

WE HAVE
**#30 MILLION
REASONS**

FOR EUROPEAN

ACTION

ON RARE DISEASES



ASK YOUR MEP TO BECOME A MEMBER OF THE NETWORK OF PARLIAMENTARY ADVOCATES FOR **RARE DISEASES**

EURORDIS-Rare Diseases Europe has created a [network of members of the European and national parliaments](#) who can help support us in the European Parliament, by raising awareness, participating in debates, and by applying political pressure on the other European institutions.

By growing this network we can ensure we have even more support to improve the lives of people living with a rare disease in Europe.

Ask your MEP to join!

Your MEP is elected to represent you at a European level. We have drafted a letter that can be used to invite your MEP to join the network of Parliamentary Advocates for Rare Diseases.

Five steps to asking your MEP to join the network of Parliamentary Advocates for Rare Diseases:

- 1. Identify your MEP, or MEPs in your country to join the network, by [searching here](#).** There may be more than one. Bear in mind that those who are part of Committee on the Environment, Public Health and Food Safety (ENVI) may have more of an interest in health!
- 2. Copy and paste** the below email into your own email or letter template. Just make sure to add your details to the sections in pink!
- 3. Add any additional details.** Your MEP might be interested in knowing more about your organisation, or disease area. Are there any issues you are interested in in particular? Or are you working with a hospital in their hometown? Feel free to add but be concise!
- 4. Send the email!** You can find the contact details for the MEP on their webpage.
- 5. Let us know!** We would love to know if you have invited them, so please email kostas.aligiannis@eurordis.org, or put him in copy.





Dear [MEP NAME]

I am writing to you [as your constituent/on behalf of my patient organisation, {insert name}], to ask you to become a member of the Parliamentary Network of Advocates on rare diseases.

There are 30 million people living with a rare disease in Europe. Yet no country can tackle the challenges of rare diseases alone. Their future depends on policy makers taking European action now.

The network of Parliamentary Advocates for Rare Diseases will help tackle challenges faced by the rare disease community by fostering cross-border EU collaboration.

Through the network of Parliamentary Advocates for Rare Diseases, EURORDIS-Rare Diseases Europe aims to bring together members of the European and national parliaments to ensure strong international and local action, shape political input for current and future legislation and integrate rare diseases into all relevant policies at all levels. There are several [current and upcoming opportunities](#) where we can continue to raise our points.

In particular, the Parliamentary Advocates will play a crucial in the [#30millionreasons campaign](#), calling for an EU Action Plan on rare diseases to improve the lives of the 30 million people living with a rare disease in Europe by 2030.

This is based on the Rare 2030 Foresight Study, spearheaded by the European Parliament, which concluded by setting out eight overarching recommendations as a roadmap for the next decade of rare disease policies. It's main call was for a coordinated European framework on rare diseases. You can help us by supporting our call and helping to shape the next decade of rare disease policies through questions and direct communication with the other institutions.

I hope you will consider joining the network to raise rare diseases on my behalf in the European Parliament. To join, please contact the secretariat, [Kostas Aligannis](#), to join the group. You can also [read the brochure](#) on the network of Parliamentary Advocates for Rare Diseases to find out more.

[Anything else you want to add?]

We would be happy to meet with you to tell you more about what you can do for people living with a rare disease like me. I look forward to hearing from you.

Best wishes,

[Your name]

[Your organisation]

[Your address]

