



CHARITABLE FOUNDATION «ORPHANNI SYNYTSI»

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Executive Director
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CHARITABLE FOUNDATION «ORPHANNI SYNITSY»



Donees –
patients with rare (orphan) diseases,
80% of which are children

FOUNDERS –
parents of children with rare diagnoses, activists of non-government public unions and organizations (members of Eurordis) that defend the rights of people with orphan diseases in Ukraine to a high-quality life and access to treatment:

- Association “Orphan Diseases of Ukraine”
fb.com/orphandisua

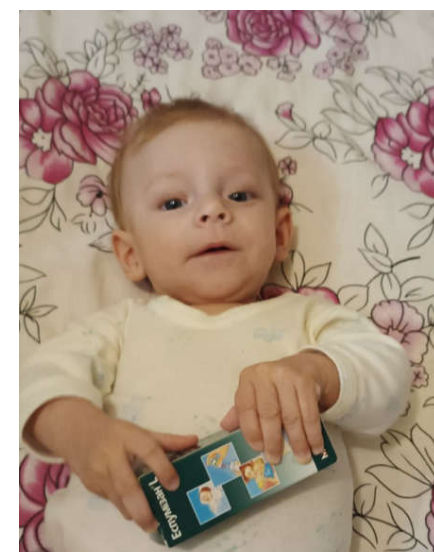
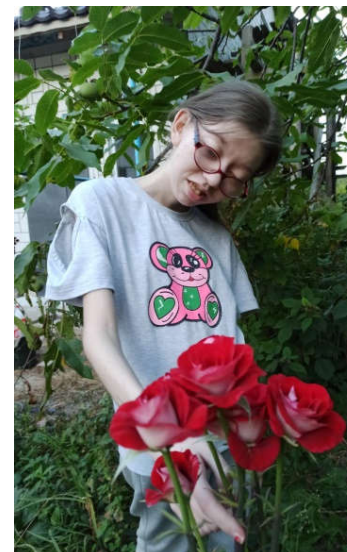
- International NGO “Dermatologists for Children” Debra-Ukraine fb.com/DebraUkraine

- NGO “Ukrainian Association of Help for People with Cystic Fibrosis” fb.com/cysticfibrosisua

- NGO “Association of Patients with Pulmonary Hypertension” fb.com/pha.org.ua

RARE (ORPHAN) DISEASES occur less than **1 case** per **2000** population, are life-threatening or causing disabilities, incurable, require expensive long-life treatment and comprehensive support from the State, socially responsible business and society:

- ✓ **3,5–5,9%** – people all over the world have rare diseases;
- ✓ **256** rare diseases are officially registered in Ukraine;
- ✓ **80%** of all rare diseases are genetically determined, have a severe and chronic course;
- ✓ **2-4** years are to establish a rare diagnosis;
- ✓ **30%** of children – patients with rare diseases in Ukraine do not live to the age of 5 years (mainly due to the lack of implementation at the State level of the comprehensive system of diagnosing, preventing, effective treatment, medical and social care for patients with rare diseases).





MISSION:

- supporting people living with rare (orphan) diseases in Ukraine;

STRATEGY:

enhancing the quality of life of people with rare diseases in Ukraine. This means that patients live long, reach retirement age, have children of their own, work and benefit the State, and are fully valid members of society;

MAIN GOALS:

drawing the attention of socially responsible business to the problems of people with rare diseases, raising public awareness about rare diseases and patients needs;

providing information, legal aid and psychological assistance to patients with rare diseases and their families through the "**Hot Line**";

implementation of systemic projects to ensure the crucial needs of patients in medications, medical devices, nutrition, special medical equipment, diagnostics and rehabilitation in case these needs are not covered at the expense of the State and / or local budgets.



