.11.2008
COM(2008) 679 final

COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS

on Rare Diseases: Europe's challenges

[SEC(2008)2713]
[SEC(2008)2712]



COUNCIL OF
THE EUROPEAN UNION

Brussels, 5 June 2009
(OR_en)

10122/09


Interinstitutional File:
2008/0218 (CNS)

LIMITE

SAN 142
RECH 167
MI 219

LEGISLATIVE ACTS AND OTHER INSTRUMENTS

Subject: COUNCIL RECOMMENDATION on an action in the field of rare diseases.



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PUBLIC HEALTH

European Commission > DG Health & Consumers > Public health > Rare diseases > Policy

RARE DISEASES

Search

[All topics](#) **Policy** [National plans](#) [Reference networks](#) [Orphan medicinal products](#) [Committees](#) [Projects](#) [Partials](#)

Go back to: [Rare diseases](#) > [Policy](#)

Rare diseases – what are they?

Life-threatening or chronically debilitating diseases – mostly inherited – that affect so few people that combined efforts are needed to:

- reduce the number of people contracting the diseases
- prevent newborns and young children dying from them
- preserve sufferers' quality of life and socio-economic potential.

In EU countries, any disease affecting fewer than 5 people in 10 000 is considered rare. That number may seem small, but it translates into approximately 240 000 people throughout the EU's 27 member countries. Most patients suffer from even rarer diseases affecting 1 person in 100 000 or more.

It is estimated that today in the EU, 5-8000 distinct rare diseases affect 6-8% of the population – between 27 and 30 million people.

→ **What is the EU doing?**

Helping to pool scarce resources that are currently fragmented across individual EU countries. Joint action helps patients and professionals share expertise and information across borders. Specific measures include:

- improving recognition and visibility of rare diseases
- ensuring that rare diseases are adequately coded and traceable in all health information systems
- supporting national plans for rare diseases in EU member countries
- strengthening European-level cooperation and coordination
- creating European reference networks linking centres of expertise and professionals in different countries to share knowledge and identify where patients should go when expertise is unavailable in their home country
- encouraging more research into rare diseases
- evaluating current screening population practices
- supporting rare diseases registries and providing a European Platform for rare diseases registration.

Patient organisations are particularly important because they provide additional incentives for developing orphan drugs to combat rare diseases.

→ **Legal basis of EU policy**

- Communication on rare diseases: Europe's challenges COM(2008) 679 final [PDF](#)
- Recommendation on an action in the field of rare diseases (2009/C 151/02) [PDF](#)
- Other EU legal documents on rare diseases

e-newsletter 12 December 2013

[EMNR: Protecting citizens against new health r...](#)

Highlights

- [2013 Report on the State of the Art of Rare Diseases Activities in Europe - EUCERD Joint Action](#)
- [EUCERD Recommendations on core indicators for Rare Disease national plans/strategies](#)
- [New web site of the International Rare Disease Research Consortium \(IRDRC\)](#)

Related information

- [Press material](#) [Key documents](#)
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- [Events](#) [Consultations](#)
- [Publications](#) [Projects](#)



EUCERD





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EUCERD

The European Union Committee of Experts on Rare Diseases is charged with aiding the European Commission with the preparation and implementation of Community activities in the field of rare diseases, in cooperation and consultation with the specialised bodies in Member States, the relevant European authorities in the fields of research and public health action and other relevant stakeholders acting in the field. [Read more](#)



2013 edition of the State of the Art of RD Activities report now

8th EUCERD meeting: New recommendations adopted

IRDIRC delivers a successful and inspiring conference: a common

New EUCERD Recommendation on RD European Reference

Latest news








Search

Newsletter

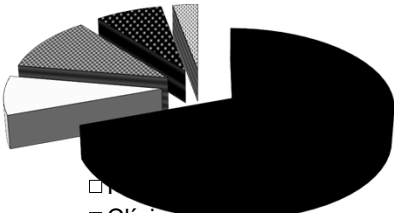
[Read the latest newsletter](#)







Proyectos




- Otras
- Dx y Biomarcadores
- Clínica

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	Medical device/instrumentation development	25
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	Epidemiological study	228
Diagnostics & biomarkers	Diagnostic tool / protocol development	301
	Biomarker development	149
Other	Health sociology study	80
	Health economics study	14
	Public health / health services study	75
Total		4690

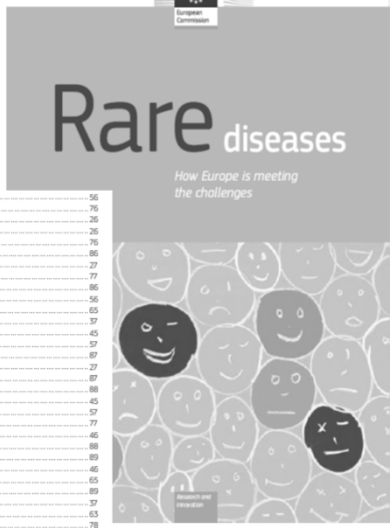


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Rare diseases
How Europe is meeting the challenges

