



A full European Year to put rare diseases in the spotlight



Be part of the movement!

Everyone within the rare disease community and beyond has a role to play to support the nomination of 2019 as the European Year for Rare Diseases.

This important initiative will mark a turning point in the history of rare diseases, but we cannot do it without your support!

Sign-up now at eurordis.org/eyrd2019

We need a European Year for Rare Diseases!

We need you!

More information is available at eurordis.org/eyrd2019



Any questions can
be addressed to:
eyrd2019@eurordis.org





Campaign for European Year for **RARE DISEASES 2019**



When?

2019 is an important year for the rare disease community:

- 20 year anniversary of the adoption of the EU Regulation on Orphan Medicinal Products
- 10 year anniversary of the Commission Communication and Council Recommendation on rare diseases



Why?

- To raise public awareness.
- To find solutions to the challenges faced by patients, families and their care-givers both in the public and political spheres.
- To encourage researchers to focus on these rare, mostly unknown, seriously debilitating and often life-threatening diseases, which affect children and adults, in their physical, mental, emotional and behavioural capacities.
- To create the conditions for better health, medical and social care for all.



What?

Every year since 1983, the EU has chosen a different subject for the European Year to encourage debate and dialogue within and between European countries. The aims are to raise awareness for specific topics, encourage debate and shift attitudes. It also sends a strong political message and demonstrates commitment from the EU institutions and Member State governments that the subject will be considered in future policy-making. In some cases, the European Commission may propose new legislation on the theme.



Where?

Throughout the 28 EU Member States and in the rest of Europe



Who?

The European Year for Rare Diseases is for everyone!

EURORDIS is initiating the campaign at the EU level with the support of European Federations. Rare Disease National Alliances and patient groups will provide support at national levels. A European Year will be the opportunity to communicate about **all** rare diseases.

The campaign will also involve public health authorities, researchers, orphan medicinal product manufacturers, health professionals and everyone else who wishes to join.

The more, the better!



How can I get involved?

Show your support for the European Year for Rare Diseases 2019 by signing-up to join the coalition here: eurordis.org/eyrd2019 and tweeting with the hashtag #EYRD2019