Inspiration Family Cancer Foundation

Foundation for support of adult cancer patients

Annual report 2022

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A letter from Anna Uzlova, director of the Adult Cancer Support Fund

> Despite the threat of a full-scale Russian invasion, we expected 2022 to be a year of positive change for the field of adult oncology.

On February 4, the fourth Cancer Patient Forum was held, where we talked about the development of the care delivery system and how the pandemic affected cancer treatment. We discussed the National Cancer Control Strategy and how managed access agreements will allow patients to receive expensive medicines at the state's expense. But on February 24, an enemy invaded and upturned life in the entire country, destroying homes, shelling hospitals and torturing people. An enemy that kills not only with bullets, but also by preventing access to medicine and medical care.

The year 2022 promised us great changes, but we could not imagine how painful they would be.

Since the first day of the war, the foundation's team has been in contact with patients to help find answers to hundreds of questions. Closed pharmacies, laboratories and hospitals, blocked roads and fear of what will happen tomorrow. After all, we had to fight against two enemies: external and internal.

This year we worked without days off, vacations and sometimes sleep: from storage rooms, basements and corridors, without electricity and communication, but with light in our hearts. Thanks to the support of volunteers, among whom were oncologists, translators, copywriters, managers and journalists, we provided operational information about the work of cancer centers and the availability of drugs. Our team has grown: patient managers and consultants Nataliya Sytnikova and Nataliya Yershova have joined us.

We continue to participate in the creation of systemic changes in the field of adult oncology, because we understand that the cancer care system needs to be restored and developed now. We believe in victory and thank everyone who is with us.

Systemic changes in the field of adult oncology

Cancer patients' forum

A major breakthrough for oncology, the Forum of Oncology Patients is a platform for interaction between patients, doctors, and large organizations.

It is in operation until the World Day of Fighting Cancer on February 4.

oncoforum.com.ua

The Forum provides information about:

- government policy regarding cancer
- innovations in cancer treatment
- availability of free treatment and services
- preservation of patients' quality of life

Systemic changes in the field of adult oncology

Forum of cancer patients

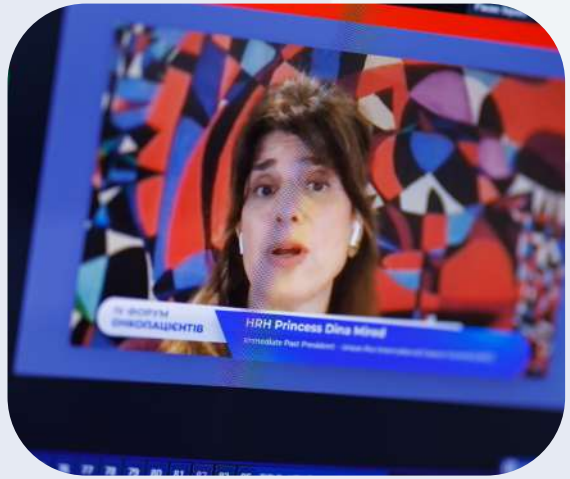
- **38 speakers.**
- **7 lively panel discussions** between patient organizations, doctors, Ministry of Health, NHSHU, State Medical Procurement, regarding the development strategy of cancer service in Ukraine, access to medicines, the impact of the COVID-19 pandemic on cancer treatment, and preserving the quality of life and dignity of cancer patients.
- **Lectures by leading experts** on personalized medicine, innovations in cancer treatment and mental health.
- In the final part, the audience heard patents' and doctors' inspiring stories.

