Advocacy for CML During Challenges

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Vilnius, Lithuania
24–26 May 2024

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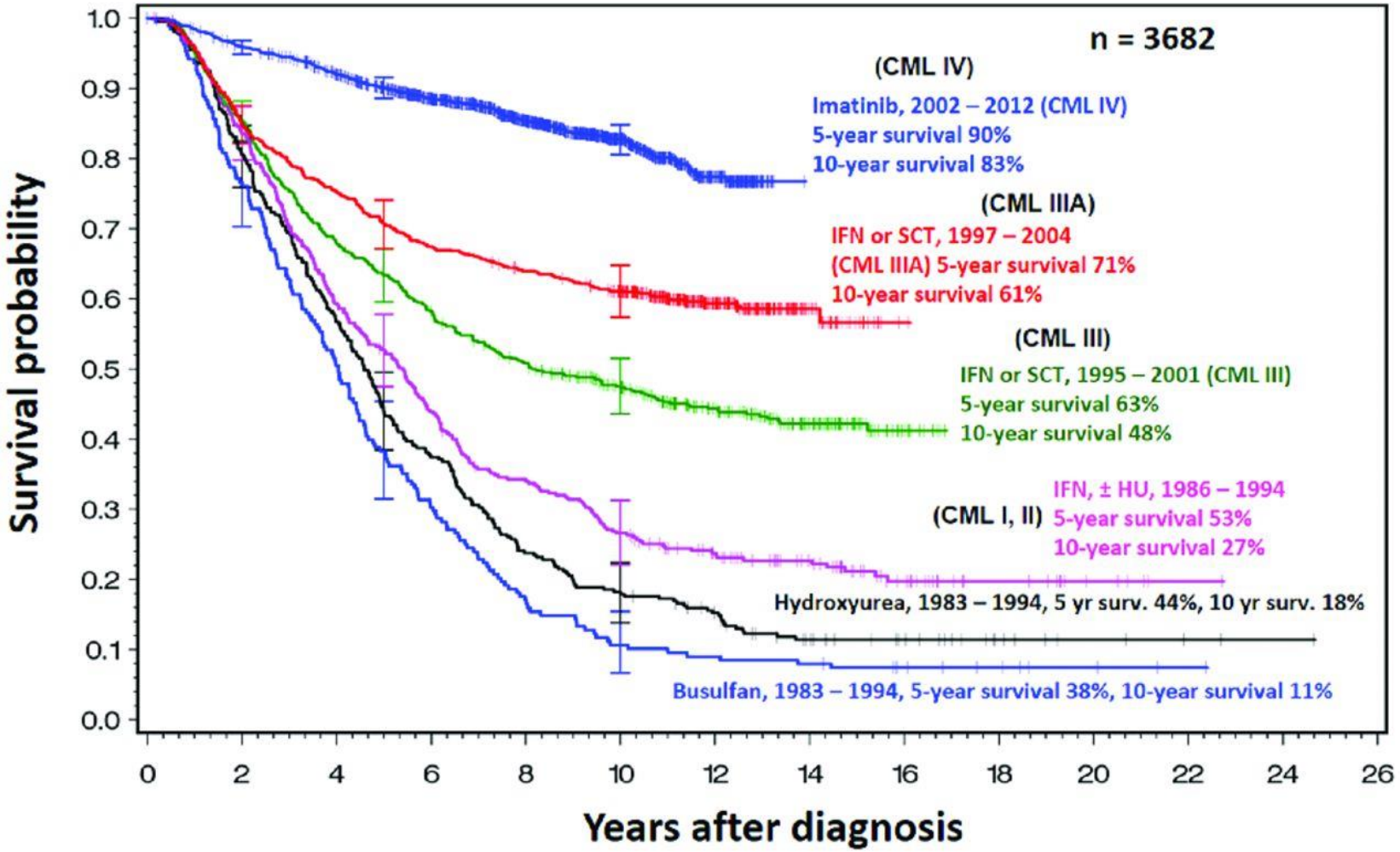
In most cases, CML patients require lifelong treatment



Rüdiger Hehlmann. Innovation in hematology. Perspectives: CML 2016. Vol. 101 No. 6 (2016): June, 2016. https://doi.org/10.3324/haematol.2016.142877

Have we built a stable global CML network to protect CML patients against challenges?

