

GLAS ONKOLOŠKIH PACIJENATA

Regionalni sastanak pacijenata
6. — 7. rujna 2024. Zagreb

THE VOICE of ONCOLOGY PATIENTS

Regional Patient Meeting
September 6th — 7th, 2024, Zagreb



ZAGREB DECLARATION 2024.

Cancer is a public health crisis affecting an increasing number of our citizens. Despite current public policies, the burden of cancer has not been adequately reduced, and disparities in health-care access and quality persist across different countries and even within regions of the same country. These inequalities lead to significant differences in treatment outcomes and patients' quality of life. It is our collective responsibility to address these challenges and work toward a fairer and more effective healthcare system.

We, the patient associations of Central and Eastern Europe, participating in the Regional Meeting "The Voice of Oncology Patients," stand united as the voice for oncology patients across Europe. As advocates for cancer patients, dedicated to prevention and providing support, we are committed to improving overall care and ensuring that every patient, regardless of where they live, has access to the highest standards of prevention, early diagnosis, treatment, and clinical outcomes.

We agree on the following:

1. Enhancement of Prevention

We demand the development and implementation of comprehensive prevention programs that educate the public about risk factors and promote healthy lifestyles.

2. Improvement of Early Diagnosis

We advocate for the improvement of early malignant diseases detection, particularly by increasing the availability of services in existing screening programs and necessary diagnostic procedures to ensure timely and adequate intervention. We propose organizing new, improving existing ones and to increasing efforts to enhance the response to programs for early detection of oncological diseases.

3. Enhancing Treatment Options

We emphasize the importance of improving treatment options by ensuring that all patients have access to all the necessary and understandable information, the right to co-decision on their treatment, standardized treatment protocols, timely access to the latest and most effective treatments, including participation in clinical trials, and the right to precision medicine and personalized treatment.

4. Optimizing Clinical Outcomes

We support and seek to optimize clinical outcomes by fostering a patient-centered approach that prioritizes quality of life and long-term survival, while collecting, monitoring, and analyzing data on treatment outcomes.

5. Implementing Strategies and Plans to Fight Cancer

We stress the necessity of implementing strategies and plans to fight cancer. Therefore, we emphasize the importance of harmonizing national strategies and plans with European documents and ensuring their effective implementation.

Our Call to Action

We are strongly committed to individual and collective efforts and cooperation. We appeal to all stakeholders – policy creators, public policymakers, healthcare providers, professional societies, the pharmaceutical industry, the diagnostic and medical products industry, researchers, the wider community and every individual – to enhance connections and make greater efforts in the fight against cancer. By working together, we can create a future where every cancer patient receives the care they need and deserve, regardless of where they live.

Recommendations for Reducing the Burden of Cancer

1. Prevention Improvement:

- **Education, Health Literacy and Awareness Campaigns:** Launch and sustain national campaigns tailored to target populations, educating the public about cancer risk factors such as tobacco use, unhealthy diets, physical inactivity, and excessive alcohol consumption. Education on healthcare and disease prevention must become an integral part of teaching curricula in the educational process. To promote lifestyle changes to preserve health and prevent cancer and other chronic non-communicable diseases.
- **Vaccination Programs:** Promote vaccination to prevent cancer-causing infections and ensure access to vaccines, such as the hepatitis vaccine for liver cancer and the HPV vaccine for cervical cancer and other cancers caused by this infection. Provide screening for at - risk populations and treatment of infections to prevent cancer.
- **Environmental Health and Workplace Safety:** Advocate and reward policies that reduce the presence and exposure to environmental carcinogens and support occupational safety regulations to ensure a healthy work environment and minimize cancer risk factors.

2. Early Diagnostics Improvement:

- **Screening Programs:** Implement and expand accessible screening programs for common cancers, such as breast, cervical, colon, prostate and lung cancer, ensuring they reach underserved and high-risk populations.
- **Integration of Primary Healthcare:** Train and empower primary healthcare providers to recognize early signs and symptoms of cancer and refer patients to appropriate diagnostic testing. Actively involve workers in primary health care into comprehensive oncological care from primary and secondary prevention to care at the end-of-life care.
- **Innovative Diagnostic Technologies:** Investing in the latest diagnostic tools and technologies that improve the accuracy and speed of cancer detection, including molecular and genetic testing, and ensure their optimal availability.

3. Treatment Options Improvement:

- **Access to Standard and Advanced Therapies:** Ensure all patients have adequate, comprehensible, and acceptable information enabling them to participate in decisions about their oncological treatment (including oncological surgery). Patients should have access to the entire spectrum of cancer treatments, from standard chemotherapy and radiation to advanced therapies such as immunotherapy, targeted therapy and personalized treatment. Patients should also have right to supportive therapies and all therapies for treating and preventing relapse of the disease, and have the right to a second opinion.