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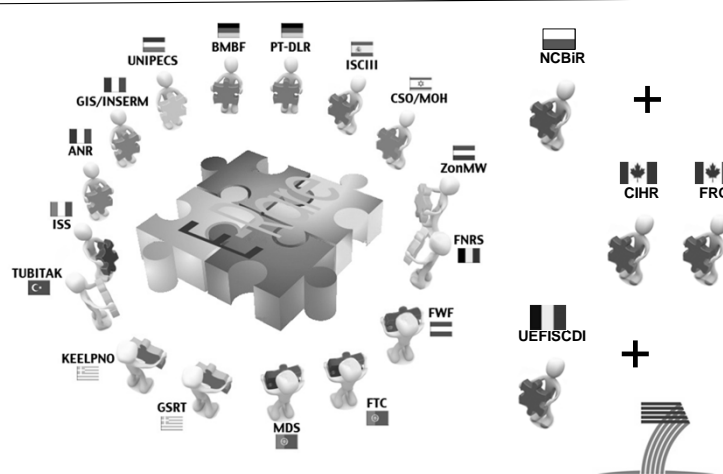


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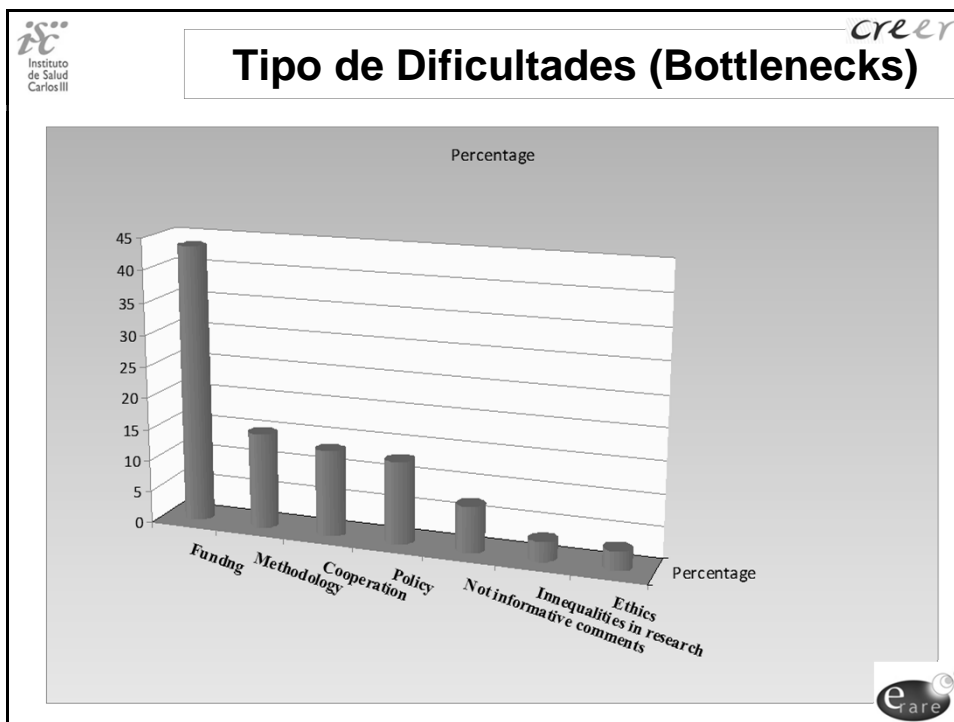
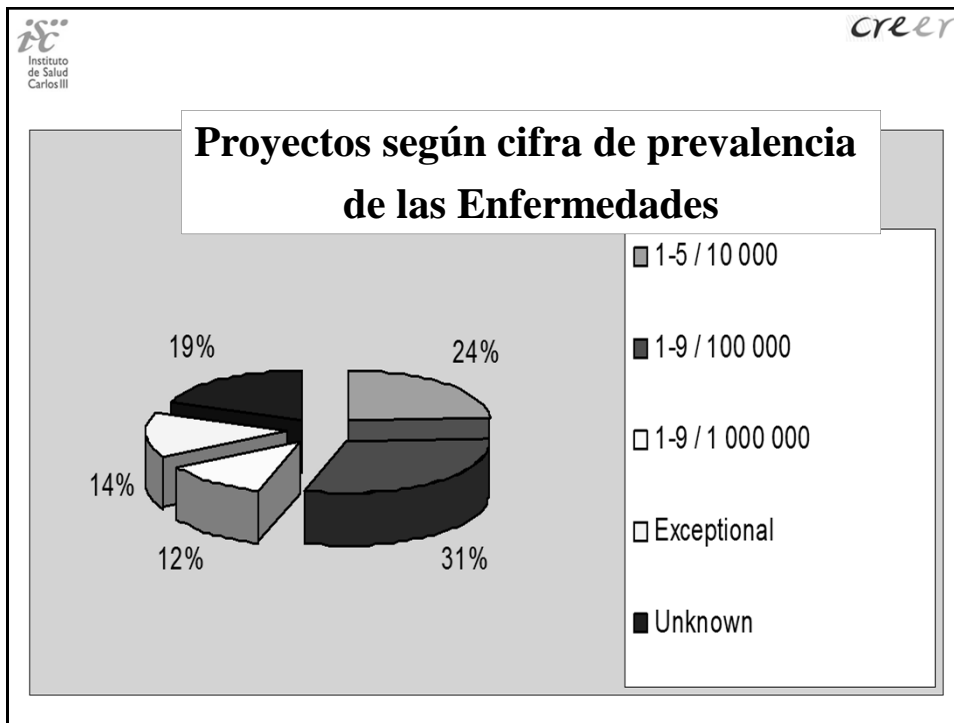


E-Rare-2 (Consorcio 2011 - 2014)