Systemic changes in the field of adult oncology

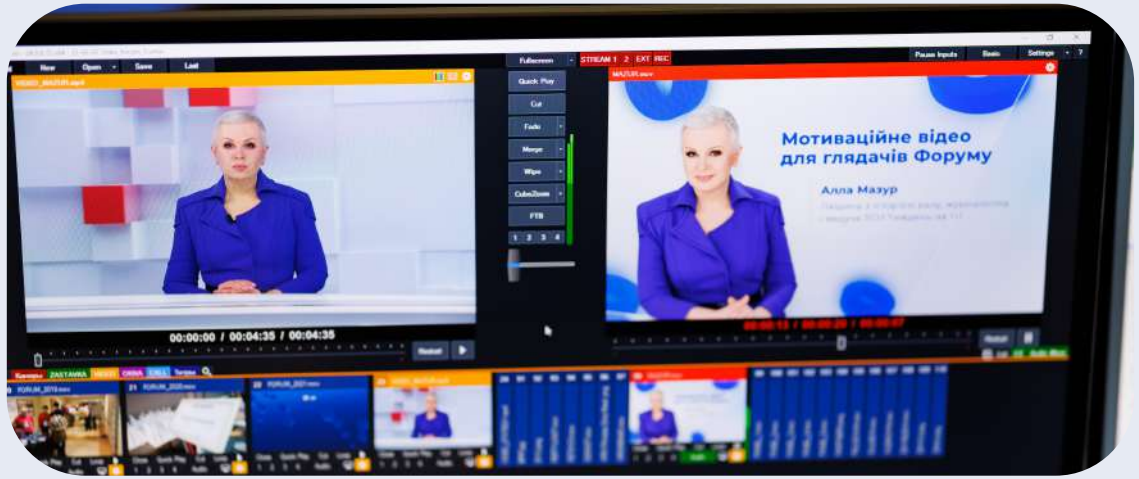
Forum of cancer patients

- **Important speakers:**

  The Forum was opened by Her Royal Highness Princess Dina Mired of Jordan, Past President of UICC - Union for International Cancer Control, Patron of the International Society of Pediatric Oncology, Member of the WHO expert group on the elimination of cervical cancer.



- **Alla Mazur, a journalist and presenter of TSN on the 1+1 TV channel**, gave a talk for the IV Cancer Patients Forum. Despite the stereotypes associated with cancer and her celebrity status, she announced her diagnosis.



Help in numbers

791 Patients received help in the form of medicines and care products.

1742 Total number of processed requests.

1389+ Consultations on patients' rights, free services and medicines, obtaining a second opinion.

353+ Consultations on treatment abroad.

182+ Cancer patients continue treatment in Europe.

85 Patients received translations of medical documents in English and German to continue treatment.

Unexpected requests: we were contacted by the "Okhmatdit" NDSL, which is now able to treat adult patients as well. We were asked to help two of the hospital's patients with dental treatment before a bone marrow transplant, because mouth infections can cause serious complications. We are grateful to Oleksandr Obabko's dental clinic for helping our patients who have already undergone a bone marrow transplant.

Medical evacuation of cancer patients

We have been in contact with our European colleagues at Youth Cancer Europe since the first days of the full-scale invasion. By joining forces, we helped more than 120 patients to continue their treatment in Poland, Romania, Germany and other countries.

Thanks to the cooperation with Netherlands for Ukraine, 28 cancer patients and their families found shelter and treatment in the Netherlands.

Think Pink Europe and OmeaLife helped Ukrainian breast cancer patients to continue treatment in Poland.

Currently, in cooperation with the Ministry of Health, we are sending Ukrainian patients to European countries for continued treatment not available in Ukraine.

Medical evacuation of cancer patients photo gallery

The story of Hanna Ilchenko

Hanna lives in the Kharkiv region, one of the places most affected by Russian aggression. Her village is located just two kilometers from the border with Russia.

