



World Bladder
Cancer Patient
COALITION

The fourth annual WORLD BLADDER CANCER Patient Forum 2024

Summary report

worldbladdercancer.org





WBCPC Acknowledgements

We would like to express our gratitude to everyone who contributed to the success of the 2024 World Bladder Cancer Patient Forum.

The Speakers:

- **Dr Martin Angel**, Clinical Oncologist, Instituto Alexander Fleming, Argentina
- **Lori Cirefice**, President, Cancer Vessie France, France
- **Michelle Colero**, Executive Director Bladder Cancer Canada and VP, WBCPC, Canada
- **Melanie Costin**, Director of Patient Engagement & Support, Fight Bladder Cancer, UK
- **Dr Stephanie Demkiw**, Co-founder of Bladder Cancer Awareness Australia, Australia
- **Dr Mario Fernández**, MD, Associate Professor Clínica Alemana de Santiago, Universidad del Desarrollo, Chile
- **Alex Filicevas**, Executive Director, WBCPC, Belgium
- **Fiorella Gagliardi**, President, VICARE GU, Argentina
- **Laurent Gemenick**, Co-founder of Canves, Spain
- **Michelle Hull**, Global Head, Patient Advocacy and Access, Johnson & Johnson, USA
- **Flávia Kavalec**, Patient Support Program Coordinator, Instituto Oncoguia, Brazil
- **Dr Lydia Makaroff**, President, WBCPC and Chief Executive, Fight Bladder Cancer, UK
- **Marie Magenhann Cueto**, Community Engagement Coordinator, WBCPC, Belgium
- **Prof. Joan Palou**, Chairman of the Department of Urology, Fundació Puigvert, Spain
- **Angela Pelletier**, Bladder cancer patient and Volunteer, Bladder Cancer Canada, Canada
- **Lauren Pretorius**, CEO, Campaigning for Cancer, South Africa
- **Eva María Ruiz de Castilla**, Executive Director, Latin America Patients Academy, USA
- **Theodoros Yfantis**, Project Coordinator, WBCPC, Belgium

The Programme Committee

- **Michelle Colero**, Executive Director, Bladder Cancer Canada and VP, WBCPC, Canada
- **Dr Stephanie Demkiw**, Co-founder of Bladder Cancer Awareness Australia, Australia
- **Alex Filicevas**, Executive Director, WBCPC, Belgium
- **Dr Lydia Makaroff**, President, WBCPC and Chief Executive, Fight Bladder Cancer, UK

The Organising Team

- **Alex Filicevas**, Executive Director, WBCPC, Belgium
- **Marie Magenhann Cueto**, Community Engagement Coordinator, WBCPC, Belgium
- **Theodoros Yfantis**, Project Coordinator, WBCPC, Belgium



Introduction

The 4th Annual World Bladder Cancer Patient Forum took place on October 1-2, 2024 in Punta Cana, Dominican Republic, extending to a two-day programme for the first time. This additional day offered more in-depth discussions, allowing our community to share insights and explore ways how all of us can work towards meaningful change together. The Forum brought together a wide range of people affected by bladder cancer, including patients, advocates, healthcare professionals, experts, and industry partners.

"This Forum reminded me that progress doesn't happen by chance-it happens when patients, advocates, and experts work together with purpose. What we build here can make a real difference for people living with bladder cancer around the world." Fiorella Gagliardi, VICARE GU, Argentina

This Forum matters because bladder cancer continues to be a challenging diagnosis that impacts millions globally. Yet, bladder cancer awareness remains low and it receives less research funding compared to other cancers of similar incidence.



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



**Click here
to watch
the event
highlights**

Many people affected by bladder cancer face obstacles in accessing the treatment and care they need and deserve, whilst also experiencing limitations in support and information available to them. By gathering as a global community, we create momentum for change, share strategies, and make progress toward more understanding, stronger patient advocacy, and better patient support and care worldwide.

