

## Fabry International Network open letter to Fabry Expert Centres:

FIN praises the action, efforts and dedication of all health and social care professionals, as well as policy makers at EU, national and regional levels, who are facing difficult decisions.

Through this open letter, we implore policy makers and authorities in Europe and around the world to take action to protect people living with Fabry Disease from becoming even more vulnerable during this crisis in line with the recommendations set out further below.

We want to highlight the need for continuous care and monitoring for Fabry disease patients and remind them of the actions needed for newly diagnosed patients, those in the midst of the diagnostic process or those experiencing symptoms for the first time and needing assessment. We also want to emphasise the need for ongoing clear and consistent communication from the centres about patients' care and having regular appointments (in-person or telehealth).

We would therefore like to bring to their urgent attention the concerns and needs of people living with Fabry disease, their families and carers during the current situation.

Why is it important for Fabry patients to have continuous access to care?

- There is an urgent need to safeguard the continuity of care and access to medical consultation for people living with Fabry disease.
  - Comprehensive and timely treatment of adult patients with Fabry disease is important in the prevention of further progression to irreversible tissue damage and organ failure.
- To diagnose patients experiencing symptoms of Fabry disease, healthcare professionals need access to baseline testing to enable a quick diagnosis so that patients can receive the healthcare they need. During the pandemic, the access to these baseline tests has been disrupted significantly and should be reviewed by the healthcare authorities.
- Studies have shown that up to two-thirds of people with Fabry disease experience depression; to avoid further anxiety and impact on the mental health of Fabry disease patients, there is a need for clear and regular communications from the Fabry expert centres about their Fabry disease care and appointment.

We want to refer to the EURORDIS rare barometer survey results and EURORDIS open letter to policy makers: Recommendations to protect people living with a rare disease during the COVID-19 pandemic

- COVID-19 caused a severe disruption to care for people living with a rare disease. 83% of rare disease patients' care was disrupted and of those who experienced a disruption to care, 7 in 10 had appointments cancelled or postponed.
- Appointments for medical imaging and for other screening tests are being postponed or cancelled due to the lack of medical personnel or the need to use the laboratory facilities for the testing of COVID-19 samples
  - Screening techniques such as medical imaging and laboratory tests can lead to the diagnosis of a rare disease. Not performing them in a timely fashion can be detrimental to the health of those who are yet undiagnosed or those who are affected by a degenerative disease as they are put at risk of severe progression of their disease if it is overlooked.

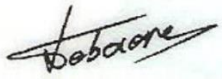
As a reference we want to share the outcome WHO's pulse survey on continuity of essential health services during the COVID-19 pandemic.

- The World Health Organisation's pulse survey on continuity of essential health services during the COVID-19 pandemic indicates that the pandemic is testing all national health systems, with an impact on essential health service delivery and utilisation in almost every country in the five WHO regions surveyed. The extent of the impact at the population level is generally partial (5–50%), but large enough to affect availability of and access to high-quality services for the most vulnerable populations in every society.

We strongly feel that every patients has the universal right to have a say and be involved in the decision making regarding his/her therapy.

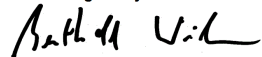
The effect of COVID-19 on healthcare and social systems is immense, and directly impacts the care that people living with Fabry disease receive during this stressful time, as well as their socio-economic status, education and employment.

On behalf of the Fabry Community,  
The Board of Fabry International Network

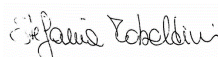



Lut De Baere, President FIN

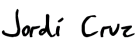
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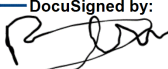
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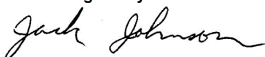
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Associazione Italiana Anderson-Fabry

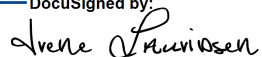
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