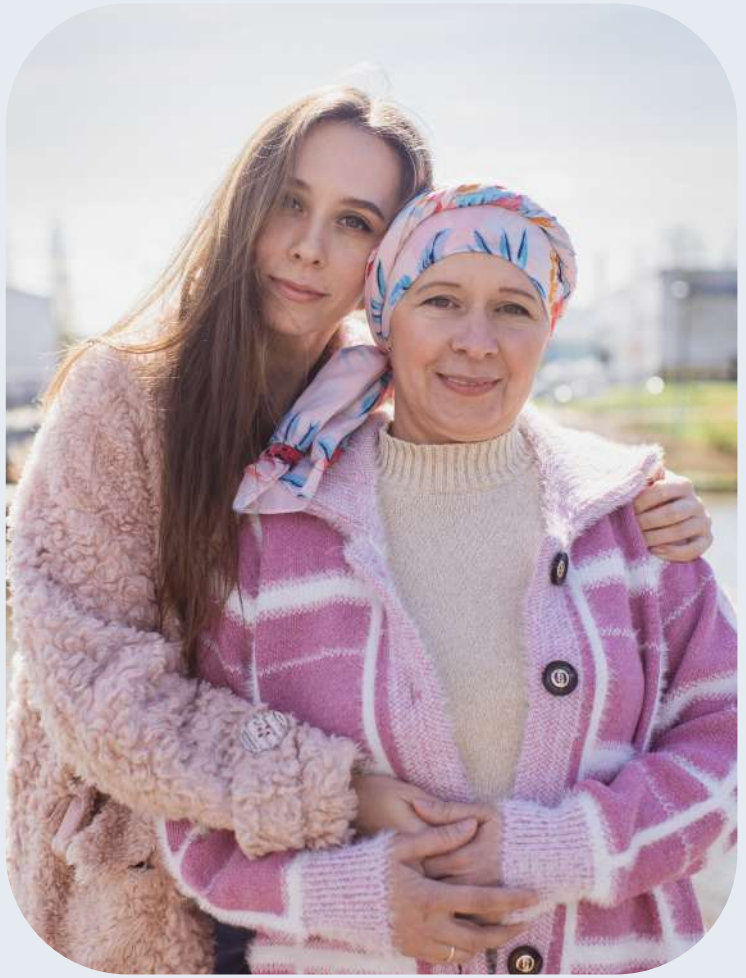
Together with her daughter, Hanna left for treatment in the Netherlands in April 2022, where she still resides. Hanna had an extremely complicated operation, and now she is receiving expensive treatment with a drug that is not available in Ukraine.

> "War and cancer are scary words," says Hanna. "It's especially scary when these words come together against you."

“I didn't know where to get treatment. In Kharkiv, they told me that they were constantly being shelled, and the professor who operated on me had left. Then my daughter called and said, ‘Mom, I found an organization on the Internet that provides treatment in Europe. Should I submit a questionnaire?’ ‘Do it,’ I said. I had just gone through a course of chemotherapy, the next one was forthcoming.

“When I learned that there was an opportunity to go abroad for treatment, I cried. The road to Transcarpathia was very difficult: we drove for 30 hours in a car, I don't know where we got the strength to go on. It's a miracle that I made it. In the Netherlands, it felt like I ended up in a fairy tale. Even if they don't save me, I didn't think I would ever see such a thing. All this beauty, and most importantly, such kindness.

“But I believe that I will explore this beautiful city, I will go sightseeing, see the cathedrals and churches, admire the tulips. I constantly think about how many of them I planted at home. I am very worried about how they will survive now."



Hanna Ilchenko went to the Netherlands for treatment thanks to the cooperation of the Inspiration Family and Netherlands for Ukraine foundations.

Watch a video on the foundation’s YouTube channel about Hanna's story.

Coordination headquarters

Two managers work in the headquarters to process appeals of cancer patients regarding treatment in Ukraine and abroad. Nataliya Sytnikova and Nataliya Yershova have a history of cancer treatment; even before the war they completed a training course within the framework of the "Equal Consultant" project, which was conducted by professional cancer psychologists. They have basic knowledge of psychological support for cancer patients.

Natalia Sytnikova

"Working as a coordinator requires a lot of attention and empathy towards the person asking for help, so the biggest difficulty for me in this job is that sometimes I get deeply affected by a patient's situation. It is especially difficult to find out that the person with whom you communicated and whom you tried to help has passed away, and therefore your help is no longer needed.

"However, I get a lot of joy from the realization that my work gives a person a chance for quality treatment and life; it inspires and gives me strength to continue to help people in a difficult and desperate situation."

Natalia Yershova

"I am inspired by patients' feedback, when we help them solve their problems: they get the necessary drugs for free and the opportunity to continue treatment abroad, they find 'their' doctor whom they can trust completely, they get a second expert opinion, high-quality pain relief or qualified psychological and legal assistance. It gives me wings! That is why the most difficult thing a coordinator's work is cases when all we can do for a person is simply to be there and provide psychological support."