This year, we focused especially on understanding patients' needs for information and support. We shared excellent examples of patient information and support materials from our community, exploring how we can work together to bring these resources to more people in more languages around the world. Regional insights, particularly from Latin America, added valuable perspectives to our global efforts for our first Forum in Latin America. We also took time to reflect on the progress made by the World Bladder Cancer Patient Coalition (WBCPC) over the past five years and to envision the path ahead.

This report shares the main ideas and key takeaways from the World Bladder Cancer Patient Forum 2024. We hope it encourages everyone involved in bladder cancer patient care and patient advocacy to keep working together and set strong ambitions for the years ahead. As always, we welcome your thoughts and invite everyone to continue the conversation with us and with each other.

Foreword

The 2024 World Bladder Cancer Patient Forum marked a turning point for our community, and one word captures our experience: momentum. This year, with two dedicated days of discussions in Punta Cana, our community took a significant step forward in ambition and impact. The Forum was more than just a meeting – it was a powerful call to action.

Bladder cancer remains one of the most under-recognised cancer challenges, and every patient deserves access to the best possible support, treatment, and advocacy. This year's Forum brought together voices from around the world, each offering insights and solutions to address the real, pressing needs of those affected by bladder cancer. Our discussions spanned essential topics, from building patient groups to influencing policy, all with a common goal: to empower individuals and amplify patient voices.

At the World Bladder Cancer Patient Coalition, we believe in the strength of a united community. When we come together across countries, backgrounds, and experiences we unlock the potential to create meaningful, lasting change. This Forum has shown us what's possible when collaboration leads the way and has laid out a clear path for the future.

We sincerely thank everyone who made this year's Forum possible. Your dedication, expertise, and shared commitment inspire us all to move forward with purpose. Together, we are advancing our mission and building a world where those affected by bladder cancer can face the future with hope, confidence, and unwavering support.



Alex Filicevas
*Executive Director,
WBCPC*



Dr Lydia Makaroff, PhD
*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

Outcomes

Raising Awareness: Regional and global perspectives on bladder cancer

The discussions on bladder cancer care and advocacy highlighted the diverse challenges across regions and the shared opportunities to create lasting change. From Latin America to Africa and Europe, speakers emphasised the importance of global collaboration, cultural understanding, and innovative approaches to improve patient outcomes.



Dr Fernández emphasised that empowering bladder cancer patient advocacy will be essential to driving these changes.

A central theme was the urgent need to address disparities in care. In Latin America, Dr Mario Fernández highlighted the growing burden of bladder cancer driven by smoking prevalence and environmental factors including arsenic exposure. He called for the need of systemic improvements in healthcare, including increased funding, specialist training, and investment in research to address inequities. Dr Fernández emphasised that empowering bladder cancer patient advocacy will be essential to driving these changes and ensuring all patients receive timely and equitable care across the region.

Advocates, including Fiorella Gagliardi from VICARE GU underscored the power of patient advocacy to protect bladder cancer patient rights and tackle barriers to timely diagnosis and treatment. She stressed the importance of improving national health policies and fostering international collaboration to facilitate learning by sharing best practice and patient education resources. These efforts, she noted, can help dismantle the stigma often associated with the diagnosis and provide bladder cancer patients and their families with the tools they need to make informed decisions about their care.

Speakers emphasised the importance of global collaboration.



The power of awareness campaigns was another key discussion area.



Lori Cirefice from Cancer Vessie France spoke about the importance of partnering with professional agencies to amplify outreach, sharing how their expertise in digital media, messaging, and campaign strategy helped reach wider audiences and strengthen engagement with both the public and healthcare professionals. While Lauren Pretorius from Campaigning for Cancer and Amy Samuel from Senegal stressed the need for culturally sensitive campaigns that resonate with local communities.