**15 Estados Miembros UE y Países Asociados
20 Agencias Financiadoras Públicas / Ministerios**



UNICEPS, BMBF, PT-DLR, ISCIII, NCBIR, GIS/INSERM, ANR, ISS, TUBITAK, KEELPNO, GSRT, MDS, FTC, FWF, FNRS, ZonMW, FRC, FRQ, UEFISCDI, SEVENTH FRAMEWORK PROGRAMME



EUROPLAN
European Project for Rare Diseases National Plans Development
2012-2015

Public Health EUROPLAN

EUROPLAN
EUROPEAN PROJECT FOR RARE DISEASES NATIONAL PLANS DEVELOPMENT

FUNDED: EUROPEAN COMMISSION PUBLIC HEALTH PROGRAM 2008-08
PRIORITY AREA: 1. HEALTH INFORMATION (IN 2007)
ACTION: 1.4. DEVELOPING STRATEGIES FOR INFORMATION EXCHANGE AND RESPONDING TO NON-COMMUNICABLE HEALTH THREATS
CONTRACT NUMBER: 051120
PROJECT COORDINATOR: DOMENICA TARASCIO (ISS)
MAIN PARTNER: ISTITUTO SUPERIORE DI SANITA' (ISIT)
ASSOCIATED PARTNER: IS
PROJECT PERIOD: 1 APRIL 2008 - 31 MARCH 2013
REFERENCING PERIOD: N.A.

Selecting indicators to evaluate the achievements of RD initiatives

EUROPLAN
Mariano Pizzetti, Maria José Castellanos, Maribel Pizarro Prieto and EUROPLAN Working Group on Indicators
Revision Date: 22 February 2013
Revision Level: Final
Intended Target:
Key words: indicators
Reference Year: 19.9. Process a proposal of indicators to be developed in experts

EUROPLAN (2008-2011, 2012-2015) is project co-funded by the EU Commission (DC-SANCO) to promote and implement National Plans or Strategies to tackle rare diseases, to share relevant experiences within Countries, linking national efforts with a common strategy at European level. This "double-level" approach ensures that progress is globally coherent and follows common operations throughout Europe. [read more]

EUROPLAN 2012-2015 is 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. [read more]

Download the Europlan flyer

Click on the flag to see the actions of the country to tackle rare diseases

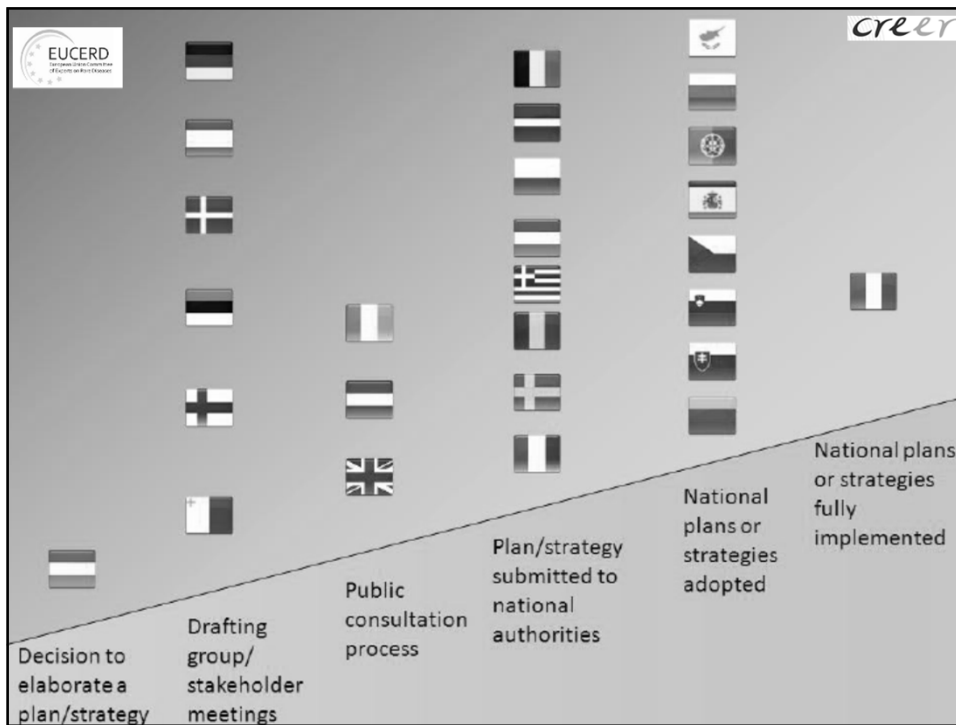
www.europlanproject.eu

EUROPLAN: (2008-2011; 2012-2015) project, funded by the EU Commission

57 Partners
Associated & Collaborating:
**clinicians,
scientist, health
authorities, patients'
Groups**
34 Countries

EURORDIS
Rare Diseases Europe

www.europlanproject.eu



is
Instituto de Salud Carlos III

Epirare - European Platform for Rare Diseases

EPIRARE
European Platform for Rare Disease Registries

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

In Europe a disease is considered rare when it affects no more than 5 individuals among 10,000 persons

Rome first Epirare meeting
11 - 12 July 2011
ISS

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

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

Would you like to join Epirare?