Collection of funds for medicine

- Thanks to the funds collected on the Be kind, we were able to purchase 41 packages of Capecitabine.
- Despite the war, Ukraine still managed to join the largest international race in support of women with breast cancer, Race for the Cure, which brought together more than 170 participants from Ukraine, Poland, Spain, Germany, England, Israel and even the United States.
- For the second year in a row, we are holding the Rozhevten “Pink October” campaign.

We are delighted that more and more socially responsible businesses are joining us, such as Zhilyova lingerie, Huizit, Love Space, because this is not only about helping women with breast cancer, but also about caring for their clients. This is how brands raise awareness and remind the public about the importance of regular checkups.

We decided to combine the funds collected from the **Race for the Cure** and the **Rozhevten** campaign and purchase the drug **Letrozole**, which is prescribed for women with hormone-dependent breast cancer. Thus, we provided **431** patients with the necessary drug.

Humanitarian aid in cooperation with other organizations

Our Foundation Inspiration Family became a bridge between the charity organisation "Pride" and hospitals, so that patients with myelodysplastic syndrome, myeloid leukemia and juvenile myelomonocytic leukemia could receive the drug Azacitidine (Vidaza) free of charge. Luckily, because the Pride Foundation had a large amount of the drug, and we are in contact with all cancer centers in Ukraine, we were able to contact the following organizations.

- Cherkasy regional oncology dispensary – **1,000 vials**
- Ivano-Frankivsk Regional Clinical Hospital – **144 vials**
- • Dnipro City Clinical Hospital No. 4 – **144 vials**
- • Carpathian Clinical Oncology Center – **144 vials**
- • Feofania Clinical Hospital – **296 vials**

A total of **1728 vials** of the drug extended the quality of patients' life.

Humanitarian aid in cooperation with other organizations

As humanitarian aid, the Americare organization from the US gifted the Inspiration Family Foundation 46 free packages of "Tamoxifen" (20 mg).

Thus, **46 women received the necessary medication.**

There is no such thing as little help, and we are grateful to our colleagues for their trust. Help will always reach those in need!

International cooperation

An important component of our work was participation in discussions and conferences at the level of the international cancer community. Yes, we became participants of the **European cancer summit, UICC World cancer congress**, and **London cancer week** to make Ukrainian cancer patients visible and raise the issue of access to medicines. Also, as a member of the **ECO-ASCO Special Network on the Impact of the War in Ukraine on Cancer**, we regularly report on the current situation in Ukraine. With our assistance and thanks to the partnership with the **European cancer organization**, Ukraine is involved in the political cooperation network **National and European Parliamentarians for Cancer Action**, which was officially presented at the **European Cancer Summit 2022**. This project was created to strengthen political will and the connection between national and European initiatives against cancer, as well as increasing the drive to tackle cancer inequalities.

Online meetings and talks:

- 13 meetings of the ECO-ASCO Special Network on the Impact of the War in Ukraine on Cancer, at which we had the opportunity to report regularly on the current situation regarding the treatment of cancer during war, on the lack of drugs and other challenges faced by patients in the last year. The participants of the meetings were representatives of WHO, European and American patient communities, as well as doctors.
- 6 founding meetings with the European cancer organization (Belgium).
- 4 founding meetings with Youth Cancer Europe, regarding the continuation of treatment of Ukrainian cancer patients in Europe (Romania). From the first days of the full-scale invasion, thanks to our cooperation, we helped not only hundreds of patients to continue treatment in safe areas, but also drew public attention to the treatment of cancer in wartime. For example, Youth Cancer Europe set up a stand dedicated to this topic at the largest European oncology congress ESMO 2022 in Paris.
- 4 meetings of the Global Medical Knowledge Alliance (USA).
- 4 meetings with oncologists of Klinikum St.Georg Leipzig (Germany).
- 3 meetings with the co-founders of the Blue heron foundation (Moldova, USA).
- A talk at London cancer week, entitled "Cancer Care During War – Ukrainian Prospective.»
- The Youth Cancer Europe webinar “WAR AND CANCER” about the current situation regarding cancer treatment in Ukraine in the first 4 months of the full-scale invasion.

