

Press release

EURORDIS and Airbnb.org team up to support people living with a rare disease fleeing the war in Ukraine

11 April, Paris - EURORDIS-Rare Diseases Europe and Airbnb.org are working together to offer people with rare diseases and their families fleeing Ukraine with temporary housing outside the country to aid them during this time of need.

Many of the estimated 2 million Ukrainians who live with a rare disease have already fled their homes in search of a safe haven. To ease the challenges faced by the patient rare disease community, Airbnb.org is offering free accommodation abroad to people with rare diseases and their carers fleeing Ukraine – as part of Airbnb.org’s larger effort to [offer housing to up to 100,000 refugees fleeing Ukraine](#).

“This partnership will provide real value for people with rare diseases who were living in Ukraine and who were displaced by the war. Very often people living with a rare condition need extra care and support. Many don’t feel safe in their homes in Ukraine but are afraid to leave because they don’t know what awaits them on the other side of the border. Many others have left their homes and are currently displaced in inappropriate emergency housing. We hope this initiative will give hundreds of vulnerable families breathing space to focus on themselves.” – **Michael Wilbur, EURORDIS Chief Operating Officer**.

Across Europe, EURORDIS plays a key role in raising attention to and catalysing support for the 30 million people living with a rare disease. Today, in the face of renewed tensions in Europe, it is our shared responsibility to ensure that no Ukrainian citizen living with a rare disease, whose conditions are often debilitating or need frequent and complex medical attention, is left behind. This starts with a safe place to stay and a community to be supported by, before preparing medium- and long-term actions.

“Airbnb.org is proud to collaborate with EURORDIS to offer patients and their families free, temporary housing as they flee Ukraine. We believe that welcoming someone to a home is one of the best ways to welcome them to a new community, and we hope that this offering will extend some hope and comfort to the rare disease community in Ukraine during an unimaginable time.” – **Katherine Woo, Executive Director of Airbnb.org**.

Since the outset of the conflict, patient organisations have been playing a strong role to support this vulnerable community. Patient organisations for Spinal Muscular Atrophy, Duchenne, Prader Willi syndrome, Cystic Fibrosis, Epidermolysis Bullosa, Myeloma, Melanoma, and Hemophilia have already helped hundreds of families. We also would like to recognise the efforts of National Alliances, disease-specific European Federations, respite care centres and individual member organisations who have reached out to their networks.

EURORDIS has been fully mobilised from day one of this crisis, to help people with rare diseases in Ukraine and those fleeing the country during these difficult times. In particular, we have set up an [online resource centre](#) for patients and patient organisations trying to help in and around Ukraine.

Airbnb.org is a nonprofit organization dedicated to facilitating temporary stays for people in times of crisis around the world. The inspiration for Airbnb.org began in 2012 with a single host named Shell who opened up her home to people impacted by Hurricane Sandy. This sparked a movement and marked the beginning of a program that allows Hosts on Airbnb to provide stays for people in times of need. Since then, the program has evolved to focus on emergency response and to help provide stays to evacuees, relief workers, refugees, asylum seekers, and frontline workers fighting the spread of COVID-19, including those affected by the devastating

floods across Western Europe. Over the past five years, Airbnb and Airbnb.org have connected more than 54,000 refugees and asylum seekers – including from Syria, Venezuela and Afghanistan – to temporary housing through Airbnb.org partners. Airbnb.org is a separate and independent entity from Airbnb, Inc., and Airbnb, Inc. does not charge service fees for Airbnb.org supported stays on its platform.

People with rare diseases fleeing Ukraine in need of temporary housing can go to eurordis.org/ukraineresources/rarebnb.

Anyone who is interested in supporting Airbnb.org's initiative to help refugees fleeing Ukraine can go to airbnb.org/help-ukraine to get involved, including by offering free or discounted stays to refugees or donating.

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 995 rare disease patient organisations from 74 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. Follow [@eurordis](https://twitter.com/eurordis) or see the [EURORDIS Facebook page](https://www.facebook.com/eurordis). For more information, visit eurordis.org.

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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