Download Epirare flyer

News

October 4, 2011 - London EUCERD/EMA Workshop
[Site - Epirare](#)

October 27-28, 2011 - Tbilisi 3rd South Caucasian Conference
[Site](#)

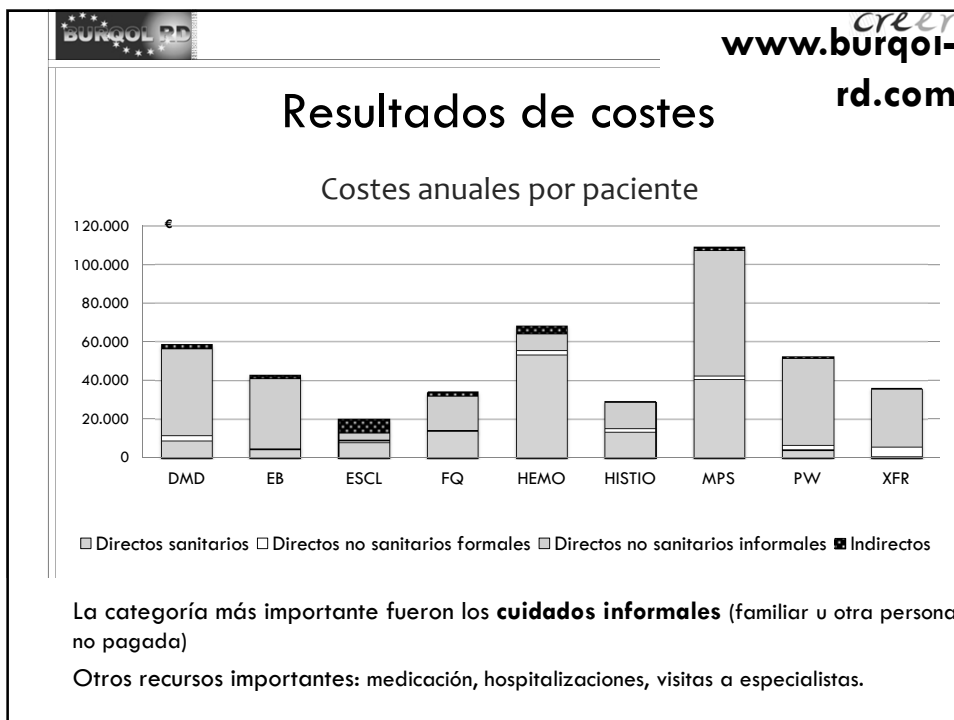
May 22-23, 2012 - Brussels First Announcement Second Epirare Meeting
[\[see all news\]](#)

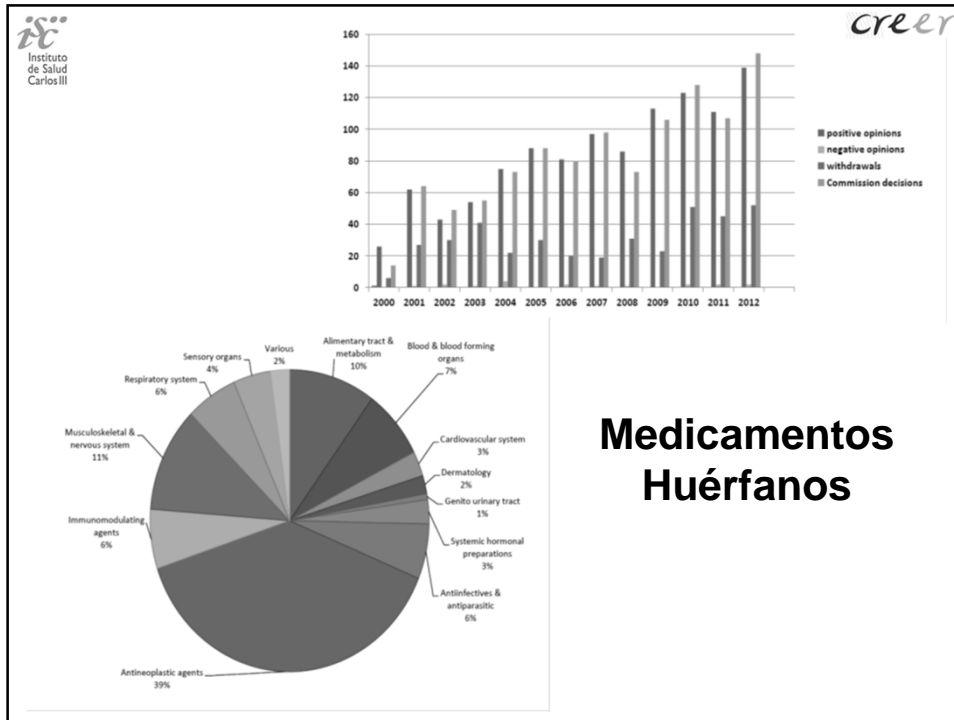
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The screenshot shows the BURQOL RD website interface. At the top left is the logo of the Instituto de Salud Carlos III. The browser address bar shows 'www.burqol-rd.com'. The main navigation menu includes: Home, Introduction, Objectives, Outcomes, Partners, News, Publications, Intranet, and Contact. A 'Main Menu' sidebar lists: Home, Introduction, Objectives, Outcomes, Partners, News, Publications, Intranet, and Contact. Below this is a 'Questionnaires' section with icons for various countries. A Facebook widget is also present. The main content area features the title 'SOCIAL ECONOMIC BURDEN AND HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH RARE DISEASES IN EUROPE'. It includes a brief project description, a list of 10 rare diseases, and a list of objectives.