Offline talks and discussions:

- Participated in a panel discussion “Supporting Ukrainian Cancer Patients and Cancer Services: Immediate Needs and Longer-term Rebuilding” at the European Cancer Summit.
- Represented Ukraine among the 30 countries that held the Race for the Cure this year: shared the experience of organizing such an event in wartime and reported the results of the race at the annual meeting of representatives of Think Pink Europe.
- Met the board of directors of the UICC solidarity fund at the World cancer congress 2022 in Geneva for discussions.
- Attended the international conference “The Cancer Policy & Research Landscape in the meta-COVID Era.” The purpose of the trip was not only to learn about the international experience of protecting patients' rights, but also to talk about the war in Ukraine and the challenges faced by Ukrainian cancer patients.
- Made a working trip to establish cooperation with the Hadassah clinic (Israel), which resulted in the internship of Ukrainian doctors in the bone marrow transplant department.
- Met with the Ambassador Plenipotentiary of Ukraine in Israel, Yevhen Korniychuk, to outline the problems of cancer treatment in Ukraine and to enlist his support.

Internship of doctors in Israel

Thanks to our cooperation with the Hadassah clinic, Ukrainian doctors had the opportunity to undergo a three-month internship in the bone marrow transplant department under the guidance of Professor Polina Stepenski.

Shokun Nazar, an oncologist, wrote about his impressions:

"When you come to the Hadassah clinic, you realize how much needs to be done in the future and how much has already been done at the Cancer Institute. What I liked the most, in addition to the high level of security and professionalism, was the attitude towards patients. Everything is done to make the patient's stay in the clinic as comfortable as possible. A whole team of specialists, besides doctors, ensures bespoke patient care: psychologists, social workers, rehabilitators, staff of the "Pain Clinic". For us, this knowledge and support will become the foundation for the development of allogeneic transplantation next year and, in the future, for the development of CAR-T therapy in Ukraine."

Advocacy for cancer patients

We continue to participate in pushing for systemic changes in the field of adult oncology because we understand that the cancer care system needs to be restored and developed. For this purpose, our team joined the working group on improvement and development of cancer care at the Ministry of Health of Ukraine. Together with representatives of oncology medical institutions, the Ministry of Health, the National Health Service and patient organizations, we are working to improve the work of oncology service in wartime.

Further details:

- Working group on improving the development of cancer service at the Ministry of Health - **3 meetings**
- Working meetings of the National Health Service with patient organizations – **2 meetings**
- Regular meetings of the Supervisory Board of the National Cancer Institute – **5 meetings**
- Meetings of a group of experts on the development of project specifications and conditions for the purchase of medical services under the program of medical guarantees in the field of "Oncohematology" – **3 meetings**
- Meetings of a multidisciplinary working group (MWG) on the development of industry standards of medical care regarding Hemoblastosis – **3 meetings**
- Multidisciplinary working group (MWG) on the development of industry standards of medical care regarding Colorectal cancer – **3 meetings**

We make cancer understandable

We continued a series of cancer education webinars **"Making cancer understandable for patients with gastrointestinal cancer"** – pancreas, stomach and intestine. We provide up-to-date information in an accessible language about the causes, risk groups, diagnosis, the course of action and treatment of these diseases.

The course consists of 10 webinars, which we broadcast live on our **Youtube** channel and the Inspiration Family Facebook page. Recordings are freely available on our websites.