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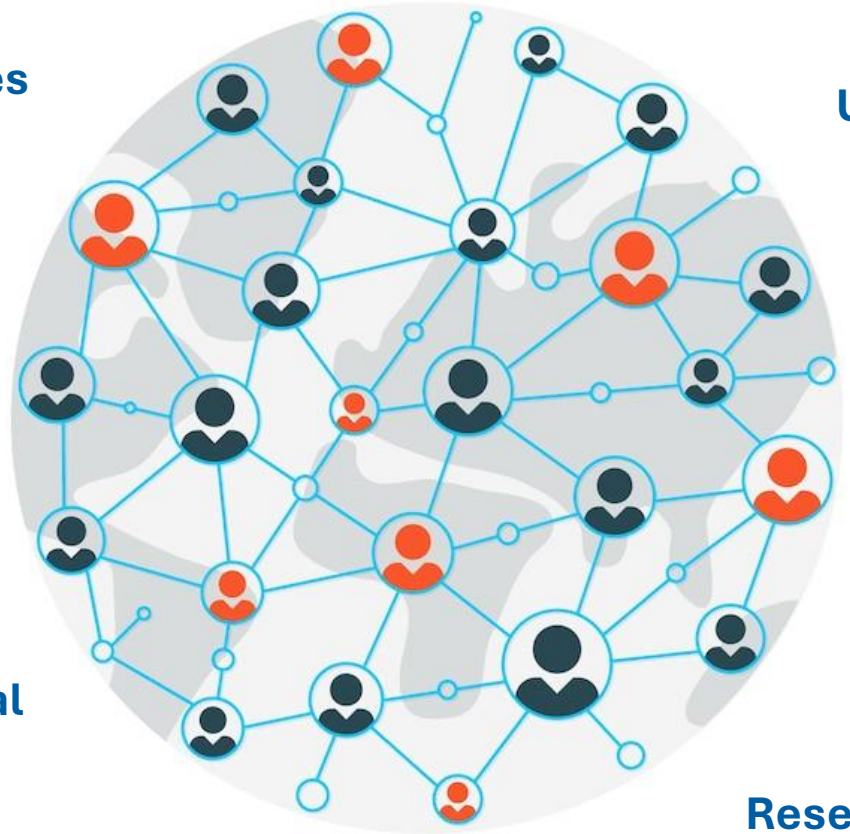
Specialized societies

Universities



CML Advocates Network

Hospitals

LeukaNET

The Max Foundation

Pharmaceutical companies

Research institutes

The CML Network is stable, but the world is not...

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Crash test for the CML community: A two-year experience

Conditions and context during Challenges

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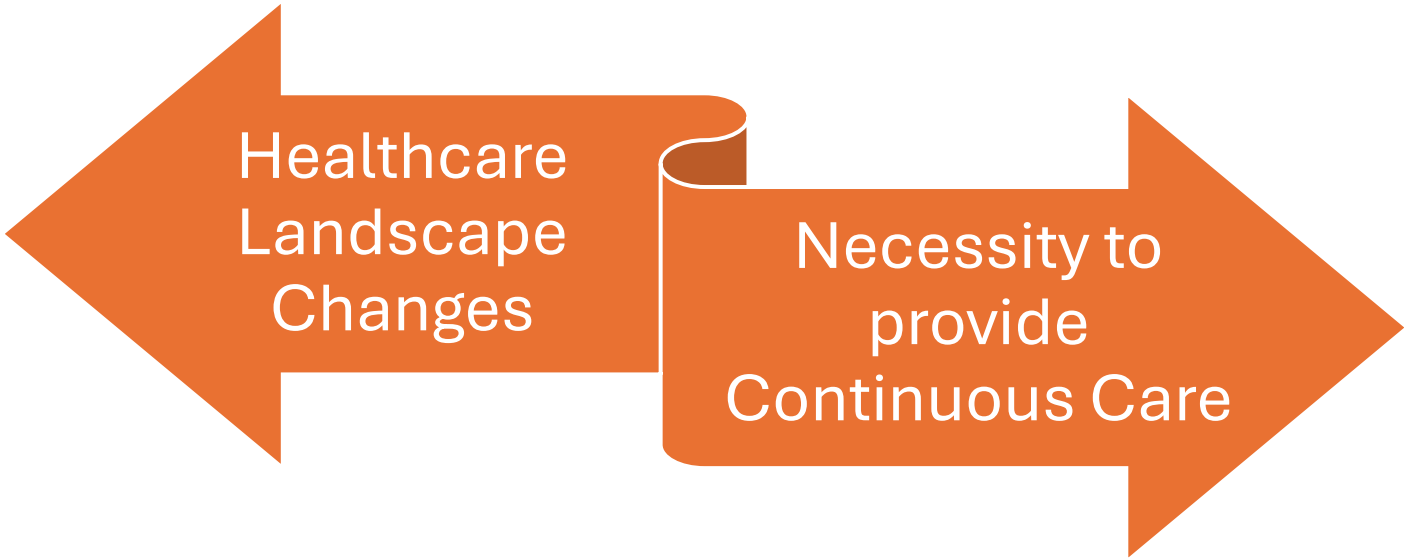
- Displacement of Patients and medical staff
- Destruction of Healthcare Facilities
- Drug Supply Disruptions