After a thorough selection process, a set of 10 rare diseases to be targeted was decided:

- > Cystic fibrosis
- > Prader-Willi Syndrome
- > Haemophilia
- > Duchenne Muscular Dystrophy
- > Epidermolysis Bullosa
- > Fragile X Syndrome
- > Scleroderma
- > Mucopolysaccharidosis
- > Juvenile Idiopathic arthritis
- > Histocytosis





Acciones en España

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Planes Nacionales y Autonómicos

- Andalucía
- Extremadura
- Castilla-La Mancha
- Murcia

Estrategia en Enfermedades Raras del Sistema Nacional de Salud

MINISTERIO DE SANIDAD Y POLÍTICA SOCIAL

- Estrategia del Ministerio de Sanidad y Consumo (España)

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www.ciberer.es

ciberer GOBIERNO DE ESPAÑA MINISTERIO DE CIENCIA E INNOVACIÓN

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Castellano - English

CIBERER ACTIVIDAD CIENTÍFICA PROGRAMAS INVESTIGACIÓN GRUPOS INVESTIGACIÓN ENFERMEDADES RARAS

"Nuestro principal objetivo es comprender por qué y cómo se producen las enfermedades raras genéticas y no genéticas"

Reportaje del progr

AGENDA

- VIII Course on Micro Neurobiologic Development 26-ene-12 - 29-ene-12
- V Annual Meeting CIBER on Rare Diseases 31-ene-12 - 01-feb-12
- 7ª Reunión Internacional sobre Investigación Tradicional y Medicina Personalizada 02-feb-12

DESTACAMOS

Reportaje del programa Dossier de Canal 9 dedicado a las Enfermedades Raras

Concursadora E-RARE para proyectos de investigación tradicional colaborativos

Ayudas de la Executive Agency for Health and Consumers para el desarrollo del Programa de Salud

Programa de ayudas a la investigación de la Asociación Española Contra el Cáncer 2012

orphanet
ORPHANET-ESPAÑA

Programas
Plataformas
Convocatorias
Perfil del Constatante
Agenda
Área de Prensa
Documentación

Bienvenido a CIBERER
Las enfermedades raras, que afectan a unos 3 millones de españoles, son un problema sociosanitario de primera magnitud. El Centro de Investigación Biomédica en Red de Enfermedades Raras (CIBERER), estructura en red constituida como una iniciativa del Instituto de Salud Carlos III, agrupa y potencia la investigación de excelencia que se realiza en nuestro país con el objetivo de encontrar diagnósticos y terapias para los afectados con la mayor rapidez posible.

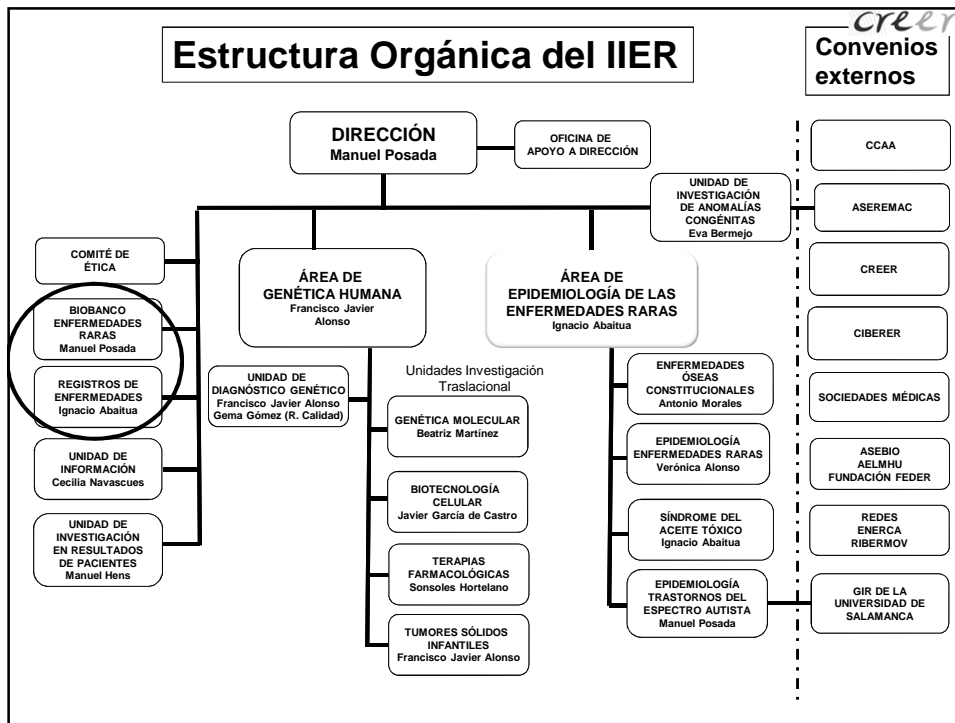
NOTICIAS



La doctora Carmen Ayuso (U704) coordina una reunión sobre medicina genómica el próximo 2 de febrero
26/12/2011
Caso Fundación Jiménez Díaz organiza la Séptima Reunión Internacional sobre Investigación Tradicional y Medicina Personalizada: Medicina Genómica en los Hospitales del siglo XXI el próximo 2 de febrero. El CIBERER colabora en esta jornada en la que participan investigadores de las unidades 704 y 704. En este evento, se abordarán patologías como el Alzheimer, el cáncer colorrectal o la talia baja.

Más información


La profesora María Luisa Martínez-Frías (U724), galardonada con un Premio Especial de EDIMSA
22/12/2011
El pasado 20 de diciembre se celebró en Madrid el acto de entrega de los XXVIII Premios EDIMSA. La profesora Martínez-Frías, jefe de grupo de la U724 CIBERER, fue galardonada con uno de los Premios Especiales "por su dilatada e importante contribución al estudio, prevención e información de las malformaciones congénitas".