Across all discussions, one unifying message emerged – collaboration is essential. By working together, advocates, healthcare professionals, and patients are building a global movement that prioritises bladder cancer patient voices and creates solutions tailored to regional and local needs. These efforts reaffirmed the strength of the global bladder cancer patient community and our collective commitment to a future where no patient is left behind.

The power of awareness campaigns was another key discussion area. From the Stop Red Walk in Italy to Canada's Light Up campaign, examples from around the world demonstrated how community-driven initiatives can raise awareness, bring more visibility to important challenges faced by bladder cancer patients and promote symptom awareness and early detection. In South Africa, locally led programmes provided free screenings, educational materials, and support groups, bridging critical gaps in underserved regions.

Speakers also emphasised how to scale these successes.

Across all discussions, one unifying message emerged – collaboration is essential.



Outcomes


Building a community: Stronger bladder cancer patient support and advocacy together cancer

The sessions on building and strengthening support for bladder cancer patients emphasised how collaboration, shared resources, and innovative approaches can create meaningful change. Advocates, healthcare professionals, and patients explored ways to address diverse needs in the bladder cancer community, focusing on the power of collective, patient-centred support.

One main theme was the importance of complete care that goes beyond medical treatment. Dr Martin Angel shared how cross-speciality teams can enhance patient care by addressing physical and emotional challenges, giving patients a clearer understanding of their treatment and confidence in managing side effects.

This comprehensive approach was echoed by survivor and advocate Angela Pelletier from Bladder Cancer Canada, who highlighted the value of accessible resources and peer support. Bladder Cancer Canada offers a range of resources to help patients navigate their diagnosis and treatment journey.

These include detailed guidebooks, educational webinars, and step-by-step materials tailored to the challenges patients face. Their peer support programme connects newly diagnosed patients with experienced survivors, creating a safe space for sharing personal experiences, advice, and encouragement. Angela emphasised that these resources were invaluable in helping her manage the emotional and practical challenges of her diagnosis, particularly the adjustment to living with an ostomy.



One main theme was the importance of complete care that goes beyond medical treatments.



Collaboration, shared resources, and innovative approaches can create meaningful change.



The universal need for reliable information, community support, and advocacy was clear.



Accessible information and multilingual support emerged as another vital area. Melanie Costin from Fight Bladder Cancer spoke about the impact of online forums and support groups in building community and providing around-the-clock assistance. Similarly, Flávia Kavalec from Instituto Oncoguia in Brazil described how their WhatsApp-based support services provide a lifeline for patients, offering real-time emotional support and practical guidance. These services have been especially vital during Brazil's ongoing BCG shortages, helping patients navigate alternative treatment options, connect with specialists, and address concerns promptly. By offering a direct and accessible line of communication, the programme ensures that patients feel supported and informed despite significant healthcare challenges. These initiatives show the value of culturally sensitive resources that empower patients to navigate their journey with confidence.

By offering a direct and accessible line of communication, the programme ensures that patients feel supported.



The experiences of patients and carers who have built bladder cancer support groups from scratch underscored the possibility of creating vital patient support networks anywhere in the world. Laurent Gemenick who has just started the first bladder cancer patient alliance in Spain, talked of inspiration and support from WBCPC on their journey following the World Bladder Cancer Patient Forum 2023. Dr Stephanie Demkiw from Bladder Cancer Awareness Australia shared her own learnings from bringing the patients and carers together which has grown into a supportive peer community in Australia.

In a networking session, members discussed practical resources for patients and carers, reinforcing that effective support thrives on shared knowledge and collaboration beyond our immediate environments. While bladder cancer challenges vary worldwide, the universal need for reliable information, community support, and advocacy was clear. These discussions underscored the strength of a united bladder cancer patient community working towards a future where every patient can access the support they need and deserve.