- **Clinical Trials Participation:** Facilitate patient participation in clinical trials by providing clear information and support, removing barriers to inclusion, and ensuring diverse representation in study populations. In the region of Central and Eastern Europe, it is necessary to encourage the implementation of a greater number of clinical trials and raise awareness of the importance and benefits of clinical trials for patients, healthcare providers, the healthcare system and the states themselves.
- **Multidisciplinary Teams:** Advocate establishment and operation of multidisciplinary care teams that include all specialties necessary to ensure comprehensive and coordinated treatment plans.
- **Centers of Excellence:** Encourage the development and establishment of centers of excellence for optimal cancer patient treatment and care.
- **Precision Medicine and Personalized Treatment:** Improve the possibilities for molecularly guided, optimal treatment of patients in accordance with the molecular characteristics of their tumors and their personal life circumstances, taking care of the patient's quality of life.
- **Palliative Care:** Ensure the conditions for palliative treatment to be an integral part of comprehensive oncology care from the moment of diagnosis. For patients facing the end of life, to provide adequate and dignified care. Adopt plans and strategies for palliative care and implement them according to the needs of patients and families.

4. Clinical Outcomes Optimization:

- **Patient-Centered Care:** Develop care models that prioritize the patient's quality of life, addressing not only the disease treatment but also the preservation of physical health, as well as emotional, social and psychological well-being. Implement survivorship care plans that support long-term health and well-being and return to work or school.
- **Health Infrastructure:** Strengthen health infrastructure and professional resources to ensure facilities are adequately equipped and staffed to provide high-quality care for cancer patients, especially in rural and underserved areas. With the availability of IT technologies and the reach of telemedicine, there is no reason why a patient from any environment should not have access to a multidisciplinary team and an adequate individual oncology care plan.
- **Data Collection:** Invest in data collection and analysis on cancer and patient treatment outcomes to identify best practices, improve treatment protocols, and monitor outcomes while protecting and preventing data misuse. Foster collaboration between research institutions, healthcare providers and patient organizations to foster innovation and continuous improvement in cancer care. To develop awareness among sick people and their families about the importance of personal health data of every single sick person to improve treatment outcomes for everyone like them. It is also necessary to define which specific data will be collected and which outcomes will be measured, both from the position of health care providers and from the position of sick persons. Make treatment outcome results available and reward the most successful and make treatment outcomes a fundamental criterion for management.

Implementation of Cancer Strategies and Plans

We have collectively adopted strategies and plans to fight cancer, at national and EU level, all aimed at improving cancer treatment outcomes and improving care for cancer patients. However, the real effect of these plans will be seen only through their implementation.

Patients have waited long enough to see plans and strategies, and they no longer want to wait too long for their implementation.

Now is the time for all stakeholders to turn their commitments into actionable results. And it is crucial to recognize the invaluable role that patients can play in this process. Patients are not only users of health services, they are also the only ones who have life experience with the disease, treatment and consequences of treatment and are the most important partners for their treatment, which can significantly increase the effectiveness of political and public initiatives. Our insights can help us identify gaps, prioritize and ensure that care delivered is truly patient-centered.

By involving patients and patient associations in the implementation of cancer strategies and plans, you not only respect our voices, but also use our wisdom to jointly create more effective solutions to reduce inequalities, improve treatment outcomes and reduce the burden of cancer.

We are united in ensuring that every aspect of the adopted plans and strategies is realized without further delay.



Signatory Organizations:

1. Alivia - Fundacja Onkologiczna, Poland
2. Association of cancer affected and treated women EVERYTHING for HER, Croatia
3. Association of cancer affected and treated women We Are Not Alone, Croatia
4. Association "Renesansa" Sarajevo, Bosnia and Hercegovina
5. Cancer Patients Voice, Czechia
6. EZRA, North Macedonia
7. Hrvatska udruga leukemija i limfomi (HULL), Croatia
8. Hrvatski forum protiv raka dojke Europa Donna Hrvatska, Croatia
9. JEDRA, Udruga za pomoć oboljelima od raka i drugih bolesti pluća, Croatia
10. Koalicija udruga u zdravstvu, Croatia
11. Krijesnica - udruga za pomoć djeci i obiteljima suočenim s malignim bolestima, Croatia
12. Male pelvic cancers, Czechia
13. Nana Gladwish - One in 8 Foundation, Bulgaria
14. NVO Brini o sebi, Montenegro
15. Savez žena oboljelih od raka dojke ISKRA, Bosnia and Hercegovina
16. Srpski forum protiv raka dojke - EVROPA DONA SRBIJA, Serbia
17. Udruga žena oboljelih i liječenih od karcinoma – Caspera, Croatia
18. Udruženje pacijenta obolelih od melanoma UPOOM, Serbia
19. Udruženje pacijenata Srbije, Serbia
20. Udruženje za borbu protiv raka jajnika i grlića maternice Progovori, Serbia
21. Udruženje za podršku edukaciju i prevenciju ženama obolelim od kancera dojke "Žena uz ženu", Serbia
22. Women association for fighting BC in Kosovo – RENESANSA, Kosovo
23. Združenje Europa Donna Slovenija, Slovenia
24. Zveza organizacij pacientov Slovenija, Slovenia
25. Ženski centar Milica - Nacionalno udruženje za zastupanje onkoloških pacijenata sa rakom dojke i ginekoloških karcinoma, Serbia

ORGANIZATORI



PARTNERI

