The first annual
WORLD BLADDER CANCER
Patient Forum 2021

Summary report

Changing bladder cancer patient care together

#BladderCancerForum

worldbladdercancer.org

World Bladder
Cancer Patient
COALITION

Program

Speaker biographies are online here

You can watch the forum here

Welcome & introduction

Moderator: Dr Lydia Makaroff (UK)
President, WBCPC & Chief Executive, Fight Bladder Cancer

Session I: Patient centricity – from research to care

KEYNOTE: Patient involvement in bladder cancer research

Dr Ashish Kamat (USA)
Professor, Department of Urology, MD Anderson Cancer Center

PANEL DISCUSSION AND Q&A:

Susan Mullerworth (UK)
Bladder Cancer Patient Advocate

Lauren Pretorius (SA)
CEO Campaigning for Cancer

Dr Maria Rivas (USA)
Senior VP, Chief Medical Officer, Merck/EMD Serono

Nathalie Bere (NL)
Patient Engagement, European Medicines Agency

Dr Bente Thoft Jensen (DK)
Chair, Bladder Cancer Group, European Association of Urology Nurses

PRESENTATION: Capturing patient and carer experiences globally

Alex Filicevas (BE)
Executive Director, WBCPC

Session II: Patient advocacy – sharing knowledge, driving change

FEATURING:

Laura Magenta (IT)
Associazione PaLiNUro

- **A 'Trip Advisor' for hospitals:** Helping patients navigate bladder cancer clinical pathways in Italy, by establishing an application that transparently ranks and evaluates quality of care delivered by Italian hospitals and clinics.

Tony Cornacchia (CA)
Bladder Cancer Canada

- **Canadian Bladder Cancer Information System (CBCIC):** Working to create a core information system housing clinical data for patient-centred research and care.

Melanie Costin (UK)
Fight Bladder Cancer

- **Patient information booklets:** Helping to fulfil the information needs of patients and families in the UK, by creating a series of free and accessible patient information booklets.

PANEL DISCUSSION AND Q&A

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

Alex Filicevas

We are proud to host the first-annual World Bladder Cancer Patient Forum virtually on September 22, 2021. It was a great success, with over 150 registered attendees from 35 countries. Our theme this year was *'Changing bladder cancer patient care together'* and shone a light on the importance of the bladder cancer patient voice. This report documents the discussions had, and ideas generated.

The World Bladder Cancer Patient Coalition aims to play a positive role in ensuring the patient voice is always accounted for in everything we do as a healthcare and patient advocacy community.

Alex Filicevas
Executive Director, World Bladder Cancer Patient Coalition

Lydia E Makaroff

The World Bladder Cancer Patient Coalition is a young organisation. Founded in 2019 by a group of dedicated patient organisation from Canada, the UK, and the USA, who saw the need for an organisation to represent global patient interests. What began as a team of 3, has expanded to 11 patient organisations across 4 continents.

Bladder cancer is a disease that does not recognise country borders and is a global crisis. It was incredibly inspiring to see so many people represented at this years' Patient Forum.

Lydia Makaroff
President, WBCPC, & Chief Executive, Fight Bladder Cancer UK

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

Session I: Patient centricity – from research to care

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 *"Patient centricity: from research to care"* featured a scene-setting presentation on patient involvement in bladder cancer research from Dr Ashish Kamat, MD Anderson Cancer Center. It was then followed by a multidisciplinary moderated panel discussion on the unique challenges and opportunities for integrating the patient voice into all aspects – from research design, to care delivery and policy change. Attendees heard different perspectives including from patients, patient advocates, industry, regulatory authority, and clinicians.

Amplifying the patient voice through patient advocacy:

Patient groups, and patient advocates, are key to ensuring the patient voice is widely heard. Vibrant patient communities are the platform needed to bring people's voices and experiences to the centre of the conversation that shape bladder cancer policies, informs clinical practice, and influence research.

Susan Mullerworth, a Bladder Cancer Patient and Advocate in the United Kingdom, provided her thoughts on ensuring the patient voice is incorporated throughout her work. She provided examples that have proven successful, including engagement with patient advisory boards, and collecting patient data through surveys, or other means. Patient insights are then brought into market research, clinical trials, research publications, and patient-driven projects or initiatives.

> "The patient voice needs to be authentic, coming from patients themselves. It is vital for quality of care, better outcomes, and patient survival."
>
> **Susan Mullerworth** (UK)
> *Bladder Cancer Patient Advocate*

> "If you are doing something, and you have not consulted the patient, then it is probably not worth doing."
>
> **Lauren Pretorius** (SA)
> *CEO Campaigning for Cancer*

Lauren Pretorius, CEO of Campaigning for Cancer in South Africa, agreed that patient advisory boards are key to ensuring the work they do in South Africa is patient-driven – and commented on the usefulness of other forums that allow for direct dialogue with people in her community, such as live events and social media. As a result of this direct patient engagement, each project they conduct in South Africa is a direct result of insights gained from the patient community, addressing the challenges they face.