Displacement of people (patients and doctors)

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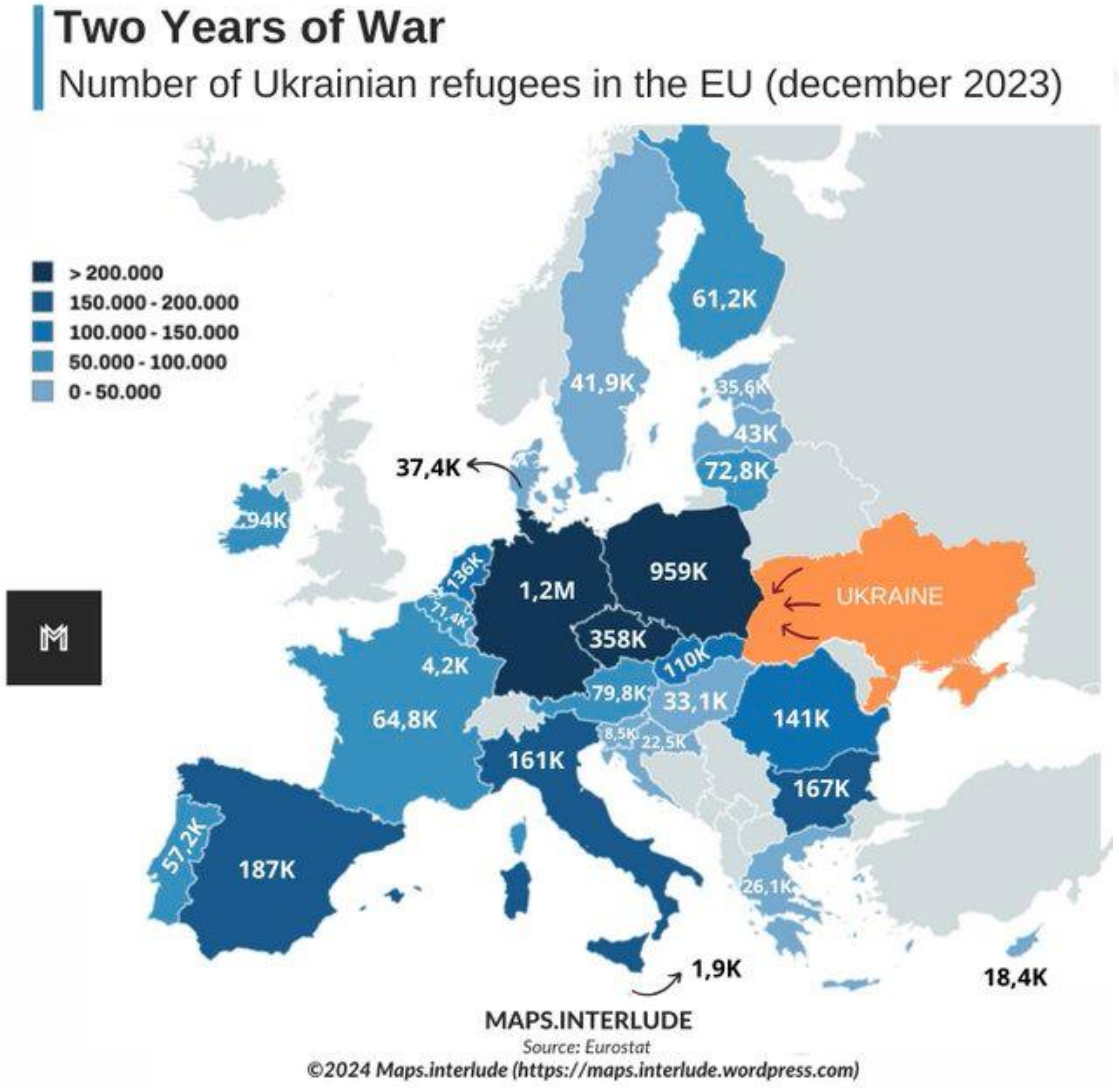
- Ukraine is 40 million population country
- UNHCR projected 6.5 million refugees in receiving and hosting countries (including medical staff)
- 5.1 million persons internally displaced



