



The second annual
WORLD BLADDER CANCER
Patient Forum 2022

Summary report

Changing bladder
cancer patient
care together

#BladderCancerForum

worldbladdercancer.org



World Bladder
Cancer Patient
COALITION



Introduction

The second World Bladder Cancer Patient Forum took place in 2022, bringing our community together in Paris, France and virtually. This year's Forum was a milestone event for our international community. Both because we got to get together for the first time in person and as we shared insights from our first **bladder cancer patient and carer survey** for the first time.

This year's theme, 'Taking bladder cancer patients' voice forward', was a stepping stone for action. The theme recognises the need for international multi-stakeholder collaboration to achieve our goal of improving the lives of people affected by bladder cancer no matter where they live.

This report documents the many ideas and perspectives discussed during the Forum. We hope the exchanges summarised here to inform and inspire you. We welcome feedback to continue the dialogue and invite all stakeholders to connect with the **World Bladder Cancer Patient Coalition** and work together.

Click [here](#)
to watch
the event
highlights:



If you
missed the
event, you can
view the event
recording
here



Ensuring the patient voice drives bladder cancer research, treatment, and care



Lori Cirefice



Lydia E. Makaroff

The World Bladder Cancer Patient Forum 2022 was a special second edition of our now-annual event hosted with our member organisation Cancer Vessie France. It is the first time since 2019 that our bladder cancer patient advocacy community has joined together in person. We now count 15 member organisations from around the world, and it was wonderful to bring them together in Paris. Our members have led many impactful initiatives over these last few years. We were thrilled to welcome their presentations at this event.

Knowledge and inspiration are what drive improvement in the support, information and advocacy for people affected by bladder cancer around the world. We are proud that our member organisations are committed to sharing knowledge and empowering each other.

This year, we also shared the key insights emerging from our Bladder Cancer Patient and Carer Survey. The findings set the scene for an engaging discussion with patients, bladder cancer, and policy experts centred around the Forum theme of 'Taking bladder cancer patients' voice forward.'

For the second year in a row, our Forum event proves the commitment to collaboration in our community and with many stakeholders and partners we work with. This summary report highlights key outcomes of the event and the discussions. It serves as a guide for concrete next steps and actions to continue our work to take forward patients' voices and improve the lives of people affected by bladder cancer around the world.

Lori Cirefice
Vice-President, WBCPC

Dr Lydia Makaroff
President, WBCPC

Our mission is to:



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, policy makers, academics, researchers, and industry

Dedicated session for bladder cancer patient advocates

This year, we were thrilled to welcome our member organisations from across the world. These bladder cancer patient organisations offer incredible inspiration with their efforts to support people affected by bladder cancer and drive much-needed change locally.

Together with our member organisations, we held a dedicated session where we reflected on areas of most urgent needs, which will help all of us to collaborate more effectively, to continue to grow and improve the support for the bladder cancer patient community around the world.

We started the session by brainstorming on how WBCPC and our members can better work together to strengthen, support, and address the needs of people affected by bladder cancer in their respective countries and collectively make an impact globally through the work of the Coalition.

One of the core challenges identified when addressing the needs of patients and carers is the diversity of language and culture. The healthcare systems vary significantly across countries, and universal healthcare coverage still isn't a reality for many patients. We also recognised the impact of a limited number of existing bladder cancer patient groups around the world and the difficulty in connecting directly with patients.



To promote a strong network that supports people affected by bladder cancer internationally, we have concluded that firstly, we need to reach out to healthcare decision-makers, researchers, bladder cancer patients and caregivers. Secondly, by order of priority, we need to work on the following areas:

- **We need to work with healthcare professionals to identify new advocates**
- **We need to identify common advocacy issues to work collectively on**
- **We need to share our projects and initiatives with other advocates to inspire and support each other and strengthen our community organisations.**

Dedicated session for bladder cancer patient advocates

The session was followed by a discussion on how the World Bladder Cancer Patient Coalition can better support and promote collaboration with member organisations, future members, and start-up groups.