"Patient advocates have a responsibility to represent the thoughts and views of patients around the world"

The patient voice in research:

Dr Ashish Kamat, Professor of Urologic Oncology, MD Anderson Cancer Center, provided a thought-provoking account on the importance of involving patients in all aspects of clinical research – from the start.

He expressed that the research community must go beyond simply raising awareness about a study among the public or involving people in study recruitment. Far too often in clinical trials, patients are only consulted after the study has concluded.

> "To truly have meaningful patient involvement in research, research must be carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them."

This means involving patients in research early – in initial study design, and equally over the course of study implementation. It would only strengthen the design and usefulness of the research output.

Urging the research community, he asked them to remember that a failure to consider the patient voice upfront, means that more time and resources will be invested into a study that may not be meaningful to patients.

He provided countless examples of where patient involvement in clinical research has shifted study design and increased the usefulness of study outputs.

> "Researchers should engage with patient advocacy organisations early on to ensure their work is meaningful to patients and their families."
>
> **Dr Ashish Kamat** (USA)
> *MD Anderson Cancer Centre*

> "Only by understanding patients needs, can we truly delivery better care and outcomes."
>
> **Dr Bente Thoft Jensen** (DK)
> *Bladder Cancer Group, European Association of Urology Nurses*

The patient voice in treatment and care:

Dr Bente Thoft Jensen, Chair of the Bladder Cancer Group at European Association of Urology Nurses – provided the healthcare professional perspective.

At the European Association of Urology Nurses, patient education materials are always created alongside patient advocacy groups to ensure that patient needs are appropriately interpreted and understood. In turn, the information in the support materials reflect the patient voice. This can significantly impact the information included within the educational materials, as she noted 'what patients need to know is not always what we as nurses think they need'.

In clinical care, she stressed the importance of carrying out in-depth needs assessments for all bladder cancer patients to fully understand their treatment and care needs, but equally the value of patient educated to allow patients to fully participate in their care and joint decision making.

In Denmark, the patient voice is given proper value in designing clinical pathways, with a specialist group of bladder cancer patients invited to adjust the national clinical guidelines for bladder cancer management, every two years, resulting in a greater focus on patient needs.

Patient involvement in regulatory affairs:

For over 25 years, the European Medicines Agency (EMA) has incorporated the patient voice into decision-making.

Nathalie Bere, working on patient engagement within the EMA, shed light on these approaches – including having patients on their management boards, members of their medicine evaluation committees, and involvement in the entire regulatory lifecycle.

She encouraged people interested in working with their national regulatory bodies to reach out directly and see what opportunities exist at the country-level.

Nathalie gave advice for other regulatory bodies around the globe wishing to better engage patients:

"Take a stepwise approach to doing so. Conduct pilot projects to learn how to best capture their perspectives, and then implement more concrete and long-term ways to bring in patients across your organisation."

Lifescience commitment:

Dr Maria Rivas, Senior VP and Chief Medical Officer, Merck/EMD Serono, expressed that they have adopted has adopted a patient directed approach to the work they do.

In research, they partner with patients, advocates, and caregivers; and they have also placed a strong focus on improving diversity of clinical trial recruitment and research participation – to ensure that a variety of patients from different backgrounds can better understand the impact of treatments on their physical and mental health.

Industry is also beginning to focus on examining the impact of treatment interventions on not only the patient, but also on the caregiver.

She believes that industry should listen more carefully to the patient voice, and not assume that the knowledge already exists within their corporations. She said, *"always keep a moral compass and ensure everything you do is in the best interest of the patient".*

WBCPC Global Bladder Cancer Patient Survey: Understanding bladder cancer patient experiences

The WBCPC presented their inaugural Global Bladder Cancer Patient Experience survey that launched October 1st this year.

Executive Director Alex Filicevas said that *"the study aims to give a voice to people living with bladder cancer, and both deepen and quantify the understanding of their experiences."*

The worldwide unique insights and experiences of patients and carers have not previously been measured, and are thus not appropriately integrated into policy, advocacy, and research decisions

The survey findings will fill a global evidence gap that exists on the experiences of bladder cancer patients and carers around the world shed light on common challenges, roadblocks to access, and ways to improve experiences and outcomes.

"We hope to gain a clear mandate on priorities for care improvements, that will guide our advocacy and policy work for years to come."

The survey can be completed here

Please help us spread the word, by circulating the survey within your bladder cancer network

Session II

Patient advocacy – sharing knowledge, driving change

By sharing information, knowledge, experiences, and successes with each other we can more effectively drive forward positive change.

Giving the floor to patient organisations during the second session *"Patient advocacy: sharing knowledge, driving change,"* WBCPC President Dr Lydia Makaroff invited three member organisations from the coalition to share their recent and imminent projects making a positive impact in their country.