Outcomes

Engaging in advocacy: Strategic growth and future vision



Marking its fifth anniversary, the World Bladder Cancer Patient Coalition took this year's Forum as an opportunity to reflect on past achievements and look forward to the next chapter. Led by Dr Lydia Makaroff, WBCPC President and Chief Executive of Fight Bladder Cancer, and Alex Filicevas, WBCPC Executive Director, this session celebrated key milestones of the organisation and the global bladder cancer advocacy.

Since its founding in 2019 with just three member organisations, WBCPC has grown into a global network of 16 organisations across 12 countries. This growth has strengthened advocacy efforts at local, national, and international levels, empowering patient organisations to amplify their voices and work together to improve outcomes for bladder cancer patients worldwide.

Reflecting on these milestones, Alex Filicevas shared:

“What inspires me every day is the commitment within our community to improve outcomes for others, often motivated by personal experiences. Our goal is to ensure that every individual affected by bladder cancer, regardless of where they live, has access to the information and support they need.”





The fireside chat also explored WBCPC's role in shaping the future of global advocacy. Supporting member organisations with tailored tools, training, and opportunities for collaboration remains a priority, ensuring they can address challenges unique to their regions while learning from each other.

Dr Lydia Makaroff reflected on these achievements, saying:

"It has been a privilege to work with such a dedicated and resourceful community. From evidence-based advocacy to establishing new member organisations, we have made meaningful progress together"



Key Milestones

1.

Global Bladder Cancer Patient and Carer Survey: Reaching over 1,200 respondents, this survey has become an important evidence base for advocacy efforts. Published in European Urology and presented at major scientific conferences, the findings have shaped policy discussions and strengthened national initiatives led by WBCPC members.

2.

Bladder Cancer Awareness Month (BCAM): BCAM has grown into a powerful annual initiative. The introduction of the Unsure Icon, a symbol encouraging early action on symptoms like blood in the urine, has united organisations worldwide. The BCAM grants programme has expanded significantly, with applications rising from 7 in 2022 to over 100 in 2024, supporting awareness efforts in low- and middle-income countries.

3.

Global Growth and Collaboration: Over five years, WBCPC has fostered the creation of new bladder cancer organisations and strengthened existing ones, building a more connected, inclusive, and supportive global community.

Outcomes

Sessions: Advancing Treatment, Research, and Policy

The sessions on advancing treatment, research, and policy highlighted the importance of patient involvement, innovative approaches, and collaboration in improving outcomes for people affected by bladder cancer. Experts, advocates, and patients shared practical insights on ensuring healthcare systems, research environment, and clinical trials reflect patient needs and experiences in the real world.

A key theme was meaningful involvement of the patient voice in healthcare decision-making. Lauren Pretorius, CEO of Campaigning for Cancer, explained how Health Technology Assessment (HTA) shapes decisions on treatments and interventions. Speakers emphasised that patient input in HTA ensures real-world challenges are considered alongside statistics. Examples from Bladder Cancer Canada and Cancer Vessie France illustrated how patient organisations have successfully influenced HTA outcomes by sharing lived experiences and humanising processes that are often overly technical and detached from patient realities.

The sessions on advancing treatment, research, and policy highlighted the importance of patient involvement.



The latest advances in bladder cancer research were a new keynote presentation for a second year in a row. Professor Joan Palou outlined promising developments in imaging, intravesical therapies, and innovative clinical trials. Techniques such as fluorescence cystoscopy and narrow-band imaging (NBI) are transforming bladder cancer detection. Fluorescence cystoscopy uses a special dye to make cancer cells glow under blue light, helping clinicians identify tumours that may be missed under standard white light. Similarly, NBI enhances visibility by using specific wavelengths of light to highlight blood vessels and tissue structures, making it easier to detect small or flat tumours. These advanced imaging methods allow for more accurate diagnosis, better tumour removal, and improved treatment outcomes for patients. While research into chemoresection and immunotherapy offers new hope for bladder preservation and reduced recurrence. Prof. Palou highlighted ongoing trials like VESPER and NIAGARA, which are exploring ways to combine chemotherapy and immunotherapy to improve survival rates for patients with muscle-invasive bladder cancer.