With this objective in mind, we have concluded and prioritised the following focus areas:

- Link up and share our member organisation's information to help other organisations and start-up groups with new initiatives
- The importance of having more members in the Coalition to have a bigger and stronger voice internationally
- Help our member organisations by providing them with information regarding securing financial support and grants for projects



We would like to thank our member organisations for the engaging conversations during this session and for joining us for the World Bladder Cancer Patient Forum 2022. Our collective efforts help move the conversation forward to improve the lives of bladder cancer patients worldwide.

Program overview

Session I: Shining a light on bladder cancer patients & carer experiences

GLOBAL BLADDER CANCER PATIENT SURVEY 2022 RESULTS:

The first ever survey of its kind to shine a light on bladder cancer patient experiences around the world concluded in 2022.

Alex Filicevas World Bladder Cancer Patient Coalition, Belgium

DISCUSSION OF SURVEY FINDINGS:

Following the presentation of the findings, we will hear further perspectives on the insights emerging from the survey findings and what it means in practice.

Dr Ashish Kamat MD Anderson Cancer Center, International Bladder Cancer Group, International Bladder Cancer Network, Société Internationale d'Urologie, USA

TAKING BLADDER CANCER PATIENTS' VOICE FORWARD THROUGH ACTION:

Multi-disciplinary moderated panel discussion will share their views, and concrete actions on taking patients' voices shared with us in the survey forward.

- **Dr Lydia Makaroff** World Bladder Cancer Patient Coalition; Fight Bladder Cancer, UK
- **Liesbeth de Boer-Oosterhuis** Leven met blaas- of nierkanker, Netherlands
- **Dr Ignacio Durán** Hospital Universitario Marqués de Valdecilla, Santander, Spain
- **Sarah Collen** European Association of Urology, Belgium
- **Stephen Head** Astellas, UK

Session II: Rising to the challenge – Examples from the patient community

COMMUNITY SUPPORT AND ADVOCACY PROJECTS LEADING CHANGE:

WBCPC member organisations will showcase initiatives from their countries that drive improvements and better support for people affected by bladder cancer.

- **Dr Stephanie Demkiw** Bladder Cancer Awareness Australia
- **Laura Magenta** Associazione PaLiNUro, Italy
- **Michelle Colero** Bladder Cancer Canada

Closing remarks



Bringing different perspectives towards a common goal

Session I: Shining a light on bladder cancer patients & carer experiences



For relevant research and optimal care for bladder cancer, the patient's voice needs to be at the centre of the conversation.

The first session, *"Shining a light on bladder cancer patients & carer experiences"*, featured the early results from the Bladder Cancer Patient and carer Survey presented by Alex Filicevas, WBCPC Executive Director. A summary of key highlights offered insight into lived experiences of people affected by bladder cancer around the world, which will be published in 2023.

It also featured an interview with Dr Ashish Kamat, Chair of the Expert Advisory Committee and Dr Lydia Makaroff, President of the World Bladder Cancer Patient Coalition. The brief interview focused on the most prominent findings emerging from the global survey and the more critical ways to address some of the results.



This was followed by a multi-stakeholder moderated panel discussion on concrete ways of taking the patient's voice forward. Attendees heard different perspectives from patient advocates, medical society, healthcare professionals and industry representatives.

Dr Lydia Makaroff, President of the World Bladder Cancer Patient Coalition and Chief Executive of Fight Bladder Cancer in the UK, moderated the discussion and invited four speakers to share their perspectives:



Bringing different perspectives towards a common goal

Session I: Shining a light on bladder cancer patients & carer experiences



Liesbeth de Boer-Oosterhuis, President of **Leven met blaas- of nierkanker**, highlighted the importance of providing sexual counselling to all patients before radical cystectomy surgery. The need for patients to know and understand the symptoms of bladder cancer was also highlighted. Liesbeth stressed that it is especially important for female patients, as they often tend to be misdiagnosed during menopause.