https://data.unhcr.org/en/situations/ukraine
https://x.com/Maps_interlude/status/1761345737642660248

Destruction of Healthcare Facilities

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- In Ukraine, 1,523 medical facilities have been damaged and 195 have been completely destroyed

https://moz.gov.ua/article/news/vtrati-medichnoi-sistemi-za-ponad-23-misjaci-vijni-rosija-poshkodila-1523-ob%e2%80%99ekti-medzakladiv-ta-sche-195-zrujnuvala-vschent-

Survey of 154 cancer patients in Ukraine in April 2022
Have war influenced your treatment?

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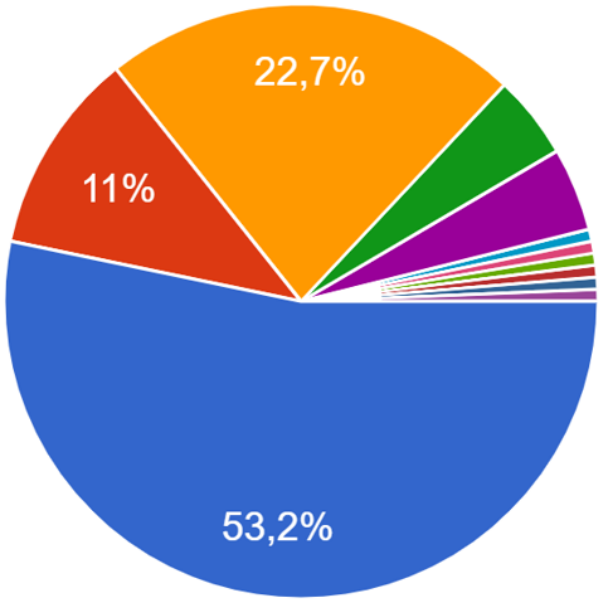

- Problems getting medications
- The lack of physicians
- Not able to arrange diagnostics (CT, MRI, IHC…)
- Not able to pass OP
- Not able to pass radiotherapy
- The scheduled CT was missed
- Did PET-CT but with 2 month delay
- The treatment was interrupted

Other challenges

- Ukrainian currency devaluation lead to increase of price for medical devices and supplies
- 5 million jobs have been lost in Ukraine
- Electricity, gasoline problems
- Logistical problems (broken supply chains, cold chain difficulties, air traffic stop, postage problems)

Challenges in providing hematology care in Ukraine

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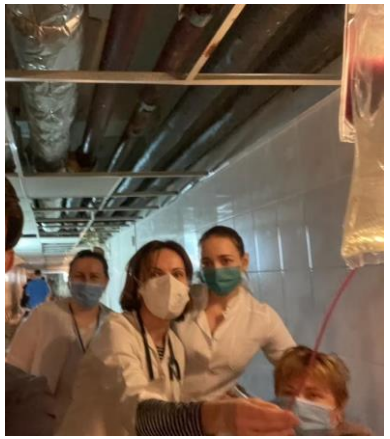
- Not working or damaged state hematological wards and private hematological departments and labs in occupied areas and close to fighting theater
- Limited activity of hematological departments even in “safe” areas due to the need to ensure the safety of patients during air raids from possible missile attack and difficulties to move them into the shelter
- Not working private hematological departments and labs even in “safe” areas due to decrease in the number of solvent patients
- Reduced diversity of diagnostic laboratories and the risk of monopolization of laboratory services
- Diagnostic radiology not working because of risks of radiopharmaceuticals transportation and destroy of radiological facilities
- Patients might have difficulties to attend the hematological wards and laboratories due to transportation problems, risks when crossing the occupied territories and areas of fighting
- Declining affordability of drugs and diagnostic procedures
- Decreasing physical accessibility of drugs and laboratory reagents



