



# NGO “All-Ukrainian Association of care of patients with cystic fibrosis”

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To all CF association

Dear Sirs,

NGO “All-Ukrainian Association of care of patients with cystic fibrosis”

Today, the whole world had to talk about the day of the orphan patients, and then talk about the war in Ukraine. So it's true. At the moment in our country there is a brutal war, the aggressor country does not spare anyone. Constant threat from the sky, prohibited weapons and indifference to civilians.

We, as a patient community with 995 patients with rare orphan disease, ask you to help Ukrainian patients.

Currently, they are in very difficult conditions, living in bomb shelters without the ability to do inhalations, and those who are on oxygen, not all have oxygen concentrators. We do not have the opportunity to undergo all the necessary procedures on time, in most cases, the basic drugs end: creon, ursofalk, antibiotics and more.

Please:

1. Send this letter to all CF Association you know.
2. Maybe our partners have the opportunity to support children and adults with cystic fibrosis in Ukraine? The main things that we need : Portable inhalers and portable oxygen concentrators (for those who are oxygen dependent) Drugs: enzymes, antibiotics, vitamins, Ursofalk, sodium chlorine 3% , 6%,7%. We will be infinitely grateful for any help, that will help our patients hold out until better times. And we are currently doing everything possible to get the supply of medicines in Ukraine.
3. Urgently on March 2 at 10.00 Ukrainian time, to find an opportunity to hold a meeting of the heads of all CF associations of the world. This is a time that Ukraine is more or less quiet and we can get zoom meeting.
4. Find an interpreter to communicate.

We hug you! We are strong, victory is behind us!!!

Thank you all!

President of NGO “All-Ukrainian Association of care of patients with cystic fibrosis”

Larysa Voloshyna