"One of the call-to-action items is to increase the awareness of bladder cancer signs and symptoms in general but also specifically to primary care physicians."

Dr Ashish Kamat
MD Anderson
Cancer Center



"Symptoms in female patients are commonly attributed to infections or gynaecological issues which delay diagnosis and treatment of bladder cancer."

Liesbeth de Boer-Oosterhuis
President of **Leven met blaas- of nierkanker**



Dr Ignacio Durán, the medical oncologist at the Hospital Universitario Marqués de Valdecilla, emphasised the important role of patient advocacy organisations in providing information and support to patients affected by bladder cancer. He noted that patient advocacy organisations could play a crucial role in shared-decision making, which is fundamental for the patients.



"Patient groups have a role in the whole structure of treatment. Healthcare professionals can do so much but cannot cover everything."

Dr Ignacio Durán
Universitario Marqués de Valdecilla

Stephen Head, Senior Director, Patient Partnerships at Astellas, underscored the importance of raising our collective voice when it comes to bladder cancer. There is very low awareness of the signs and symptoms of the disease. He further discussed the caregivers' impact as they are often overlooked and have an equal disadvantage.



"Bladder cancer is often forgotten. This is why awareness is a huge tool regarding that disease. We need to keep talking about it and raise our voices about the risk factors and symptoms."

Stephen Head
Patient Partnerships at Astellas



"Building alliances and partnerships is fundamental. Similar issues are being experienced by other cancer patients. Therefore the voice of patients must be prominent in networks and policy forums both nationally and internationally."

Sarah Collen
European Association of Urology



Sarah Collen, EU policy manager at the European Association of Urology, spoke about the importance of building multi-stakeholder partnerships at the European and International level. She mentioned various policy and research initiatives, such as Europe's Beating Cancer Plan and EU Cancer Mission, which offer opportunities for all stakeholders, including the patient community, to get involved.



Session II: Rising to the challenge – Examples from the patient community.

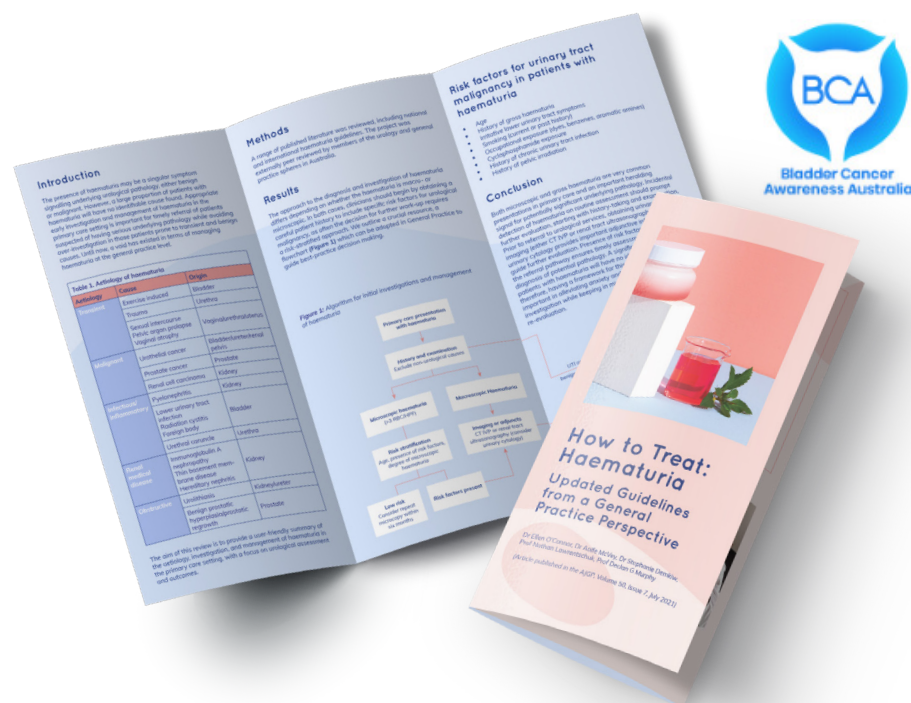


The *“Rising to the challenge – Examples from the patient community”* session featured three initiatives from the World Bladder Cancer Patient Coalition member organisations working to support patients and carers in Australia, Canada and Italy.

