

# World Bladder Cancer Patient COALITION

### **Bladder Cancer Focus**

for "Patients Steps" (<u>Βήματα Ασθενών</u>)

15 May 2021

# Alex Filicevas Executive Director

# **The Global Voice**

for bladder cancer patients

Currently in eight countries



Until 2019, there was not one single organisation to speak as the **global voice** for people living with bladder cancer.

The World Bladder Cancer Patient Coalition is an association bringing together representatives of national bladder cancer organisations.

## **Our mission**





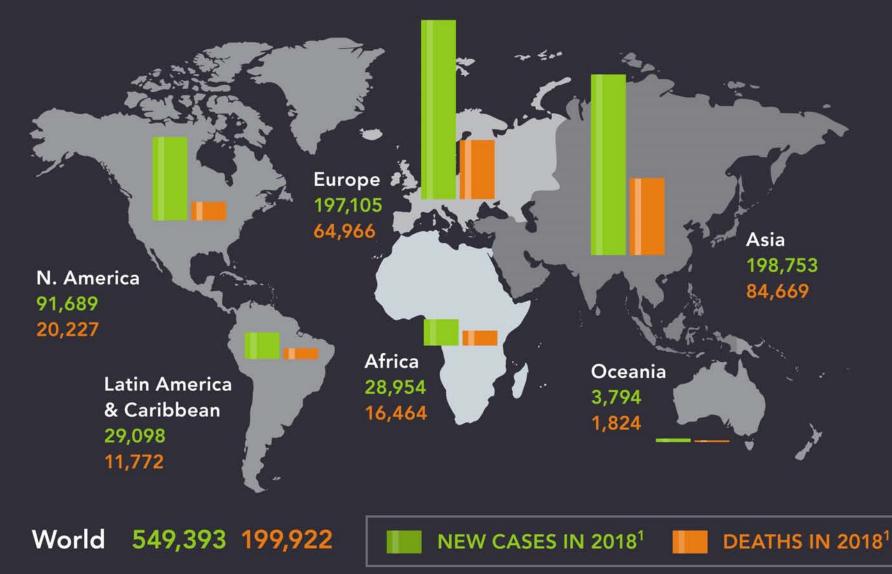
Foster an international community of people affected by bladder cancer

Advocate for access to the best possible bladder cancer information, support, and care

#### Build alliances

with health professionals, policymakers, academics, researchers, and industry World Bladder Cancer Patient COALITION

### Bladder cancer across the globe





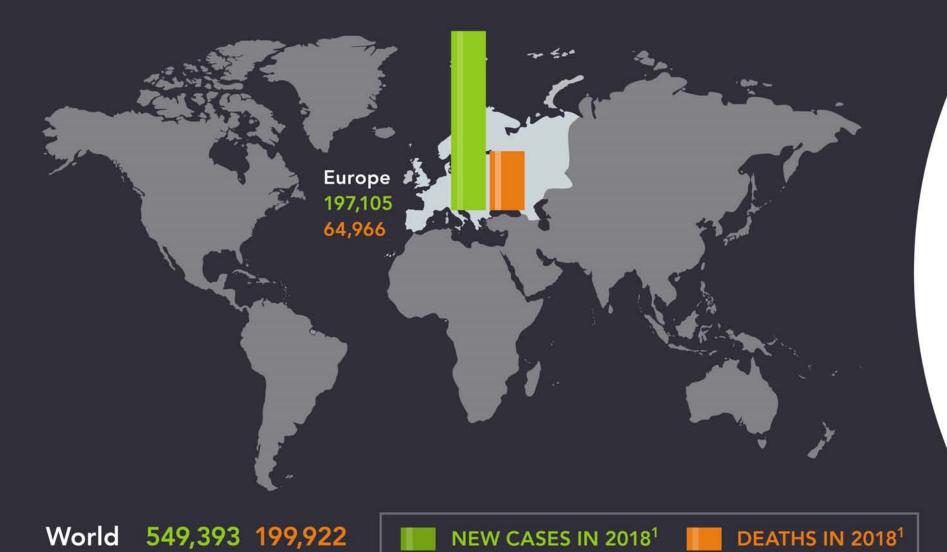
**Worldwide** Bladder cancer is the



It is the leading cancerrelated cause of death

> <sup>1</sup> International Agency for Research on Cancer (IARC). 2018. Bladder. Online

### **Bladder cancer – Europe**



World Bladder Cancer Patient

**Worldwide** Bladder cancer is the

Oth most common cancer

It is the leading cancerrelated cause of death

> <sup>1</sup> International Agency for Research on Cancer (IARC). 2018. Bladder. Online



# The value of patient voice



# The value of patient voice

National bladder cancer patient groups are close to the affected communities, enabling them to:

#### Listen

- Improve understanding of the impact of disease and also doing so at personal level
- Better respond to the needs of people affected by bladder cancer
- Support evidence-based advocacy
   & policy, partnerships & research





# **Starting one**

Our members have considered their own experiences in starting bladder cancer groups, and we have combined our collective knowledge for you in this guide.

- Promote the establishment of bladder cancer patient groups in different countries
- Provide pre-made resources and share best-practice examples for getting started
- Inform, support and create unity among bladder cancer patient groups
- **Grow** the global community of bladder cancer patient groups



## Understanding bladder cancer patient experience



#### Understanding bladder cancer patient experience

WBCPC is conducting an evidence generation study to capture bladder cancer patient and caregiver experiences around the world.

- Deepen and quantify the understanding of bladder cancer patient and caregiver experiences and preferences.
- Identify common challenges, roadblocks to access, ways to improve patient experiences and patient outcomes, which can be addressed from an international scale and locally
- Propose ways to improve outcomes and support services for people affected by bladder cancer and their caregivers.





# Patient experience World Blad Cancer Patience

- Approximatelly 75% of newly diagnosed bladder cancer is non-muscle invasive bladder cancer (NMIBC)
- 30 years of mostly unchanged treatment landscapeHighly invasive treatments, affecting quality of life
- BCG treatment and **pervasive shortages** of treatment
- High rate of reoccurance and progression leads to life-long uncertainty, fear and anxiety
- Over half of patients never heard of bladder cancer



**Bladder Cancer Awareness Month** Digital World Tour

May 2021

# Raising awareness around the globe

worldbladdercancer.org

World Bladder Cancer Patient

COALITION

### **Creating awareness beyond borders**

### In May 2021, WBCPC will bring bladder cancer community together on the Digital World Tour to:

- Increase awareness about signs, symptoms and treatment options for bladder cancer across the world
- Unite and empower world bladder cancer organisations and groups to speak in one voice while amplifying country level initiatives
- Encourage the establishment of bladder cancer organisations in countries where they do not yet exist
- Share the evidence for policy change in bladder cancer in different countries, showcasing patients' unmet needs and advocating for increased funding
- Grow and nurture a global network of national and international stakeholders to support and elevate WBCPC objectives





### Have You Ever Heard about Bladder Cancer?





### **#BladderCancerAware**

- Branding the Bladder Cancer Facts and Figures with this concept creating a series of did-you-know facts
- Turning our series of patient quotes in a series of quotes from people who experienced bladder cancer in different ways (be it a patient or a family member, a doctor, a researcher, an advocate etc.)
- Encouraging communities to take away bladder cancer facts and ask one person (online or offline) if they "Have you ever heard about bladder cancer?" share the fact and ask them to pay it forward.

# Campaign page and resources

Visit worldbladdercancer.org to explore the map, and campaign resources to help you join the campaign!



World Bladder Cancer Patient COALITION

### Thank you.

#### Get in touch:

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World Bladder Cancer Patient

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