Clinical trials also emerged as a key opportunity to advance treatment, provided patients are well informed and empowered to participate. WBCPC President Dr Lydia Makaroff highlighted a striking gap: **84% of patients surveyed had not been informed about clinical trial opportunities.** Patient advocate Michelle Colero emphasised the transformative potential of trials, sharing a moving story of a patient whose participation led to remission and renewed hope. Speakers stressed the need to simplify trial communication, expand access to underserved regions, and ensure trials are designed with patient input to reflect real-world experiences and priorities.

Policy advocacy was presented as a powerful tool to ensure healthcare systems meet patient needs.

84%

Most respondents did not receive any information about participating in clinical trials.



“Health Technology Assessment is about so much more than numbers. It’s about ensuring healthcare decisions reflect the realities and needs of patients.”

Lauren Pretorius
Campaigning for Cancer

“When patients share their stories, it goes beyond statistics—it humanises the process and ensures decisions are made with real-world outcomes in mind.”

Michelle Collero
Bladder Cancer Canada

Eva María Ruiz de Castilla, Executive Director of the Latin America Patients Academy (LAPA), guided patient advocates in a policy oriented workshop through a step-by-step approach to influencing policy, from identifying challenges and setting goals to engaging decision-makers and monitoring progress. Examples from Latin America demonstrated how patient-led efforts have improved treatment access and strengthened patient representation in healthcare policies. Collaboration, persistence, and clear messaging were essential for success in policy advocacy.

These sessions reinforced a unifying message: progress in bladder cancer treatment and care relies on research, patient advocacy, and the active involvement of patient perspectives. By ensuring the patient voice is central to clinical trials, policy decisions, and throughout the healthcare systems, we can drive meaningful change and deliver solutions that truly reflect the needs of those living with bladder cancer.

Conclusion

The 2024 Forum has showed us what we can achieve together as a global bladder cancer patient community. Over two days of sharing knowledge, we identified the most urgent needs facing bladder cancer patients and explored ways how to address them through local initiatives and global collaboration. Discussions emphasised the importance of holistic care—meeting medical needs while also prioritising patient’s mental and emotional well-being, accessible resources, and empowering patients to actively participate in the healthcare decisions of their own care.



One of the strongest messages from the Forum was the power of unity. By bringing together diverse voices from across regions, we saw firsthand how collaboration can inspire each of us to seek creative and impactful approaches to drive meaningful change.



These connections, newly built or nurtured over time, allow us to strengthen bladder cancer patient advocacy efforts in our communities but also beyond, bridge the gaps in care delivery, and create a future where every bladder cancer patient can access the best possible treatment and care as well as the support they need.

We are delighted to have received positive feedback from the participants, which reaffirmed to continue our efforts to promote collaboration and shared knowledge in our field. All of us appreciated the opportunity to learn from each other’s experiences, adding fresh perspectives and strategies to improve the situation for people affected by bladder cancer and their families across the globe, whilst strengthening the impact of the work of bladder cancer patient support groups, both well-established and new.

As we look ahead, this Forum has energised our efforts to build a more inclusive, supportive community for bladder cancer patients and their families. Together, we will continue pushing forward, ensuring every patient receives compassionate and comprehensive care.



THANK YOU FOR JOINING!

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USEFUL LINKS & RESOURCES

- WBCPC Start-up guide for bladder cancer patient groups
- Global Bladder Cancer Patient and Carer Survey

The World Bladder Cancer Patient Forum 2024 is made possible with the support of our Premier Partners Ferring, Johnson & Johnson and Merck and our Sponsors AstraZeneca and Roche. The content of the event remains the sole responsibility of the World Bladder Cancer Patient Coalition.

Our members



You can find us here:

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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 16 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 16 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.