

#UHC4RareDiseases Campaign

Template letter for National Alliances that are members of EURORDIS

Instructions for sending this letter:

- If you would like to send this letter to your national authorities, email **Clara Hervas, Public Affairs Manager (EURORDIS/RDI) to obtain a Word version of the document: clara.hervas@eurordis.org**
- Adapt the content of the letter as you please to include your own logo, wording, data, etc.
- Delete this page, add a signature and transform into PDF once edited.
- We recommend attaching the 'Factsheet to policy makers' to this letter (a Word version of it is also available if you wish to translate it or edit its content).
- Send the letter to your national authorities, like for example the Ministry of Health in your country.

**Thank you for participating in the
#UHC4RareDiseases campaign!**

[National alliance logo]



NAME OF RECIPIENT
ADDRESS

Subject: Request for **COUNTRY** to support the rare disease population as part of the national strategy to achieve Universal Health Coverage

Dear **[Name]**

I am writing to you from **[NAME OF YOUR ORGANISATION]** the **[NAME OF YOUR COUNTRY]** national alliance for rare diseases. More than **XXX** people are affected by a rare disease in **[COUNTRY]** and an estimated 300 million in the world.

In September 2019 our country endorsed the United Nations Political Declaration on Universal Health Coverage, a historic moment in global health. In the declaration, our government committed to giving special attention to the vulnerable and marginalised segments of the population, including by strengthening efforts to address rare diseases (Article 34).

UHC will not be truly universal in our country unless the needs of people living with a rare disease are addressed.

As you know, each rare disease affects small numbers but the people living with them face common severe challenges. Most people affected experience delays in diagnosis, or misdiagnosis, and they do not have access to expertise, care and treatments. Fewer than 5% of diseases have a known treatment. Rare diseases impact not only a person's health, but also their socio-economic status, family, education and labour opportunities: people living with a rare disease do not have access to the care services they need without experiencing financial hardship.

However, the tide is turning and we are encouraged by the attention rare diseases have progressively been given by our government and by an increasing number of other governments worldwide. In addition, the onset of the COVID-19 pandemic has highlighted the need to urgently address pre-existing health, social and economic inequalities. It is our firm belief this is the time to make progress towards UHC in our country, to 'build back better' and 'leave no one behind'.

We call upon you to move towards Universal Health Coverage by addressing the needs of people living with a rare disease in our country.

Please find in attachment a factsheet with recommendations of actions that will address the needs of the rare disease population, in terms of the services they need and in terms of the financial protection they require.

We would be happy to arrange a meeting with you or your colleagues, virtually or face to face, to discuss this matter in more detail. In the meantime, we encourage you to participate in the social media campaign #UHC4RareDiseases.

We, as the national alliance of people living with a rare disease in **[COUNTRY]**, welcome any action you can take to improve the lives of your constituents living with a rare disease.

Sincerely,

[SIGNATURE]

[NAME OF PRESIDENT OF NA]