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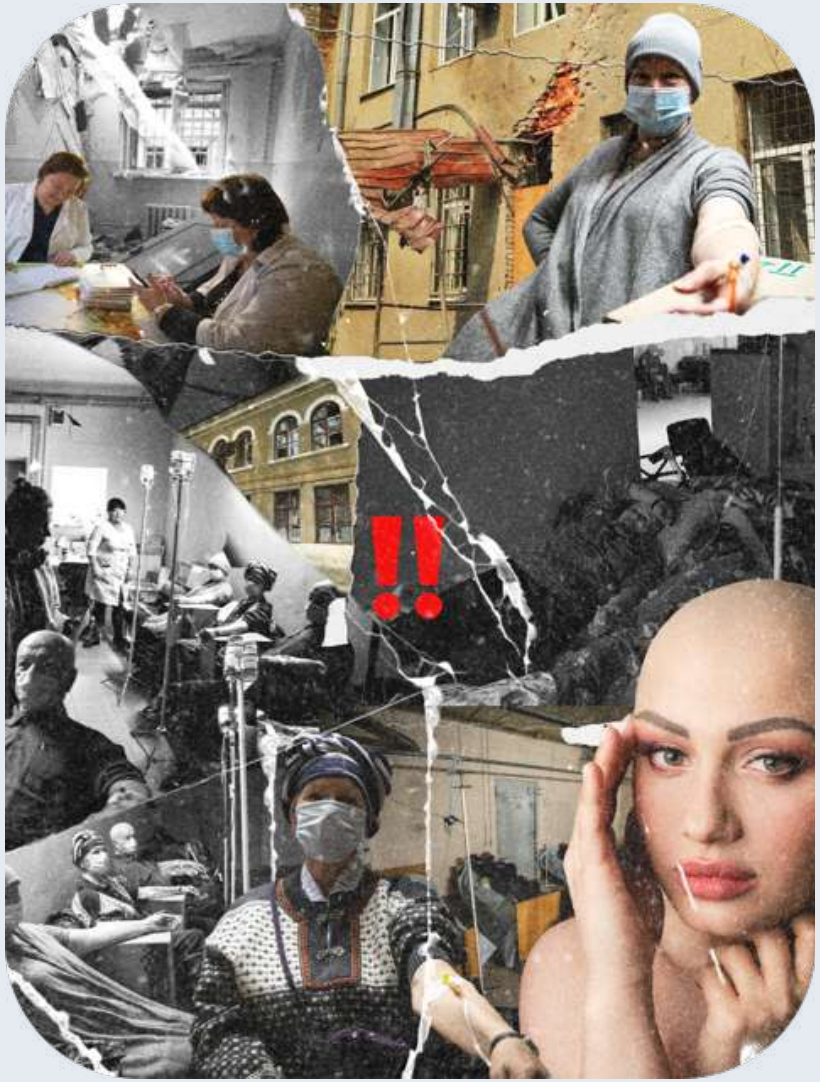
Day of people with a history of cancer

In celebration of the Day of people with a history of cancer, we held a photo marathon under the slogan **#NeedHelpToo**, which literally means "we also need help". It helped us draw attention to the challenges that patients face when treating cancer in wartime. For 35 years, the world has united to support those affected by a cancer diagnosis - patients who are being treated or have reached remission, their doctors, friends, relatives or acquaintances.

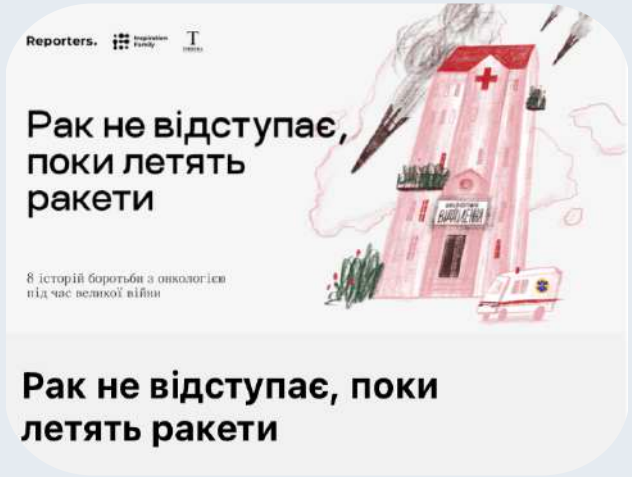


Communication with the mass media

This year, more than 6 million people learned more about wartime cancer treatment through Inspiration Family initiatives.

