



World Bladder
Cancer Patient
COALITION

The third annual WORLD BLADDER CANCER Patient Forum 2023

Summary report

worldbladdercancer.org



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Introduction

The 3rd annual World Bladder Cancer Patient Forum was held in 2023 in Madrid, Spain. Once again, it served as a platform of knowledge and partnership for the global bladder cancer patient community. The Forum brought together people affected by and working with bladder cancer – patients, patient representatives, healthcare professionals, experts, and industry representatives, **fostering knowledge sharing and inspiring conversations** on addressing some of the most pressing challenges in our patient community worldwide.

This year, we especially focused on **understanding bladder cancer patients' supportive and complementary care needs**. The Forum featured engaging presentations and facilitated insightful discussions with speakers from different corners of the world.

This report aims to provide information and highlight key points from the discussions and varied perspectives across the sessions. **We also hope it inspires collaboration, increased focus and new initiatives to support people affected by bladder cancer.** We welcome your feedback so that we can continue the dialogue. We invite all stakeholders to engage with the World Bladder Cancer Patient Coalition and collaborate towards our shared goals.

If you missed the event, you can view the event recording [here](#)



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



Foreword



Lori Cirefice

Lori Cirefice
Vice-President,
WBCPC



Alex Filicevas

Alex Filicevas
Executive Director,
WBCPC

The World Bladder Cancer Patient Forum 2023 was a genuine reflection of the tireless dedication across our global bladder cancer patient advocacy community. We were delighted to see a great turnout for this year's Forum, where we witnessed the strengthening bonds among our member organisations.

Our third annual event was a celebration of the impactful initiatives led by our members, who have repeatedly shown their commitment to continue improving support, information, and strengthening advocacy for people affected by bladder cancer. Their insightful presentations once again proved the collective wealth of knowledge and inspiration that drives progress in our coalition's communities.

The findings from the Bladder Cancer Patient and Carer Survey guided the day, and set the groundwork for an engaging and meaningful discussion with patients, advocates, policy experts and healthcare professionals. This conversation on addressing patients' needs in practice was a reaffirmation of our commitment to ensure that the voices of those affected by bladder cancer are not only heard, but that action is taken to address their needs collaboratively.

This year, our Forum once again demonstrated the power of collaboration within our community and with the stakeholders and partners we work alongside. The discussions and outcomes of this event have been carefully captured in this summary report, serving as a path to guide our actions for the future and inspire others to join us. We are committed to continuing our work to amplify the voices of patients, survivors and carers, and making a strong bladder cancer patient advocacy a reality all across the world by supporting, connecting and empowering new and existing groups. Together, we can improve the lives of those affected by bladder cancer around the globe faster than if we do it alone.

We thank everyone who has contributed to the success of this year's Forum. Our members, sponsors, colleagues and friends – your invaluable input and collaborative spirit are the pillars that support our journey towards our shared vision of a world without bladder cancer.

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

Workshops deliver strong aspirations and commitment to do more

The workshops brought together bladder cancer patient advocates for an inspiring morning of working together. Our member organisations, seasoned and new bladder cancer patient advocates, people with bladder cancer and their loved ones engaged in focused collaborative workshop sessions.

Together, we brainstormed and shared experiences on developing unique approaches to raising awareness and building locally impactful communities and a broader coalition with a global reach. This session was a brilliant showcase of our community's collective vision and the transformative changes we strive to achieve to improve the lives of people with bladder cancer.

There was a general consensus for a more diverse approach to patient support and awareness raising tactics. Members underscored the necessity of using creative digital avenues to reach a wider population to sensitise and educate the general public about bladder cancer, including signs and symptoms to look out for. Traditional methods of outreach and awareness were seen as more effective at reaching at risk populations through events, fundraising initiatives or posters in the workplace, pharmacy, or the waiting area at the doctor's. All of which could be a central part of the annual Bladder Cancer Awareness Month in May, where our global community comes together

to bring much-needed attention to bladder cancer. Personal bladder cancer patient stories are an increasingly important element for new educational resources and awareness raising activities for relatable, impactful and lasting messages.



Even beyond May, there was an undeniable strong ambition for innovative local initiatives to support the objective of building a community of support for and by people affected by bladder cancer. The Uro-H Advisor program in Italy and the "Wee Walks" organised in the UK are some examples of ways patient advocates at the national level are working to bring together the local communities.