Boletín Social
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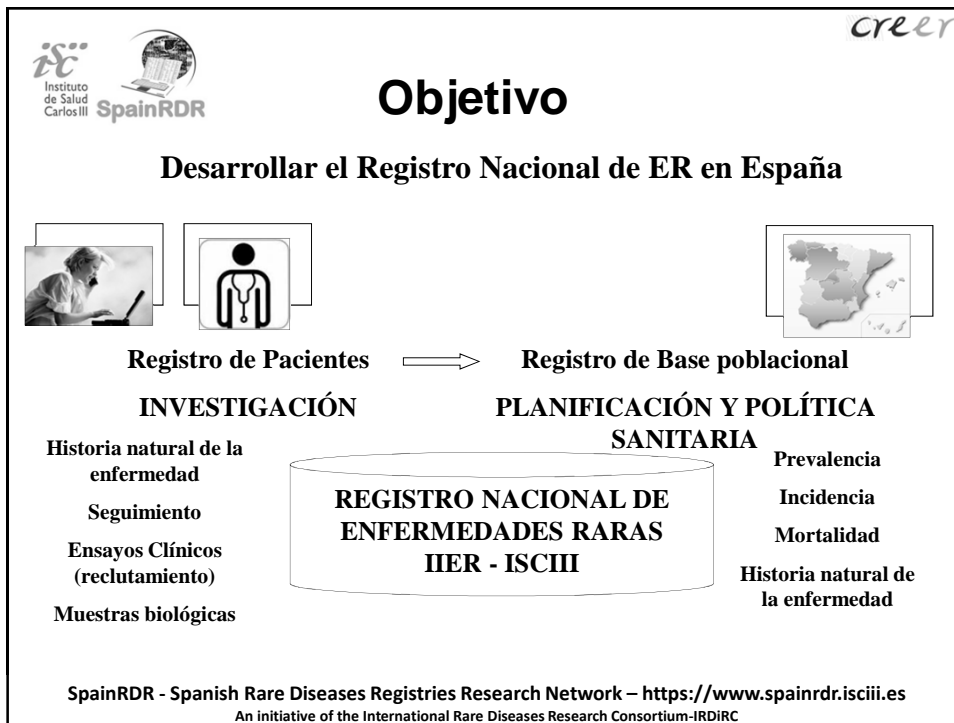
- Rare Diseases Epidemiology, 2010



ADVANCES IN EXPERIMENTAL MEDICINE AND BIOLOGY
Volume 686

Edited by
Manuel Posada de la Paz
Stephen C. Groll





Documentación SpainRDR.

Bienvenido al portal de registro de enfermedades raras

Usuario:
 Contraseña:

Últimas Noticias

01/01/2013-01/01/2013
 Mayor el acceso a los medicamentos
 01/01/2013-01/01/2013
 EURODIS: el nuevo 6 febrero 2013
 01/01/2013-01/01/2013
 ¿VER MÁS NOTICIAS?

Enlaces

[Inicio](#) [Ayuda](#) [Contacto](#) [Acerca de](#)

https://registroraras.isciii.es

SpainRDR - Spanish Rare Diseases Registries Research Network – <https://www.spainrdr.isciii.es>
 An initiative of the International Rare Diseases Research Consortium-IRDIRC

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Biobanco Nacional de Enfermedades Raras Red Europea de Biobancos de Enfermedades Raras – EUROBIOBANK Red Nacional de Biobancos ISCIII (RetBioH)

Colección verlier
NPO 725-13-013-7
Depósito Legal M21011-2013

Biobanco Nacional de Enfermedades Raras
biobanco_ner@isciii.es

Red Biobancos
Instituto de Salud Carlos III

GOBIERNO DE ESPAÑA
MINISTERIO DE ECONOMÍA Y COMPETITIVIDAD

Instituto de Investigación de Enfermedades Raras

RD@Connect

Red Biobancos

EmBioBank



Presente y Futuro

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Presente y Futuro




Proyectos internacionales relacionados



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.

[IRDiRC_Statement.PDF](#)



RARE DISEASE CONNECT

RD-Connect is a unique global infrastructure project that links up databases, registries, biobanks and clinical bioinformatics data used in rare disease research into a central resource for researchers worldwide.

[Visit RD-Connect >](#)



EUROPEAN PLATFORM FOR RARE DISEASES REGISTRIES

The aim of EpiRare is to prepare a European platform for the registration of rare disease patients and to ensure the quality and best use of the registered data.

[Visit EPIRARE >](#)



National Center for Advancing Translational Sciences

GLOBAL RARE DISEASES PATIENT REGISTRY DATA REPOSITORY (GRDR)

GRDR provides a resource to the Rare Diseases community by collecting the pan-disorder information needed to accelerate research and therapeutic advances.

[Visit GRDR>](#)

SpainRDR - Spanish Rare Diseases Registries Research Network – <https://www.spainrdr.isciii.es>
An initiative of the International Rare Diseases Research Consortium-IRDiRC




ICORD (International Conferences for Rare Diseases and Orphan Drugs)



International Conference on Rare Diseases & Orphan Drugs

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

Events

- » Past Events

Welcome to ICORD!