These initiatives showcased the diversity of incredible efforts of patient organisations to support people affected by bladder cancer and drive much-needed change locally.

Dr Stephanie Demkiw, the co-founder of Bladder Cancer Awareness Australia, presented the Australian project. They co-developed updated guidelines from a general practice perspective about how to treat haematuria. This resource summarises the cause of the disease, investigation, and management of blood in urine in the primary care setting, focusing on urological assessment and outcomes.

It is available as a brochure and a peer-reviewed publication.



“Blood in the urine is one of the most common urological presenting complaints in Primary Care and one of the main issues which can be seen in many countries around the world is that us, GPs, do not receive clear and specific general guidelines on how to approach a patient coming after seeing blood in their urine.”

Dr Stephanie Demkiw
Bladder Cancer Awareness
Australia



"For patients with the prospect of having a radical cystectomy, it is essential to be able to receive support and speak to people that have followed the same clinical path."

Laura Magenta
Associazione
PaLiNUro



Laura Magenta from Associazione PaLiNUro in Italy, presented the URO-H-Angels initiative launched in 2019. The programme with accreditation at major Italian hospitals with an onco-urology department. URO-H-Angels aims to create an additional support opportunity for bladder cancer patients with the prospect of having a radical cystectomy surgery. URO-H-Angels offers interactions with volunteers who have been through the same pathway as complimentary support. The project is currently active in 11 hospitals across Italy. The long-term mission is for URO-H-Angels to be present in every hospital in Italy where patients affected by bladder cancer need support.



**Michelle Colero,
the Executive Director
of Bladder Cancer**

Canada, presented the Canadian Bladder Cancer Information System (CBCiS). The CBCiS is a database which collects depersonalised information about current bladder cancer practice and treatment outcomes. CBCiS aims to identify the gaps in bladder cancer care, evaluate unmet needs and improve the management of bladder cancer patients in Canada.



"CBCiS, which stands for the Canadian Bladder Cancer Information System, has as a goal to identify the gaps in bladder cancer care, evaluate unmet needs and improve the management of bladder cancer patients. It is a database that collects depersonalised information such as bladder cancer history, medical information, practice patterns etc."

Michelle Colero
Bladder Cancer Canada



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Our members



Useful links & resources

- PaLiNUro Uro-H angels
- Fight Bladder Cancer UK Patient Information Booklets
- The Canadian Bladder Cancer Information System
- WBCPC Start-up guide for bladder cancer patient groups



World Bladder
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COALITION

Our story

The World Bladder Cancer Patient Coalition was established in January 2019 by dedicated patient advocates from three major national bladder cancer organisations that saw the need for a global bladder cancer coalition.

Our Coalition now brings together 15 patient organisations from five continents, uniting the vision and goals of bladder cancer patient organisations to ensure the best possible outcomes for bladder cancer patients across the world. This Coalition is the first time people affected by bladder cancer have a force connecting bladder cancer patients, groups, and organisations worldwide.

Our network

The World Bladder Cancer Patient Coalition is a global community of bladder cancer patient organisations dedicated to improving the lives of people affected by bladder cancer. Our strength comes from our members, affiliates and partners.

We are continuously growing our global bladder cancer patient community and currently work together with 15 cancer patient organisations, all of whom are members. We work closely on joint initiatives and collaborate on advocacy and awareness-raising activities. We also share tools, information and resources collectively.

If you would like to become a member or would like to start a bladder cancer patient group in your country, visit our website to learn more and get in touch with us directly.



You can find us here:

Twitter: @WorldBladderCan

Instagram: @WorldBladderCan

Facebook: WorldBladderCan

Website: worldbladdercancer.org

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YouTube: Search World Bladder Cancer
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