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RARE-Bestpractices
A platform for sharing best practices for the management of rare diseases

Advisory Board
Consorci Institut d’Investigacions Biomèdiques August Pi i Sunyer, Spain
Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitry Rogachev, Russia
Foundation Children with Spinal Muscular Atrophy, Ukraine
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Public Health Division and Clinical Services, Department of Health Government of Western Australia, Australia
Saint Petersburg State Medical Academy named after I.I. Mechnikov, Russia
Yerevan Mikhtar Heratsu Anvan Petakan Byshkaqan Hamalsaran, Armenia

Contacts
Project coordinator:
Domenica Taruscio
Istituto Superiore di Sanità
National Centre for Rare Diseases Rome, Italy
Viale Regina Elena, 299 - 00161 Roma
rare-bestpractices@iss.it
www.rarebestpractices.eu

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Why RARE-Bestpractices project

• RARE-Bestpractices addresses the patients’ and caregivers’ demand for updated and evidence-based clinical practice guidelines on rare diseases.

• RARE-Bestpractices addresses guideline developers’ demand for evaluating and developing clinical practice guidelines on rare diseases.

• RARE-Bestpractices responds to the European directive which encourages EU Member States to develop European Reference Networks in the area of rare diseases which should have the capacity to produce good practice guidelines (article (12)(3,4) Directive 2011/24/EU).

RARE-Bestpractices time frame and partnership

RARE-Bestpractices is a four year project (January 2013-December 2016) which gathers 15 partners representing nine European countries. Experts on areas of rare disease and best practice guidelines development and implementation will work together with the involvement of institutions, networks, patient organizations.

To help shape its strategy and support its activities RARE-Bestpractices has set up an Advisory Board of international experts representing European and extra-European organizations/agencies all with strong commitment in basic and clinical research on rare diseases. The Advisory Board is also composed of experts representing global networks which support evidence-based health care and work to improve health and living standards.

Partners

Instituto Superiore di Sanità - Coordinator, Italy
Jamarau, United Kingdom
Karolinska Institutet, Sweden
Healthcare Improvement Scotland, United Kingdom
London School of Economics and Political Science, United Kingdom
National Research Council, Italy
EURODIS, European Organisation for Rare Diseases, France
Associazione per la Ricerca sull’Efficacia dell’Assistenza Sanitaria
Centro Cochran Italyano, Italy
Universitätsklinikum Freiburg, Germany
Bulgarian Association for Promotion of Education and Science, Bulgaria
Fundación Canaria de Investigación y Salud, Spain
Universiteit Maastricht, The Netherlands
Newcastle University Upon Tyne, United Kingdom
The European Academy of Paediatrics, Belgium
Institute of Rare Diseases Research, Instituto de Salud Carlos III, Spain

What RARE-Bestpractices does

1. Create standards and transparent reliable procedures for the development and evaluation of clinical practice guidelines for rare diseases

2. Identify methodology for representing processes included in clinical recommendations in order to support their effective implementation into practice and to simplify auditing and economic evaluations

3. Build a comprehensive publicly searchable database of high quality clinical practice guidelines ranging from diagnostic tests and treatments to organization of care to help professionals, patients, policy makers access the best and most up to date information

4. Produce mechanisms to identify and prioritize rare disease clinical research needs to optimize as well as redefine the clinical research agenda taking into consideration both patients’ and clinicians’ needs and interests

5. Set up training activities targeted at key stakeholders to disseminate processes and tools for developing and evaluating clinical practice guidelines

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