

17 March 2020



Dear Members, Volunteers, Partners, Friends,

On behalf of EURORDIS-Rare Diseases Europe, we would like to express support for those individuals and families already directly affected by COVID-19 around the world. We stand in solidarity with everyone affected by the pandemic. Our thoughts are with all vulnerable populations, people with underlying health conditions and weak immune systems, the elderly, and every other affected community.

We are conscious of the stress the pandemic is causing on people living with a rare disease, your families and your organisations. Protective measures and containment may make it more difficult for you to go to hospital appointments or get medicines at the pharmacy, may disrupt the organisation of the specialised healthcare services or generate medicine shortages, may hinder some clinical trials or result in more difficulties that we cannot yet anticipate.

We will continue to closely follow developments in the situation, particularly those that have specific implications for the rare disease community (such as disruptions in supply of medicines and medical devices) and to liaise with ERN coordinators in order to identify issues which will require special attention.

The commitment of healthcare professionals and pharmacists is an inspiration, bravely fighting the virus on the frontline whilst still often caring for their other patients with chronic conditions.

To prevent the spread of the virus and in support of healthcare professionals, we encourage you to follow the guidelines given by the [World Health Organization](#) and your [national authorities](#).

In the face of isolation and uncertainty, now is the time to pick up the phone, make a video call and stay in touch with each other. We are here for you. Don't hesitate to contact a member of the [EURORDIS team](#) by email or to set up a video conference call online. Mutual support is key.

The experience of rare diseases is one of resilience and agility. The rare disease community has emerged with, and built its strength on new information technologies, the Internet and digital networking. We lean on the solidarity of this community, which has existed for decades across borders, to come together virtually to comfort each other and move forward with our work. Follow us on [Twitter](#), [LinkedIn](#), [Facebook](#) and [Instagram](#).

The safety of our staff, volunteers and Board of Directors is paramount. Our staff is now working from home in Belgium, France, Germany, Serbia, Spain, Switzerland and the UK, as we continue to adapt our working methods and activities for the next weeks and months. Their determination is key and we thank all colleagues for their dedication in this unprecedented situation.

We continue to adapt our events to the current situation. Last week, the EURORDIS Winter School took place online instead of in Paris. And the decision has been taken to [move the European Conference on Rare Diseases & Orphan Products 2020 online](#) in May. The health and safety of all stakeholders participating in ECRD is our primary concern. We look forward to seeing those of you who had already registered on the new online platform, and hope those of you who were previously unable to attend will now join us online.

In solidarity,

Yann Le Cam

Chief Executive Officer

Terkel Andersen

President of the Board of Directors



Official sources of information

With the fast-evolving situation surrounding COVID-19 in Europe and across the world, members of the rare disease community may be concerned about their health. Please find below links to official information sources that are updated regularly. We also advise that you refer to information published by your own national health authorities/ ministries.

- [World Health Organization](#)
- [European Centre for Disease Control](#)
 - [National information resources for the public on COVID-19](#)
 - [US Centers for Disease Control and Prevention.](#)