

EURORDIS-Rare Diseases Europe

Job vacancy – EURORDIS Ukraine Response Programme Co-ordinator

Responsible to: Chief Operating Officer

Contract type: CDD/service agreement (TBD) – 8 months starting from 1 May 2023, part time or full time (TBD)

Salary: TBD depending on location and the candidate's qualification

Location: TBD (the ideal candidate should work from Ukraine or Poland, but EURORDIS is open to consider candidates in other locations with potential relocation to our offices in Paris or Brussels or working remotely)

Start date: April/May 2023

About EURORDIS-Rare Diseases Europe

EURORDIS is a unique, non-profit alliance of over 1000 rare disease patient organisations from over 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.



Scope of the programme

EURORDIS' response is two-fold: both immediately responding to the needs of Ukrainians leaving with a rare disease (ULWRD) and advocating on behalf of their specific needs with the support of our multistakeholder networks.

EURORDIS activities are fast evolving and subject to change as our understanding of needs evolve. Current initiatives include:

1. Work with local patient groups and partners, in particular to support ULWRD to relocate or leave the country
2. Support ULWRD when arriving as refugees in neighbouring countries and relocating across the EU, through patient networks and partners catalysing new solidarities
3. Inform European, EU-national and Ukrainian authorities of the specific challenges facing ULWRD and advocate for them to address these issues
4. Liaise with humanitarian organisations to both help solve specific requests for help and to advocate more broadly that they integrate ULWRDs in their response to the crisis

To learn more about EURORDIS' Ukraine Response, please visit our [dedicated web page](#).

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Main scope of the position

The Ukraine Response Programme Co-ordinator will be a self-motivated, highly organised and resourceful person with experience in management and awareness of rare disease. The ideal candidate should have substantial experience with crisis response and rare diseases. The candidate must speak excellent English and Ukrainian. Polish would be a additional benefit.

This postholder will serve as a focal point to co-ordinate and drive our activity in response to the war in Ukraine. The postholder works closely with the Chief Operating Officer, who is the overall lead for our response, as well as other relevant EURORDIS team members, including advocacy, communications fundraising and operational links to external stakeholders and with EURORDIS' Public Affairs team.

The Programme Co-ordinator takes day-to-day responsibility for the operational components of our response and makes a link into our advocacy and communications teams. S/he helps us to refine our priorities and activities based on need, as well as determine new directions in which the programme may develop.

Key tasks & responsibilities

- Maintain and further develop relationship with Ukrainian patient organisations, clinicians, the Ministry of Health of Ukraine, the Rare Disease Hub and other relevant actors on the ground to make sure their voices are heard, and needs are taken into account by EURORDIS and other stakeholders
- Further coordinate EURORDIS' partnership in Poland ("Razem z Ukrainą"), including but not limited to – organize monthly coordination meetings, process reimbursement claims, be in touch with the project partners upon their request and prepare the project's closing event, final report and oversee the project audit
- Do day-to-day administration of different components of our Ukraine response, which includes drafting grant/partnership agreements with new partners or following-up on those already concluded; ensure that necessary reporting is collected from the partners and appropriately stored; process payments or consider requests for support from existing or new partners.
- Further develop relationship with patient organisations in the neighbouring countries to Ukraine and collect their testimonies. If the programme continues it may evolve to include engagement and co-ordination work of our work in the broader region
- Lead on the compilation of information resources that support ULWRD and the patient organisations that support them. This includes:
 - Conduct outreach to other organisations or individuals that are developing information resources, including ERNs, other patient organisations, clinicians, or public institutions
 - Do research online or by phone to update our understanding of the realities on the ground as they evolve
 - Curate our online Ukraine resource centre, from the perspective of families from Ukraine LWRD needing information to help access help or make decisions about where to go
 - Collect, write up and publish 'testimonials', articles or reports which help all stakeholders to understand the nature of the issues being faced
- Help us establish a cadence for updating stakeholders, including statements, webinars for patient organisations and companies, and other stakeholders. Work with the various EURORDIS teams to make sure these meetings are scheduled and help prepare the content so we're facilitating the flow of information.
- Develop relationships with key actors in our network to connect opportunities with need.

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- Link with EURORDIS' Public Affairs team, Communication team or other relevant team members to help define advocacy messages, gain visibility for our Ukraine response and especially to ensure actions are followed through
- Help problem-solve and case manage difficult responses
- Time allowing, help us understand how to better respond to future crises

Experience & skills

Required

- Minimum Bachelor's degree
- Fluency in English with excellent written and oral communication skills is a must (excelling in persuasive and influential writing)
- Good level in Ukrainian; other European languages especially Polish a plus.
- 5 years' professional experience in project management or emergency response (within the health and NGO sector a plus).
- Autonomous, proactive and highly driven. Comfortable working with ambiguity and with changing priorities.
- High personal resilience-able to cope with highly distressing situations outside of our control
- Sensitive to working for a cause and with genuine interest in understanding the challenges of people living with a rare disease and their families.
- Enthusiastic and flexible team player with skills including: managing meetings, presenting, reporting to management, co-creating with partners, organisational and time management abilities
- Ability to work with several operational team members and patient organisation partners with varying backgrounds and levels of English understanding.
- Proficiency in Microsoft office

Desirable

- Professional experience within the health and NGO sector a plus
- A good understanding of the European rare disease landscape is highly desirable
- Experience in community and public engagement, engaging participation of multiple partners and actors

To apply

Please send your CV and cover letter in English to ukraine@eurordis.org

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