Professor Sergiy Klymenko, hematologist, oral presentations for World hematological conferences 2022, 2024

Challenges in providing hematology care in Ukraine

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- A lot of hematologists displaced internally and abroad, some were not working because of risks while going to work
- Environment for hematologists to communicate, gain new experience, improve skills and feel competitive spirit is damaged
- Recruiting in clinical trials stopped, there are no new trials initiating
- There were a lot of troubles to continue the clinical trials participation for patients displaced abroad. Some patients were transferred to other sites in Ukraine and other countries
- Limited mobility of hematologists to attend conferences and have internship in another institutions
- Pharmaceutical companies reduced budgets for conferences support and education
- Research projects in the field of hematology are not initiated by Ukrainian government

Professor Sergiy Klymenko, hematologist, oral presentations for World hematological conferences 2022, 2024

Goals for CML Advocacy During Challenges

- Bridging the Gap in Care
  - Medication Transfer and Distribution
  - Partnerships for Humanitarian Donations
  - Collaboration with European Organizations
  - Evacuation of CML Patients
- Resilience and Innovation Model
  - Telemedicine and Mobile Groups
- Overcoming Challenges
- Continuum Medical Care

The first days and weeks of the challenges, disasters, etc.

Actions of Charity fund of patients "DROP OF BLOOD"

- Large groups of people, including patients with CML and their hematologists, begin to urgently evacuate the area of disaster (combat zone).

Kharkiv, March 2022

Communication via messengers (Viber, WhatsApp etc.)

- Initiated contact with patients and doctors displaced from homes.
- Utilized pre-existing Viber group chats for regional communication.
- get drugs for several months in advance

Medication Distribution:

- Coordinated with hematologists in frontline areas.
- Facilitated the distribution of hospital stock to patients in need.
- give the maximum amount of medicines that are in the hospital's from disaster region warehouses to the patients

Online Medical Consultation:

- Compiled a list of specialists for online consultations, available on our website and Facebook.

Psychological Support:

- Shared information on free psychological support from the Ukrainian Psycho-Oncology Association (UPOA).
- Aimed to support the emotional well-being of cancer patients during the crisis.

Take-Home Message

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- **Establish and Maintain Communication Channels:**
  - Set up and regularly update regional communication groups on platforms like Viber, WhatsApp to ensure swift and reliable communication during emergencies.
- **Preemptive Medication Planning:**
  - Encourage patients to maintain a surplus of necessary medications and facilitate advanced dispensing from healthcare facilities in anticipation of potential disruptions.
- **Expand Access to Specialist Consultations:**
  - Develop a network of specialists, including hematologists, willing to provide online consultations, ensuring continuity of care when physical visits are not possible.
- **Psychological Support Infrastructure:**
  - Collaborate with psychological associations to offer free mental health support, crucial for maintaining patient morale and mental well-being during crises.
- **Resource Sharing and Visibility:**
  - Leverage websites, social media, and patient group platforms to disseminate vital information and resources, increasing accessibility and support reach.

The second month of the challenges, disasters, etc.

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Actions of Charity fund of patients "DROP OF BLOOD"

- Large groups of people, including patients with CML and doctors, have already evacuated disaster areas and settled in safer regions of Ukraine or left the country

Regional Reports Analysis and Drug Distribution:

- Received updates from hematologists in Western Ukraine about the influx of CML patients and drug shortages.
- Ivan Zelenskiy leveraged our foundation director's role within the Ministry of Health's expert group to facilitate a new order for the redistribution of medications.
- In this way, we achieved that the rest of the drugs that were in the warehouse of the Ministry of Health of Ukraine were delivered precisely to the regions where there were the most patients - refugees.

Response to Medication Shortages:

- Recognized that some medications were trapped in occupied territories or destroyed.
- Our foundation appealed to pharmaceutical companies for medication donations.
- Ivan Zelenskiy recorded a video message to Novartis, Pfizer, Takeda management to support this request.

Take-Home Message

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- **Proactive Collaboration and Advocacy:**
  - Effective crisis response for healthcare needs hinges on proactive collaboration between health professionals and government agencies.
- **Adaptive Resource Distribution:**
  - Swift adaptation and strategic distribution of medical resources are essential to address urgent needs in dynamic crisis situations.
- **Direct Appeals for Support:**
  - Direct appeals to pharmaceutical companies for support can mitigate shortages and ensure continuous patient care under extraordinary circumstances.