International Conferences for Rare Diseases and Orphan Drugs

- **Next Annual meeting** will be held in The Netherlands in the autumn 2014, dates to be decided.
- **Invitation for expressions of interest to host the 2016 ICORD meeting**
ICORD members are welcome to send their expression of interest to host the annual ICORD meeting 2016 to the Secretariat by email: icord@isciii.es. ICORD also welcomes expressions of interest for the annual ICORD meeting 2017. Please see further information in the following documents
[Letter of intent ICORD annual meeting](#)
[Annual Meeting Proposal Submission Guidelines](#)
- **The 8th ICORD meeting** was held in St Petersburg, November 1-2, 2013. Presentations and documentation from the meeting will be published on this website.

- **ICORD Declaration for policy and action plans for rare diseases – The "ICORD Yuhimura Declaration" (PDF)**
- [Go to web page](#)
- **Full reports from the 7th ICORD meeting in Tokyo 2012** are 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](#)

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.

Stay updated!

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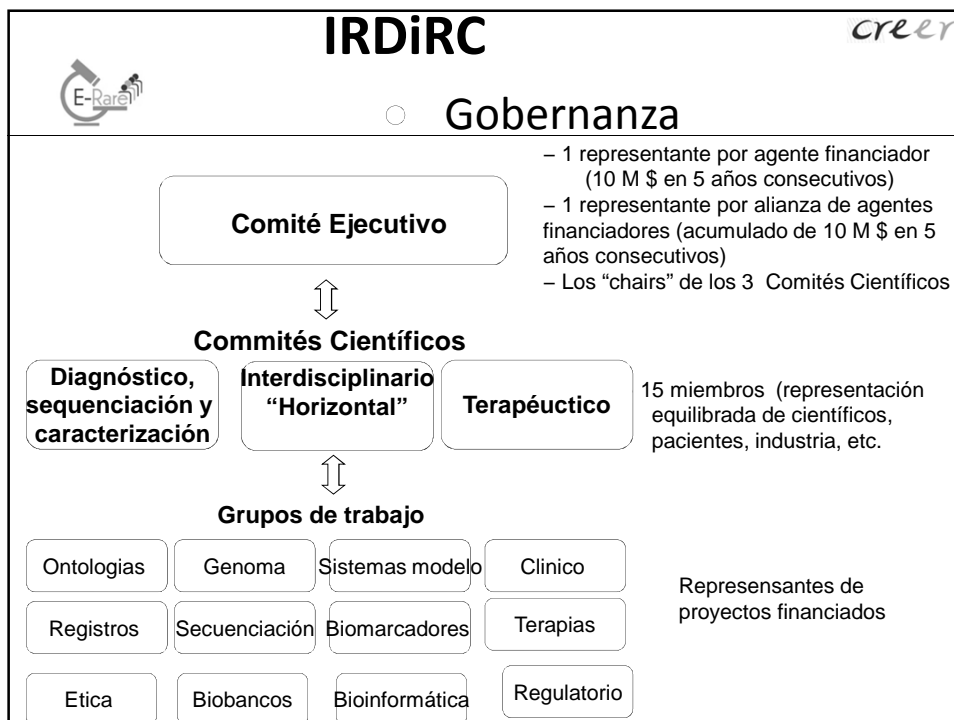
Your e-mail address

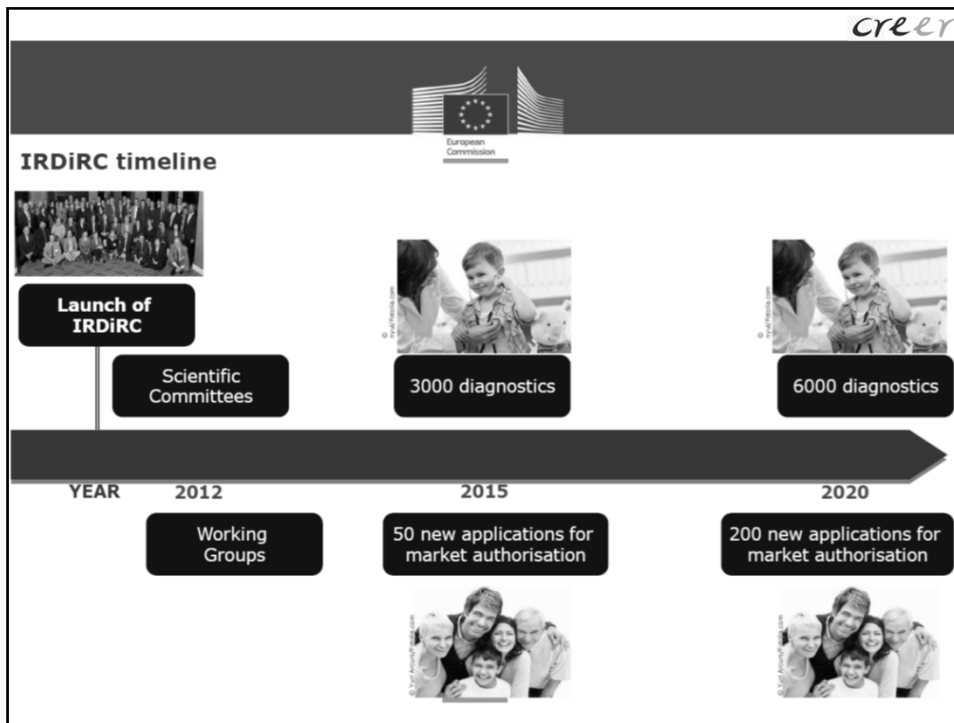
PAIS	Comité Ejecutivo, Miembros
EU	European Commission, DG Research and Innovation,
Australia	Western Australian Department of Health
Canadá	Canadian Institute of Genetics CIHR
Canadá	Genome Canada
EU	European Commission, DG Health and Consumer Protection
Europa	E-RARE-2 (ERA-Net group of funders alliance)
Francia	French National Research Agency [ANR]
Francia	French Association against Myopathies
Francia	Lysogene
Alemania	Federal Ministry of Education and Research [BMBF]
Irlanda	Shire
Italia	Telethon Foundation
España	Instituto de Salud Carlos III [ISCIII]
USA	Sandford Research
USA	Prosenza
USA	Food and Drug Administration [FDA]
USA	National Human Genome Research Institute, NIH
USA	National Cancer Institute, NIH
	Grupo de pacientes
Europa	EURORDIS
	Comités Científicos
	Chair Comité de Terapias
	Chair Comité Interdisciplinario
	Chair Comité de Diagnósticos
	<u>Invited</u>
	SUPPORT IRDiRC project