COOPERATION

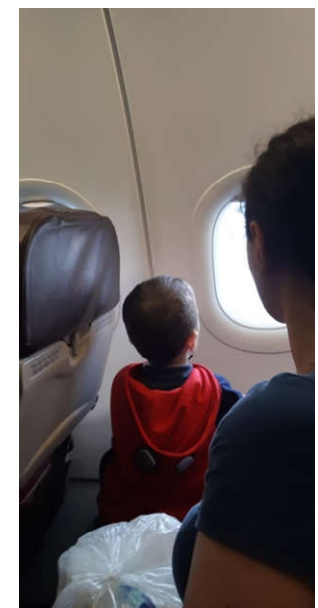


The founders of the Foundation have been actively cooperating not only with public unions and organizations, but also with government agencies - the Ministry of Health of Ukraine, regional health departments, hospitals, uniting the efforts of medical experts to provide highly specialized medical care to patients with rare diseases.



Main activities in the wartime

- ✓ Assistance to rare disease patients in treatment (providing their critical needs in medicines, medical nutrition, medicinal products, and medical equipment/devices);
- ✓ Supporting undiagnosed patients living with lasting severe disorders (mainly children) by covering genetic testing expenses;
- ✓ Support for Ukrainian hospitals and specialized centers that provides specialized medical care for rare disease patients;
- ✓ Assistance to rare disease patients/families in relocation within Ukraine and abroad for safety and continuing treatment (covering traveling expenses, temporary housing and related humanitarian needs).



Charitable and humanitarian projects of CF "Orphanni Synytsi" in the wartime Feb 2022 – Dec 2023:



- ✓ supporting **8 Ukrainian non-governmental patient organizations** in their humanitarian projects of help for rare disease patients with *epidermolysis bullosa*, *cystic fibrosis*, *pulmonary hypertension*, *phenylketonuria*, *spinal muscular atrophy*, *Duchenne* and other severe diseases, and their assistance to hospitals, statutory activities, for a total amount **USD 146,560**.
- ✓ supporting **the National Children`s Specialized Hospital “Ohmatdyt”** and **Kyiv Regional Children's Hospital** (medical equipment and repair works) for a total of **USD 26,660**.
- ✓ compensating **relocation** expenses and temporary **housing** for 9 replaced patients/families for a total amount **USD 5,584**.
- ✓ payment for **genetic testing** in foreign laboratories (which is not available in Ukraine) for 50 vulnerable patients: 45 children and 5 adults with undiagnosed diseases for a total amount of **USD 44,979**.
- ✓ providing 60 rare disease patients with **medicines, medical nutrition, rehabilitation**, expensive **medical devices and equipment**, and other critical **humanitarian needs** for a total amount of **USD 38,284**.
- ✓ The **medical** equipment purchased by the Foundation: 7 oxygen concentrators, 9 mini portable oxygen concentrators, 4 aspirators, 1 lung ventilator NIVL, 1 infusion pump, 1 inhalation equipment, 1 wheelchair, 1 neonatal pulse oximeter, 2 neonatal ventilator masks.



Opened for the partnership the “International Rare Disease Day” annual project



«Rare is many! Rare is strong!» This is the global slogan of the International Day of Rare Diseases which is held annually on the last day of February. The month of awareness about rare diseases starts annually in Ukraine on February 1st, together with the whole world.

The Day of Rare Diseases aims to strengthen the voice of patients with rare diseases. That's about 30 million people in Europe and more than 300 million people worldwide. It's important to talk as much as possible about those who usually go unnoticed. Therefore, we encourage everyone to join!





Partnership in charitable projects



CF "Orphanni Synytsi" is always open to dialogue and partnership! Offering to become a Partner of our charitable projects, we are ready to agree on terms of the partnership: financial and/or non-financial assistance, social, media or technical support. We undertake to provide regular and transparent reporting.

Thanks to our partners - GlobalGiving and Global Genes - CF "Orphanni Synytsi", together with "Orphan Diseases of Ukraine" and rare disease patients' organizations, we implemented and continue to implement a number of charitable and humanitarian projects to support rare disease patients in Ukraine and the world.