The third month of the challenges, disasters, etc.

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Drug Donations and Distribution

•Significant Pharmaceutical Donations:

- Received large donations from Novartis (nilotinib), Pfizer (bosutinib), and Vista (Ukraine) (generic dasatinib), Takeda.
- Organized and facilitated drug distribution to areas with high concentrations of displaced CML patients.

Providing Medicine in Occupied Territories

•Humanitarian Efforts:

- Established humanitarian corridors for medicine delivery to occupied territories.

International Support and Collaboration

•Building Global Partnerships:

- Leveraged relationships from CML Horizonty conferences and CML Advocates.
- Received additional drug donations through European patient organization connections.
- Acknowledgements to Ms. Cornelia Garnitz (Germany) and Ms. Mina Daban (France) for expedited drug access.
- Special thanks to Lidija Pecova and Jelena Cugurovic for transporting medicines to Ukraine.

Grant Applications for Diagnostic Support

•Pursuing Funding for Enhanced Diagnostics:

- Applied for grants to purchase PCR diagnostic reagents from the King Baudouin Foundation and the Solidarity Fund (UICC).

Humanitarian corridors for medicine delivery

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Kupyansk, transfer of medicines to CML patients

Take-Home Message

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- **International Collaboration:**
  - The crucial role of global solidarity and international partnerships cannot be overstressed. These relationships enable rapid and effective responses to healthcare crises, demonstrating the power of collective effort across borders.

- **Continuity of Care:**
  - Ensuring continuous care through innovative solutions like humanitarian corridors and international support highlights the necessity of adaptive strategies to maintain treatment regimens, even under challenging conditions.

- **Strategic Funding Applications:**
  - the importance of securing financial support to sustain comprehensive diagnostic services during ongoing crises.

The fourth and other months of the challenges, natural disaster, etc.

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Ongoing Support and Response for CML Patients During Crisis

- **Continued Needs of Displaced CML Patients:**
  - Ongoing quality treatment and medication supply for CML patients displaced from their homes.
  - Additional support for CML patients returning to areas liberated by the Ukrainian army.
- **Grant Support and Hospital Restoration:**
  - Secured a grant from the Renaissance Fund (Soros Foundation) to:
    - Evacuate patients from occupied territories.
    - Aid in hospital restorations in liberated areas, including Kherson.
    - Purchase essential medical products and medications for hematology.
- **Patient Mobility Assistance:**
  - Facilitated travel for some CML patients leaving through Russia to Europe, covering their travel expenses.
- **Enhancing Diagnostic Capabilities:**
  - Utilized grants from the King Baudouin Foundation and the Solidarity Fund (UICC) to:
    - Purchase reagents for over 1,000 PCR tests for CML at the state laboratory in Kryvyi Rih.

Ongoing Challenges and Support for CML Patients During 2 years

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- **Adaptation to challenges Conditions:**
  - CML patients in Ukraine have adapted to living with constant war and rocket fire.
  - Patients who went to European countries are accessing high-quality medical care.
- **Educational Initiatives:**
  - The Foundation conducts online Schools for CML patients every three months, informing them about changes in Ukraine's medical field during the war and providing action algorithms for disease exacerbation.
- **Support in Medical Procurement and Diagnostics:**
  - Active involvement in compiling drug lists for state procurement: imatinib, nilotinib, dasatinib, bosutinib.
  - Ongoing purchase of reagents for PCR diagnostics funded by grants, ensuring all CML patients in Ukraine have access to necessary drugs and diagnostics.
- **Gratitude to Host Countries:**
  - Expressing gratitude to countries providing free medical treatment to displaced CML patients.

