

Pulmonary Hypertension Ukrainian Rare Disease Association (PHURDA)

Annual activity report 2022

Humanitarian assistance

PHURDA started active work 24/7 to support PH patients in the times of war. We provided patients with needed medicines as government purchase and delivery was stopped. We made contacts with foreign organizations to help PH patients to go abroad and get medical care there. We managed to organize logistics for patients fleeing the war. Poland, Italy, Norway, France and some other countries accepted our patients.

Thanks to the cooperation between PHURDA and Italian organization AVIS Nazionale (Associazione Volontari Italiani Sangue OdV) we managed to settle several PH patients in Italy to get proper medical care and treatment. Also, AVIS Nazionale sent PHURDA humanitarian aid with medicines and medical equipment for PH patients who stayed in Ukraine.

We handed over humanitarian aid kits with medicines, medical equipment (pulse oximeters, tonometers, oxygen concentrators, nebulizers, thermometers etc), food sets and hygiene products, everything that is necessary for a person to survive in wartime. It has become possible due to humanitarian aid from PVRI, AVIS Nazionale, Adam Torbicki, Adrian Goretzki, Polish doctors Ewa Lewicka and Ewa Mroczek together with Lions Club Poland and Lions Danmark, the Netherlands for Ukraine Foundation, the "Anna-Maria" Foundation, the Help Center "Social Pantry", St. Jude Thaddeus Foundation, Knights of Columbus, Kamelchuk Family Foundation, CF "ZDOROVY", CF "Patients of Ukraine", Morten Aakre and shopping mall "Amfi" in Egersund, Norway.

Colombian and Greek PH associations supported us with the humanitarian aid with medicines.

We managed to provide also financial support to PH patients and to doctors. We as well provided humanitarian aid to Ukrainian soldiers.

Legal & psychological support

With the support of PHA Europe and EURORDIS we organized lines for legal and psychological support for PH patients. We organized temporary shelter. Since May we have been holding online meetings with PH patients where we discuss different topics that are interesting for them, e.g. "Problems and opportunities for PH patients during the war in Ukraine", "Question and answer session for PH patients", "Current information from the latest world conferences 2022. Opportunities for patients during the war", "Psychological support sessions", "Motherhood and PAH", "New European recommendations on PH: what to pay attention to", "How to survive during the war..."

Participation in conferences and meetings

- Our collaboration with EURORDIS seemed very important and fruitful. We are extremely pleased to be part of this working group to support PH patients in critical situations. We participated in EURORDIS zoom meeting on "How to best help people living with rare diseases in the Ukraine or seeking refuge, to coordinate efforts and be most effective" and ECRD 2022 where one of the sessions was dedicated to Ukraine.
- President of PHURDA Oksana Kulish participated in PHA Conference in Atlanta. We made invaluable contacts and global support there.

- On June 2-3 in Lviv, Ukraine PHURDA and CF "Sister Dalila" took part in a meeting with EURORDIS representatives and other Ukrainian patient organizations and the Ministry of Health of Ukraine.
- At ELF Networking Day 2022 we shared our experience in physical and psychological rehab.
- During ERS Congress we participated in the session that was dedicated to Ukraine. We got the honor to talk about the challenges that our PH patients face and ways of solutions. Dr. Joanna Chorostowska-Wynimko made extraordinary efforts to highlight the issue of Ukraine

Active projects:

- Fundraising campaign “Cork for Life”,
- Help line, Legal assistance services etc.
- St Nicolas Day celebration: children have got presents: power banks, flashlights and other non-children's items

Achievements

PHURDA was awarded with a diploma of the "Charity Ukraine" Contest for the implementation of the "O2Kids" Project.