ITALY: Supporting patients to find hospitals and clinics for their bladder cancer needs

Laura Magenta, a patient herself who dedicated her time to patient advocacy following her diagnosis, represented the Associazione PaLiNUro work during the Patient Forum.

As the only organisation in Italy working to raise awareness of bladder cancer and support Italian patients, they have an important role to play in Italy. A large quantity of their time is dedicated to helping patients navigate along the clinical pathway, following a new cancer diagnosis, and guiding patients to the correct and most competent hospital to undergo their bladder cancer treatment.

This sparked a new project, being compared to a 'Trip Advisor' but for Italian hospitals and clinics. PaLiNUro has developed an application to guide people in choosing the most competent, effective, and humane hospital for their bladder cancer treatment. The application will transparently showcase an evaluation from other bladder cancer patients themselves, on the quality of care that patients receive at different hospitals and clinics around the country, to support their selection.

The application has launched after an initial testing phase of around 6 months with a small group of patients. PaLiNUro aims to have the application running at full capacity within 4–5 years. Access the application here.

How else are you supporting patients in Italy?

Two years ago, we developed three WhatsApp chats – one for neobladder patients, one for urostomy patients and one for non-muscle invasive bladder cancer patients.

The WhatsApp groups facilitate connections for people across the whole country. It has created a positive environment for patients to share and support one another.

CANADA: Embracing the medical and research community to strengthen patient advocacy

BLADDER CANCER CANADA
CANCER DE LA VESSIE CANADA

CBCIS
CANADIAN BLADDER CANCER INFORMATION SYSTEM

Tony Cornacchia, a volunteer at Bladder Cancer Canada (BCC), is a metastatic bladder cancer survivor first diagnosed in 2014.

He shed light on BCC's work to build strong partnerships through its medical advisory and research boards in Canada – made up of urologists, pathologists, and oncologists. These partnerships help BCC validate and authenticate their patient advocacy work to improve quality of care, on research and clinical trials, in seminars and trainings, and advocacy on access to bladder cancer treatments in Canada.

BCC is a founding partner of the Canadian Bladder Cancer Information System (CBCIS), a project working to house core clinical data on bladder cancer. This data hub combines clinical data from multiple sources and will be used to conduct novel research to improve bladder cancer patient care and outcomes. Over the next several years, the aim is to have CBCIS become a rich repository to find answers to important questions about the clinical management of bladder cancer.

> "The public awareness materials in Canada are fantastic. I have seen awareness posters at bus stops, etc in Toronto. Well done BCC!"
>
> *Attendee from Canada*

UNITED KINGDOM: Providing patients with good information – a series of patient information booklets

fight bladder CANCER
Registered charity 1157763

Melanie Costin is the Support Services Manager for Fight Bladder Cancer UK and is a patient herself. When she was diagnosed with bladder cancer, she was not provided with any information at all, and what she could find was gruelling to read, text heavy and difficult to understand. Her experience is well documented by other bladder patients across the UK, which sparked Fight Bladder Cancer to create their own patient-friendly information booklets.

Most importantly the patient information booklets are written by patients, for patients. A total of 10 booklets were created, covering all aspects of diagnosis, treatment, care, and surviving bladder cancer. They include a patient story in each booklet, giving an account of individual patient experiences. Booklets have been distributed to nurses and other healthcare professionals and can be used as a discussion aide with their patients. Patients, doctors, and nurses can order and request a copy easily and for free.

> "Be sure to include real-life patient stories and experiences in patient information materials to add a richness in contents that cannot be created otherwise."
>
> **Melanie Costin** (UK)
> *Fight Bladder Cancer*

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Our members

- fight bladder CANCER Registered charity 1157763
- BCAN Bladder Cancer Advocacy Network
- BLADDER CANCER CANADA / CANCER DE LA VESSIE CANADA
- Blærekreftforeningen
- BLADDER CANCER AUSTRALIA CHARITY FOUNDATION BladderCancer.org.au
- CANCER VESSIE FRANCE LES ZUROS
- Action Bladder Cancer UK
- APS Associazione PaLiNUro PAZIENTI LIBERI DALLE NEOPLASIE UROTELIALI
- Blærekreft Norge
- BCA Bladder Cancer Awareness Australia
- CAMPAIGNING FOR CANCER

Useful links & resources

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

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 11 patient organisations from four 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 constitutes the first time that people affected by bladder cancer have a force connecting bladder cancer patients, groups, and organisations worldwide.

Approximately 500,000 people are newly diagnosed with bladder cancer around the world each year. The need to elevate a global common voice for people affected by bladder cancer is critical.

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 11 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
Facebook:	WorldBladderCan
Website:	**worldbladdercancer.org**
Email:	**info@worldbladdercancer.org**
YouTube:	Search World Bladder Cancer Patient Coalition

World Bladder Cancer Patient Coalition

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SAVE THE DATE

See you next year in Paris, France, on September 8th 2022

World Bladder Cancer Patient
COALITION