Online Schools for CML patients in Ukraine

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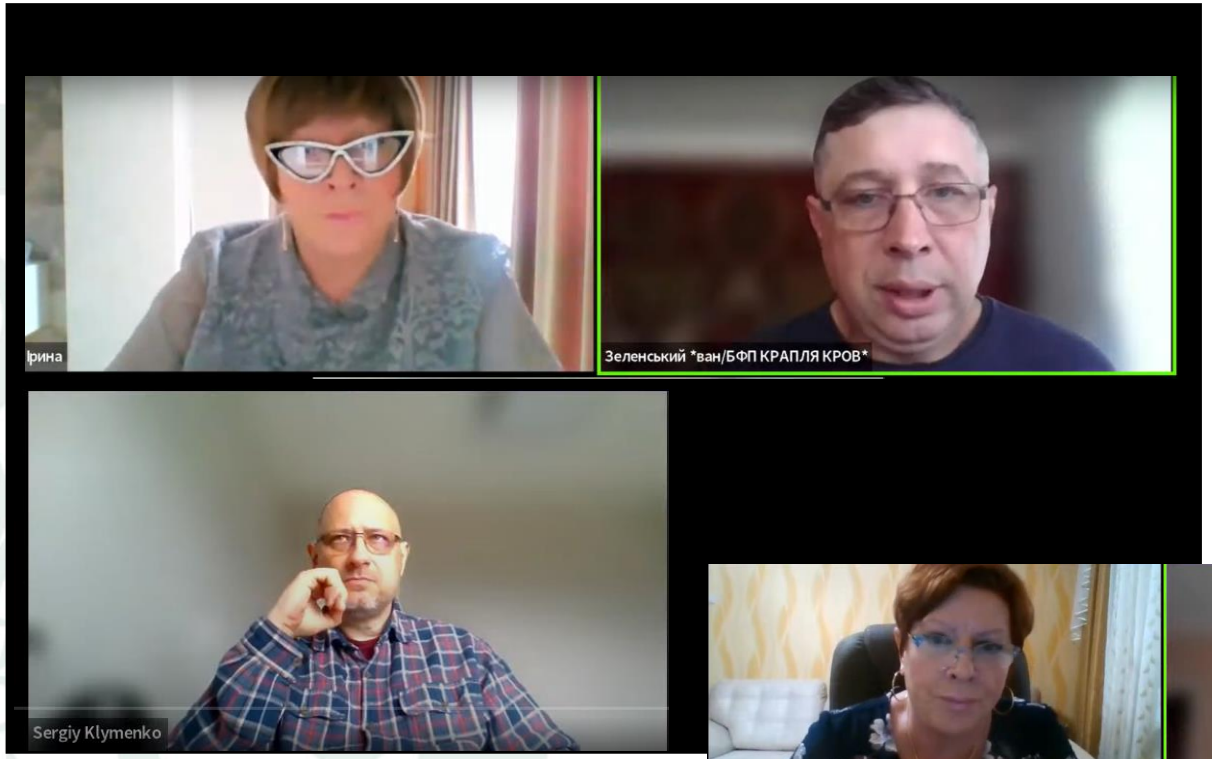

