

# NCCN Toolkit of Digital Resources



**GLOBAL POLICY WEBINAR SERIES:** 

# Patient Engagement Driving Access to Quality Cancer Care Globally

This toolkit highlights programs to support cancer patients as discussed during the Patient Engagement Driving Access to Quality Cancer Care Globally webinar series held in May 2021. This free webinar series provided an opportunity for a varied group of global stakeholders including patients, patient advocacy organizations, oncology providers, policymakers, and caregivers, to highlight and discuss meaningful patient engagement across the continuum of cancer care from diverse geographic perspectives. The sessions also provided a platform for patients worldwide to discuss opportunities and barriers to treatment options and care in their country and within their respective health systems.

To view a recording of the series, visit <a href="nccn.org/global/global-events">nccn.org/global/global-events</a>.

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# Patient-Focused Clinical Research & Advocacy

## The Patvocates Network



The Patvocates Network is a think tank, consultancy, and social enterprise in the areas of patient advocacy and patient engagement. Our goal is to help design, establish, develop and run effective engagement frameworks, policies, processes and projects. Based on decades of experience in patient advocacy and patient engagement, our team supports patient organisations, healthcare institutions, and the private sector, in strategy development, hands-on training, facilitation of interactive meetings, as well as project planning and implementation.

Patvocates is run by an experienced team of leading pan-European patient advocates with in-depth knowledge on healthcare systems, institutions, stakeholders, cultures, and the global patient community across different disease areas.

**URL:** patvocates.net

Email: jan@patvocates.net

# The African **Organisation for** Research and **Training in Cancer** (AORTIC)



The African Organisation for Research and Training in Cancer (AORTIC) is an African based non-governmental organisation that is dedicated to cancer control and palliation in Africa.

AORTIC executive members are high profile experts in the cancer field who volunteer as knowledge workers for the plight of cancer patients in Africa. AORTIC strives to unite the African continent in achieving its goal of better outcomes for cancer patients in Africa and seeks to make a positive impact throughout the region through collaboration with health ministries and global cancer fighting organisations.

**URL:** <u>aortic-africa.org</u>

Email: info@aortic-africa.org

# **Treatment & Survivorship**

## My Survival Story

My Survival Story tells authentic stories to help people affected by cancer to cope better with their situation.

**URL:** mysurvivalstory.org

Email: info@mysurvivalstory.org



### NCCN Global



NCCN's Global programs seek to further advance the organization's mission to improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives. NCCN is devoted to defining and advancing high-quality, high-value, patientcentered cancer care globally.

#### **Translation of NCCN Content**

NCCN works to translate the NCCN Clinical Practice Guidelines in Oncology (NCCN Gudielines®) and NCCN Guidelines for Patients® into multiple languages and publishes these important resources for free so that they may be accessed by clinicians and patients around the world.

#### Regional Adaptations of the NCCN Guidelines

NCCN collaborates with third party organizations across the globe to present Regional Adaptations of the NCCN Guidelines and derivative products that account for local accessibility, consideration of metabolic differences in populations, and regulatory status of health care technologies used in cancer care in the specified country or region.

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## NCCN Global

## NCCN Framework for Resource Stratification of NCCN Guidelines (NCCN Framework™)



NCCN Framework™ guide evidence-based adaptation to available clinical treatment resources, define appropriate treatment pathways based on available resources—Basic, Core, Enhanced, and NCCN Guidelines®—and deliver a tool for health care providers to identify treatment options that will provide the best possible outcomes given specific resource constraints.

#### NCCN Harmonized Guidelines™

These targeted regional resources are created as part of a collaborative effort to combat the skyrocketing cancer rates and unique care circumstances. They represent both the optimal care that low- and mid-resource countries aspire to provide and pragmatic approaches that provide effective treatment options for resourceconstrained settings.

URL: <u>nccn.org/global</u>

Email: winckworthpreisnar@nccn.org

## **Living Charity** Fund

## Живой.

Фонд помощи взрослым.

The mission of Living Charity Fund is to give a chance for a full-on life to gravely ill people and hope to their families. The fund provides targeted assistance to adults from 18 to 60 years whose life is either threatened by serious medical conditions or in need of rehabilitation. The foundation also focuses on social awareness programs, support to hospitals and health-care facilities, assistance in improving medical equipment and conducting research. The Living Charity Fund supports more than 160 individuals annually and cooperates with more than 250 hospitals throughout Russia.

In collaboration with NCCN, the Living Charity Fund has supported the translation of 16 distinct NCCN Guidelines for Patients into Russian.

**URL:** livefund.ru

Email: agnessa@livefund.ru

# Patient Engagement to Impact Cancer Care Policy

# The European **Cancer Patient Coalition (ECPC)**



The European Cancer Patient Coalition (ECPC) is the largest cancer patient umbrella organisation, established in 2003. The main aim of the organisation is to advocate for patients to be acknowledged as equal partners and co-creators of their own health and that ECPC works for a Europe of equality, where all Europeans with cancer have timely and affordable access to the best treatment and care available, from the diagnosis to survivorship or palliative care. ECPC has more than 450 members from 50 countries covering at least one member per continent.

The European Cancer Patient Coalition works by developing 3-year, multi-annual strategies. After conducting internal consultations with Board Members and reviewing patient advocacy group strategies and best practices, we develop a final strategy to increase the impact of the organisation and establish long-term aspirations. The strategy also streamlines activities, enabling a time of sustained growth. The main objective is to firmly establish ourselves as the main voice of cancer patients in Europe and focus on activities that ensure patients play a leading role in the development of healthcare programmes in Europe.

**URL:** ecpc.org

Email: info@ecpc.org

# Union for International Cancer Control (UICC)



"We unite and support the cancer community to reduce the global cancer burden, to promote greater equity, and to ensure that cancer control continues to be a priority in the world health and development agenda."

The Union for International Cancer Control's (UICC) rapidly increasing membership base of over 1200 organisations in 172 countries, represents the world's major cancer societies, ministries of health and patient groups and includes influential policy makers, researchers and experts in cancer prevention and control. UICC also boasts more than 50 strategic partners.

In the last decade, we have reached millions of people with World Cancer Day, welcomed more than 15,000 delegates at our World Cancer Congresses, and launched four new organisations: the International Cancer Control Partnership, the McCabe Centre for Law & Cancer, City Cancer Challenge Foundation and the NCD Alliance.

#### **Organizational Resources for Patients:**

- Coursebook: Multisectoral Approaches for Patient Engagement for Better Cancer Control (link)
- International Cancer Control Partnership Website & Resources (<u>link</u>)

**URL:** www.uicc.org Email: info@uicc.org



For more information on the NCCN Global Program, please visit NCCN.org/global or contact:

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