



“European Year of Rare Diseases in 2019”

Questions & Answers

May 2013

Why a European Year of Rare Diseases?

Raising public awareness as well as reaching out to policy makers is one of the main strategic aims of EURORDIS and of each National Alliance for Rare Diseases, included in their mission statement and long term vision.

Awareness raising is imperative in order to promote rare diseases as a public health priority. Only once society at large acquires a better understanding of the challenges faced by people living with rare diseases will there be an increased support for the necessary policy actions needed to address these. This in turn will result in policy makers paying the required attention to making rare diseases a public policy and budget priority.

The European Year of Rare Diseases initiative launches a new dynamic between 2013 and 2020, by maintaining the momentum of the EU policy frameworks 2008-2013 and 2014-2019, and focusing on the development, implementation and durability of community actions as well as national plans for rare diseases. This initiative also prepares for the sustainability of these policies for the period beyond 2020.

The key messages of the European Year of Rare Diseases focus on the health, research and social challenges of people living with a rare disease and how a European approach enables innovative and effective solutions, while promoting our values and overall advocacy priorities.

Our strategy is to launch a three-step public awareness campaign towards the European Year of Rare Diseases and to involve all stakeholders, thus reflecting the collaborative approach to rare disease actions.

The European Year of Rare Diseases will be the Year of Rare Diseases in each EU Member State as well as the Year of Rare Diseases in Europe at large. The European Year of Rare Diseases also provides a framework for individual organisations and alliances to have their own Year for their Rare Disease(s).

The European Year of Rare Diseases can thus be extended into a Year for each of the People Living with a Rare Disease, and those who care for them.

What is a European Year?

The first European Year, in 1983, was dedicated to Small and Medium Enterprises and the Craft Industry. Every year since then, the EU has chosen a specific subject to encourage debate and dialogue within and between European countries. The aim of a European Year is to raise awareness for certain topics, encouraging debate and shifting attitudes. For many of the European Years, extra funding has been provided for local, national and cross-border projects that address the Year's special topic.

A European Year can also send a strong political signal and commitment from the EU institutions and Member State governments that the subject will be taken into consideration in future policy-making. In some cases, the European Commission may propose new legislation on the theme.

Who makes the final decision?

At the European Union level the detailed decision making process and procedures are not clearly defined. However:

- The final decision is made by the President of the European Commission with the support of the European Parliament and the European Council.
- There exists a specific unit at the European Commission responsible for the implementation and coordination of all European Years, working in conjunction with the relevant Directorate General of the European Commission, with whom EURORDIS already interacts.

Why is 2019 a special year for Rare Diseases in Europe?

2019 is a special year for EURORDIS and the Rare Disease community because we will celebrate two important anniversaries:

1. 20 Years of the EU Regulation on Orphan Medicinal Products
2. 10 Years of the Council Recommendation on an action in the field of rare diseases and the Commission Communication on rare diseases: Europe's Challenges

In addition, 2019 marks the end of the third EU Public Health Programme "Health for Growth" and the eighth EU Research Framework Programme "Horizon 2020" as well as being a pivotal year for the EU Multi-Year Financial Framework 2020-2025 and the next Health Programme and Research Programme 2020-2025.

Why a three-step public awareness campaign towards a European Year of Rare Diseases?

Significant support from patient organisations, patients, caregivers and families, universities, scientific learned societies, health care professionals, scientists, politicians, health care corporations and other relevant stakeholders is needed to gather momentum and demonstrate the need for a European Year of Rare Diseases.

Our three- step campaign uses a bottom up approach while popular movement in growing circles paves the way towards a European Year of Rare Diseases in 2019.

1st step: 2013-2015 – Advocate for a European Year of Rare Diseases decision

The objective of this 1st step is to advocate for a European Year of Rare Diseases by a bottom up approach and popular movement in growing circles. The campaign will serve to reach out toward a larger public of individuals living with RDs or concerned by RDs 1) to gain visibility and recognition of EURORDIS and Rare Diseases and 2) to build a grass-root network base of individual donors to grow and diversify our funding.

Bottom-up approach with growing circles



2nd step: 2015-2018 - Act together for Policy Actions on a wide popular base on priority and urgent issues for EURORDIS

During this period, the policy communication will further support the planned actions to enhance:

- The momentum of EU policy in research, public health, information, pharmaceuticals & biotech for rare diseases
- The momentum of 2nd generation national plans/strategies for rare diseases
- Public opinion support in favour of an equitable access to care and higher social recognition of people living with a rare disease,
- The promotion of antidiscrimination legislation and policy actions

3rd step: 2019 Public Awareness Campaign of the actual European Year of Rare Diseases

Which type of achievements and outcomes can be expected?

The following achievements are examples from the 2012 European theme-year - The European Year for Active Ageing and Solidarity:

- Active Ageing Index (AAI) was developed in a joint project between the European Commission and the United Nations Economic Commission for Europe (UNECE)
- The European Commission opened the Invitation for Commitment to the Action Plans:
 - The Action Groups included 261 commitments, by over 3,000 stakeholders from all Member States, and the Action Plans aim to improve the quality of life of four million European senior citizens between 2012 and 2015
- The European Commission and OECD joined forces to produce “Policy Brief on Senior Entrepreneurship”
- Ireland decided that every local authority area in Ireland have its own Age-Friendly County Programme by the end of 2013
- Poland adopted a Government Programme for Senior Citizens Social Activity for 2012-2013
- Germany ran an awareness campaign. The German Anti-discrimination Agency declared 2012 the Year against Age Discrimination.

Annex:

List of European Years

- 2013 - European Year of Citizens
- 2012 - European Year for Active Ageing
- 2011 - European Year of Volunteering
- 2010 - European Year for Combating Poverty and Social Exclusion
- 2009 - European Year of Creativity and Innovation
- 2008 - European Year of Intercultural Dialogue
- 2007 - European Year of Equal Opportunities for All
- 2006 - European Year of Workers' Mobility
- 2005 - European Year of Citizenship through Education
- 2004 - European Year of Education through Sport
- 2003 - European Year of People with Disabilities
- 2001 - European Year of Languages
- 1999 - European Year of Action to Combat Violence Against Women
- 1998 - European Year of Local and Regional Democracy
- 1997 - European Year against Racism and Xenophobia
- 1996 - European Year of Lifelong Learning
- 1995 - European Year of Road Safety and Young Drivers
- 1994 - European Year of Nutrition and Health
- 1993 - European Year of the Elderly and of Solidarity between Generations
- 1992 - European Year of Safety, Hygiene and Health Protection at Work
- 1990 - European Year of Tourism
- 1989 - European Year of Information on Cancer
- 1988 - European Year of Cinema and Television
- 1987 - European Year of the Environment
- 1986 - European Year of Road Safety
- 1985 - European Year of Music
- 1984 - European Year for a People's Europe
- 1983 - European Year of SMEs and the Craft Industry