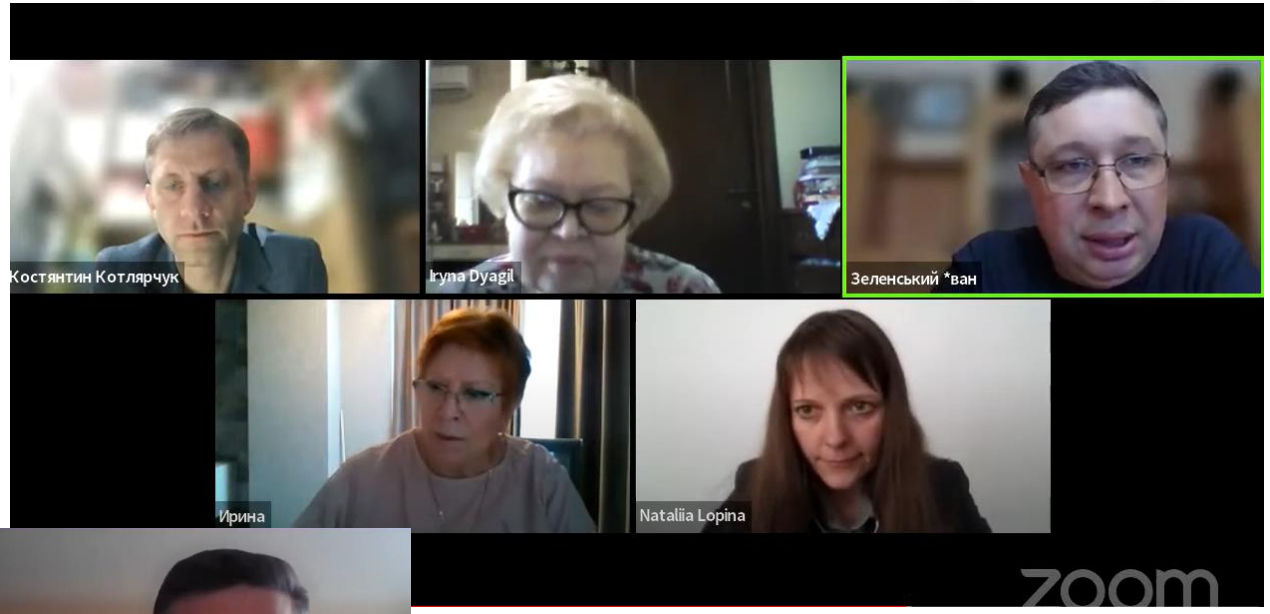

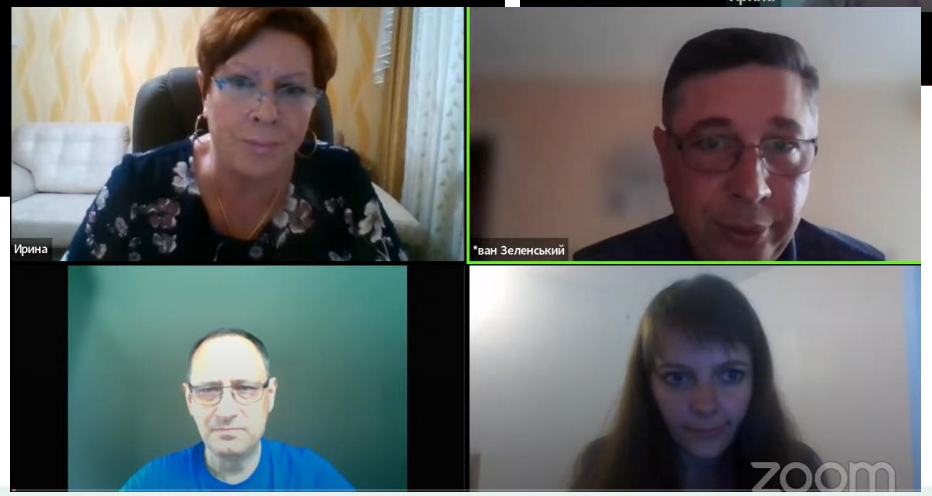

Take-Home Message

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- **Adaptive Response:**
  - Our foundation's ability to dynamically respond to evolving needs, from evacuation to hospital restoration, underscores the importance of adaptability in crisis management.

- **Comprehensive Support:**
  - Through strategic grant utilization, we have not only secured necessary treatments and facilitated patient mobility but also restored essential healthcare infrastructure in liberated areas, demonstrating the multi-faceted approach required in crisis situations.

- **Enhanced Diagnostics:**
  - Investing in diagnostic capabilities, such as PCR testing, ensures ongoing patient care and monitoring, highlighting the critical role of diagnostics in managing chronic conditions during crises.

- **Educational Outreach:**
  - Regular educational sessions ensure that CML patients are well-informed and prepared to manage their condition effectively, even under challenging circumstances.

Summarizing experience Advocacy for CML during challenges, natural disaster, etc.

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In conclusion

- The patient organization should have a clear connection with groups of patients from different regions of the country. It is very important! This will give you the opportunity to convey information about events to exactly the group of patients who need it. Chats in Viber, WhatsApp or other messengers.
- The patient organization should have good relations with doctors - hematologists from different regions of the country. This will make it possible to understand what is happening to hospitals during a disaster, and to establish online patient consultations.
- The patient organization should have a good relationship with drug manufacturers. This will make it possible to quickly receive donations of medicines for patients who have become refugees.
- The patient organization must have influence in the Ministry of Health. This will give an opportunity to influence the effective distribution of drugs specifically for your cohort of patients (patients with CML).
- The patient organization must be able to write grants to international organizations. This will provide an opportunity to obtain funds for the purchase of reagents for the laboratory, medical consumables, financial and logistical support for patients who have become refugees.
- The patient organization must have good relations with its colleagues from other countries. This will give you the opportunity to support patients who have left your country due to war or natural disaster and to receive drug donations and support from the patient community in other countries.

We are Very Grateful to our Global Hematology Family for your Support!!!

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#StayWithUkraine