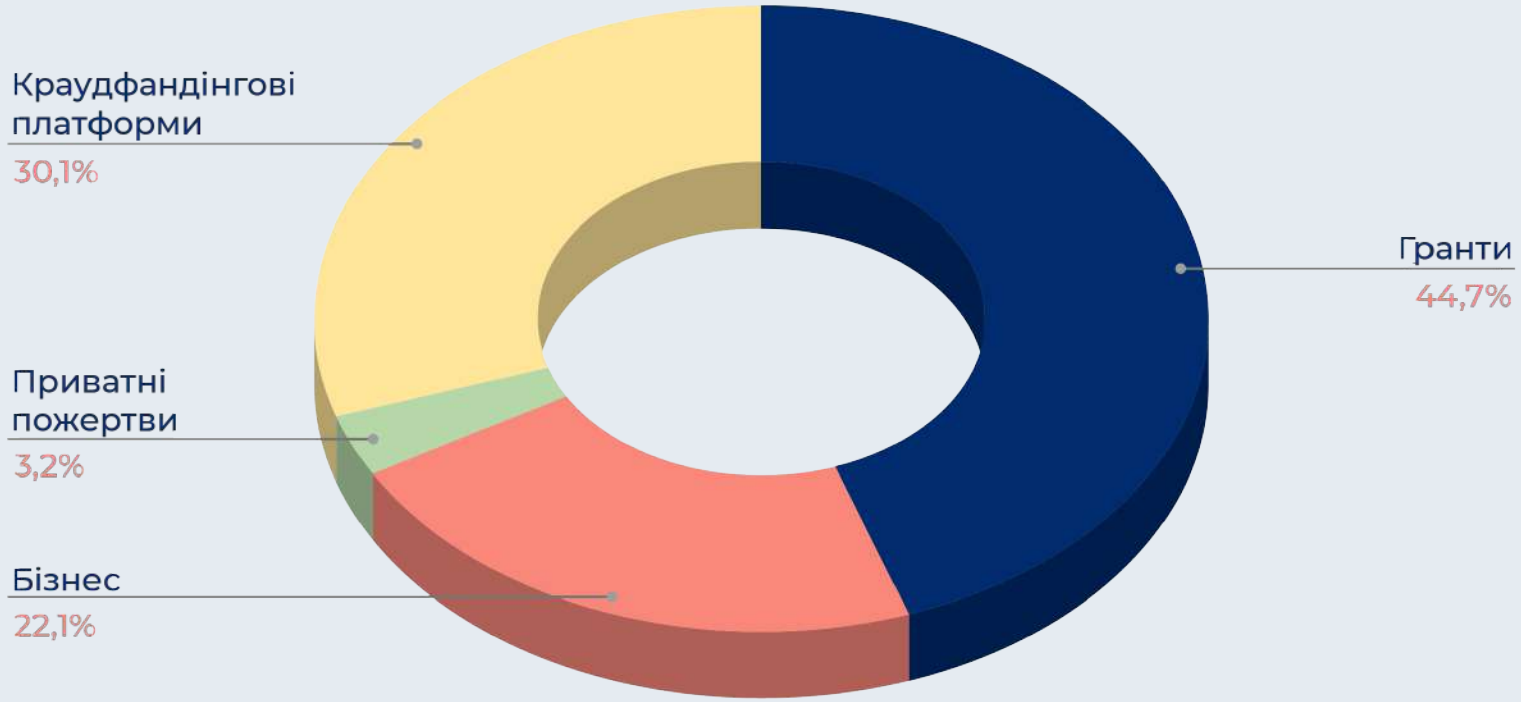
Over the course of the year, we regularly raised the topic of cancer treatment in wartime at the **Yedyni Novyny telethon: on television, online, the Ukrainian and foreign media.** We have repeatedly published the course of action for cancer patients undergoing treatment during the war, talked about medical evacuation and how to get there, debunked myths about cancer, warned about fraudsters, told stories of patients who did not give up and inspire by example. Many patients went abroad for treatment when they learnt this information from television.

