

## Template letter to National policy makers

### Re: Call for a European Year for Rare Diseases 2019

Dear [insert name],

[insert name of your association] is a [patient organisation / association] that currently represents ... people living with this rare disease in [insert country]. The majority of rare diseases are genetic, serious, chronic and debilitating. People living with rare diseases face many common challenges including timely access to diagnostics and treatments, significant financial burdens and a strong feeling of isolation. Solutions must be found for these people who are among the most vulnerable citizens in our society.

**With this letter we are asking you to join the campaign for a European Year for Rare Diseases in 2019.**

*What has been done so far for rare disease patients in [insert country?]*

[Insert information pertinent to your country]

*What has been done so far in Europe?*

The EU Regulation on Orphan Medicinal Products, the Commission Communication on Rare Diseases as well as the Council Recommendation for a European Action in the Field of Rare Diseases and the International Rare Diseases Research Consortium (IRDiRC) are a few examples of the ongoing public health and research policies and initiatives at EU level in the field of rare diseases.

As [insert job function of the recipient e.g. Minister for Health / Member of Parliament], you may be aware that the European Commission has made rare diseases a public health priority. There are over 6000 different rare diseases and the large majority of them have no treatment available. Resources are lacking in [insert country] and throughout the EU for diagnostics, treatments, social services, expert care and research. Despite undeniable successes, most of the journey to reduce health inequalities for rare disease patients and their families is still ahead of us.

Awareness and political willingness are needed to address the many current and up-coming challenges faced by the rare disease community as a whole. In particular, more interfacing and networking between centres of care, the development of more orphan medicinal products, improved access to authorised orphan products, more research into the causes and mechanisms of the different diseases and the involvement of all interested parties including industry and decision-makers are all elements needed to enable the conditions for better health, as well as for high quality medical and social care.

In collaboration with the European Organisation for Rare Diseases (EURORDIS) and its 634 Members including 33 National Alliances for Rare Diseases in Europe and beyond, we have adopted the official **Call for a European Year for Rare Diseases in 2019** that you will find enclosed.

The European Year for Rare Diseases 2019 will enhance collaborative approaches to rare disease strategies and activities and will raise public awareness about rare diseases. We will build greater understanding on a public level in [insert country] about rare diseases and the challenges that face patients, families, health professionals, social providers, researchers and manufacturers on a daily basis. It will provide a platform to break free from the isolation that rare disease patients experience by enhancing and maintaining rare diseases as a priority in public consciousness. In parallel, it will also encourage researchers to focus on these rare, mostly unknown, seriously debilitating and often life-threatening diseases.

As one step in the fight against rare diseases in [insert country], we invite you to sign-up in favour of the campaign for a European Year for Rare Diseases here: [www.eurordis.org/eyrd2019](http://www.eurordis.org/eyrd2019).

We at [insert name of your organisation] hope you will support this initiative and look forward to keeping you informed about the developments of this important campaign for the rare disease community. Please feel free to address any questions you may have to ....

Yours sincerely,