El International Rare Diseases Research Consortium [IRDiRC]

- Fue lanzado en Reikiavik, Islandia, 27-28 de Octubre 2010, convocada por NIH (USA) y EC.
- España fue el primer país en devenir miembro de pleno derecho en la siguiente reunión (Bethesda, USA, 6-8 de abril de 2011).







IRDiRC
INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM

List of projects funded by IRDiRC members

These projects are also accessible from the Orphanet website. They can be queried by disease/genre, category, institution/laboratory, professional, sponsor/funding body and partnership category.

- Canadian Institutes for Health Research (CIHR)
- E-Rare, European Union
- European Commission, European Union
- Federal Ministry of Education and Research (BMBWF), Germany
- French Muscular Dystrophy Association (AFM), France
- Genome Canada, Canada
- National Institute of Health Carlos III (Instituto de Salud Carlos III), Spain
- National Institutes of Health (NIH), USA
- NKT Therapeutics, USA

SpainRDR aims to build the National Rare Diseases Registry in Spain - Q&A with Dr Manuel Posada

The Spanish Rare Diseases Registries Research Network (SpainRDR) is a 2.4 ME project financed by the Institute of Health Carlos III (ISCIII) for the years Dec. 2011 to Dec. 2014.

This project involves all Health Departments of the Autonomous Communities (regions) of Spain, the Institute of Rare Diseases Research (IRDiRC) which acts as a coordinator and leader of the network, the Spanish Ministry of Health, the Spanish Centre of Reference of People and Families affected by RD (CEREP), the Spanish Medical Societies/our research networks, pharmaceutical and biotechnological organisations (IBRO and FABRABIOFOTEN), and the Spanish Federation of RD (FEDER) and its foundation (FEDER TELETHON FOUNDATIONS).

Interview of Dr Manuel Posada, coordinator of the Spanish Rare Diseases Registries Research Network (SpainRDR)

Prioridades para la investigación en enfermedades raras 2014-2020


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- Apoyo a los registros y otras infraestructuras
- Aumentar el conocimiento de los mecanismos de las enfermedades raras
Trasladar los resultados de investigación en tratamientos para los pacientes
- Diseñar estrategias amplias de ensayos clínicos
- Investigación en ciencias sociales




Cómo conducir la investigación en enfermedades raras

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- Empoderando a los pacientes en investigación
- Integrando acciones
- Sosteniendo a largo plazo infraestructuras y proyectos
- Instrumentos de financiación

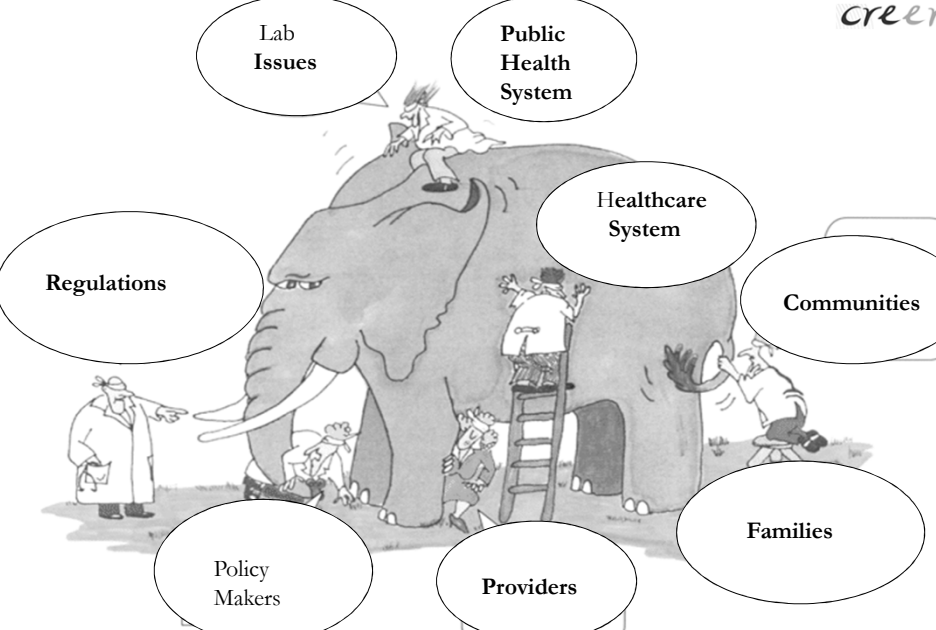
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Muchas Gracias

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