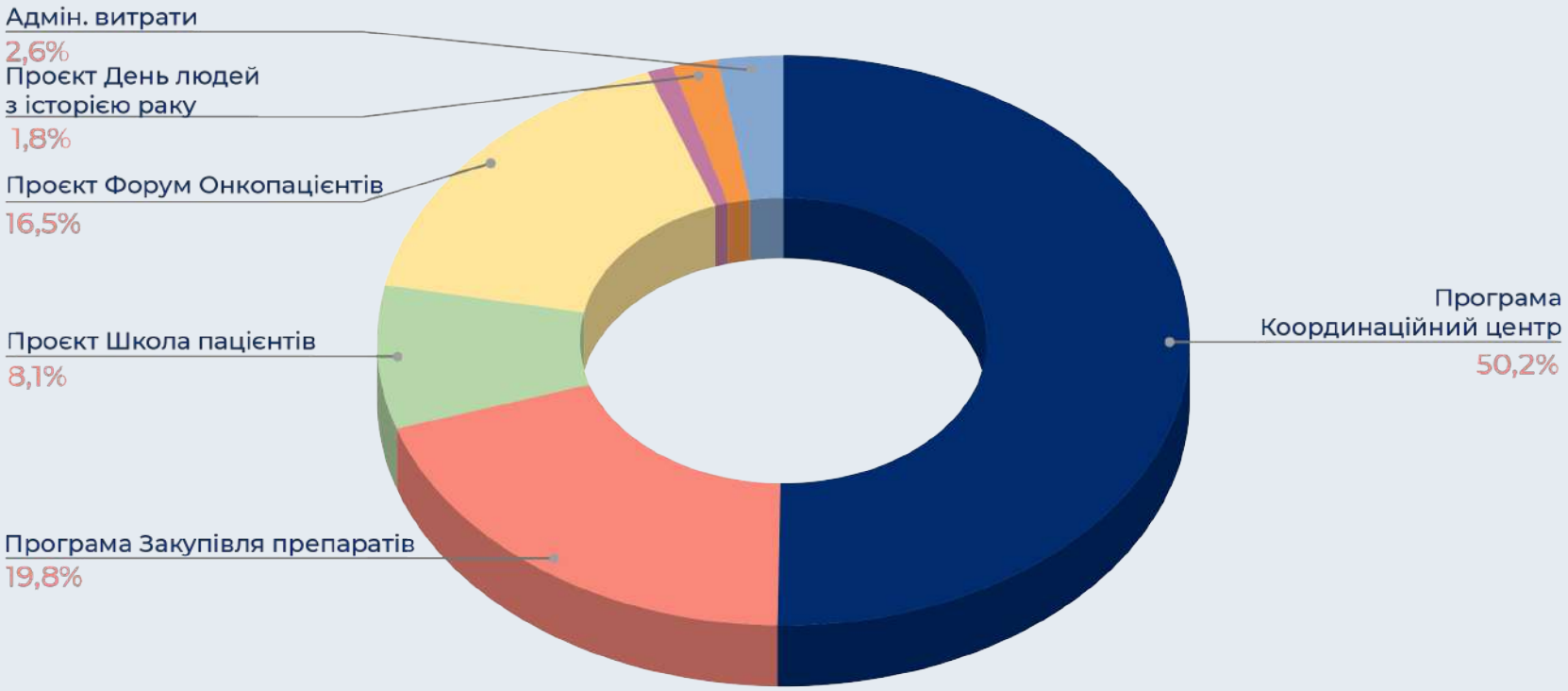
The subject of adult cancer is not very popular in our society, but there are more than 1 million cancer patients in Ukraine, which is equal roughly to the population of Kharkiv. All these people fight two wars.



Sources of income

№	Sources of income	Amount in UAH
1	Grants	738 605,77
2	Business	365 343,50
3	Private donations	52 654,58
4	Crowdfunding platforms (Be Kind, RFTC)	497 416,06
	In total:	**1 654 019,91**



Program and project costs

1	Coordination Center Program	830 060,35 UAH
2	Purchase of drugs Program	326 663,51 UAH
3	School of Patients Project	134 220,2 UAH
4	Oncology Patients Forum Project	272 325 UAH
5	Race for the Cure Project	16 973,93 UAH
6	Day of People with a History of Cancer Project	29 492 UAH
7	Admin. costs	43 255,06 UAH
	Total:	**1 652 990,05 UAH**