"Being able to talk freely and openly about my bladder cancer experience with so many people who have lived through it themselves and work to help and pave the way for a better experience for others was truly inspiring."

Workshops deliver strong aspirations and commitment to do more

Additional themes emerged as part of the discussions as commonly important challenges requiring multi-stakeholder collaboration and strengthened focus:

- Access to the best possible treatment and care.
- Promoting and achieving improvement in early detection.
- Education and sensitisation to bladder cancer, its symptoms and causes.
- Collaboration with healthcare professionals, especially General Practitioners, family doctors or primary care physicians.

Looking to the future, our global bladder cancer patient community is dedicated to enhancing peer support programmes and their access, establishing Patient Advisory Boards to guide our activities and embracing language and cultural diversity by championing inclusivity throughout our initiatives.

One of the core objectives of WBCPC is to help starting and fledgling bladder cancer patient groups, and patients and carers who are ready to start their own community in their country. Naturally, this was another major focus of the conversations. Fostering new patient support groups and organisations around the world

remains a key objective for all members of our coalition. Some ways to continue this programme are through knowledge and experience exchange, direct support and new and existing tools such as Start-up guides for bladder cancer patient groups. Also, we should emphasise connecting individuals locally, nationally, and across borders, reducing isolation through shared experiences, and helping our collective advocacy and support grow and strive for better.

"At the Forum, we saw incredibly diverse strategies from around the world for supporting bladder cancer patients. I'm excited to bring these ideas back to enhance what we do at home."

Angela Pelletier
Bladder cancer patient,
Bladder Cancer Canada

Establishing support groups: Initiating support groups, either online or in-person, for people affected by bladder cancer, providing a platform for shared experiences and information exchange.

Solid foundation: Focusing on establishing a solid foundation for new patient groups and projects from the beginning to ensure the sustainability and effectiveness of local initiatives.

Online education sessions: Develop a programme for online education sessions in 2024 for support and awareness, targeting a broader audience.

Treatment option discussions: Facilitating discussions about treatment options to provide clear, accurate information for better decision-making.

Distribution of printed materials: Providing printed materials to disseminate information and raise awareness in local communities.

The key takeaways from this session are a strong affirmation of our community's openness to creativity and commitment.

World Bladder Cancer Patient Forum 2023



This was our biggest World Bladder Cancer Patient Forum to date, and this year's event saw expanded and more inclusive participation throughout the day.

We welcomed over 100 attendees, over 50 in person and more online, joining us from 26 countries around the world.

This diverse gathering included patients, patient representatives, healthcare professionals, academia, industry representatives, and other stakeholders. By uniting such a wide range of participants, we facilitated invaluable connections and knowledge sharing that otherwise would not have been possible. This blend of perspectives and experiences enriched the discussions and fostered a deeper understanding of the diverse aspects of bladder cancer care and research.

To better understand the supportive and complementary needs of bladder cancer patients worldwide, the agenda featured presentations and discussions with key experts in different areas related to bladder cancer support, treatment, and care. By doing this, we created a holistic picture of what can and should be improved to improve bladder cancer care

- **Dena Battle, President and Co-Founder of KCCure** shared her inspiring journey within the organisation. She emphasised the pivotal role that patient communities have in driving positive changes in clinical practice and patient care. She has influenced clinical practice and patient care by establishing thriving patient communities, particularly on social media.
- **Michelle Colero, Executive Director of Bladder Cancer Canada**, presented insightful data from the Global Bladder Cancer Patient and Carer survey, focusing on supportive and complementary care needs. Her presentation underscored a critical insight: a staggering 82% of respondents expressed a need for more information, highlighting a prevalent gap in patient and carer knowledge. This highlights the pressing need for enhanced patient education and resources in the bladder cancer community.
- A thought-provoking conversation was held between **Prof Petros Grivas, Clinical Director of the Genitourinary Cancers Program at the University of Washington Fred Hutch Cancer Center**, and **Dr Lydia Makaroff**. They discussed the latest research developments in bladder cancer and what we can anticipate in the years ahead. One key area they highlighted was the potential of therapies tailored to specific genetic mutations in cancer cells, leading to better patient outcomes.



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- **Lauren Pretorius, CEO of Campaigning for Cancer**, introduced the 'Fika-Phila' project, an initiative designed to tackle the significant travel barriers faced by cancer patients in South Africa, leading to many missed appointments or medical follow-ups. The main feature of this project is developing a specialised app that loads paid transport tickets, where public transport is often inaccessible or unaffordable for many.



- **Carl-Henrik Sundin, the founder of the Swedish Bladder Cancer Society**, shared an inspiring story about his own experience with bladder cancer and how it led him to create a group to help others in Sweden facing a bladder cancer diagnosis. Recognising the crucial need for support and accurate information, he set out to build a community for people to connect and find support.

One of the first things he did was use Facebook groups. These groups were crucial, especially when

it was hard to meet in person because of the pandemic. People use these online spaces to share their stories, seek advice, and support each other. This sense of community was the foundation of the Swedish Bladder Cancer Society.

Starting the organisation came with its own set of challenging and exciting steps. Carl-Henrik talked about the positive experiences of gathering three people to officially start the group, creating rules, and getting the organisation recognised by the authorities. He also had to work on practical things such as opening a bank account, writing statutes and creating a website from scratch.

To make the organisation known, Carl-Henrik put together information packs and received support from medical companies to distribute them. This helped spread the word about the society and what it was doing to support people with bladder cancer.

The organisation aims to ensure that everyone with bladder cancer in Sweden gets the best care possible. They work on improving how bladder cancer is detected and treated, speak up for patients with authorities and in the media, support research, and share their findings. They work both in Sweden, regionally in the Nordics, and internationally.

Carl-Henrik's story and the success of the Swedish Bladder Cancer Society show the power of community and support when dealing with health challenges. It is an excellent example for anyone considering starting a bladder cancer support group in their country.



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Alongside these presentations and discussions, we hosted a panel discussion moderated by Dr Lydia Makaroff on addressing patients' needs in practice. We invited five speakers to share their perspectives and highlight areas of improvement or gaps, drawing from their personal and professional experiences.



"Ensuring patients have access to essential resources is fundamental. Collaboration and providing training on how to raise awareness of how to best support cancer patients is key and an area that needs to be improved."

Dr Silke Guenther
Director Global Medical Affairs,
Merck, Germany



"What needs to change is that we need to further incorporate patients into the decision-making process. It is imperative to institutionalise patient cancer advocacy all around the world."

Mélanie Samson
Senior Manager, Capacity
Building at UICC,
Switzerland



"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."

Lara Fernandez Rodriguez
Psycho-oncologist at
GEPAC, Spain



"It is fundamental that healthcare professionals treat the cancer patient as a person rather than a pathology. Understanding who the person is as an individual is fundamental in order to plan the journey of that patient."

Helen Lacy
Bladder cancer patient
and advocate, Australia



"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."

Comfort Maluleke
Senior Case Manager at
Campaigning For Cancer,
South Africa



World Bladder Cancer Patient Forum 2023

This year's Forum powerfully highlighted the critical gaps in bladder cancer care and support, laying out clear action points for the future. The discussions and presentations underscored the urgent need to view and treat patients medically and as whole individuals, focusing on their psychological well-being and personal journey. It became evident that there is a pressing requirement for better psychological support, more accessible resources, and stronger patient involvement in decision-making processes. Financial support emerged as a key area in making treatments more accessible and affordable globally.



Our ambition is that this event serves as a catalyst, motivating us to work towards a more collaborative approach among healthcare professionals, patients, and support groups. As we move forward, these insights pave the way for us to collectively bridge these gaps, striving for a future where every bladder cancer patient receives comprehensive and empathetic care tailored to their individual needs.



Following our Forum, we conducted a survey to gather feedback from all participants, which re-emphasised the points raised by our speakers. There is a need for increased collaboration to effectively address patient needs in practice and share the latest advancements in bladder cancer. Additionally, our members highlighted that the Forum is an excellent platform for learning from each other's diverse experiences and cultural perspectives, all of which contribute significantly to improving the support and care provided to bladder cancer patients.



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Our members



Useful links & resources

- Empowering Cancer Patients: Fika-Phila project eases transport barrier to treatment
- PaLiNUro Uro-H Angels
- WBCPC Start-up guide for bladder cancer patient groups
- Wee Walks
- Global Bladder Cancer Patient and Carer Survey



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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 14 patient organisations from six 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 14 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 want to become a member or 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

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