World Bladder Cancer Patient Forum 2025

Highlights report

worldbladdercancer.org

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Acknowledgements

SPEAKERS

- MEP Vytenis Povilas Andriukaitis – *S&D, Lithuania*
- Maddalena Benivento – *Associate Program Director, The Synergist*
- Alessandro Boni – *Bladder cancer patient & Board Member, Associazione PaLiNuRo*
- Sarah Coffey Dégrange – *Bladder cancer patient & advocate, Social Media Manager, Cancer Vessie France*
- Michelle Colero – *Vice President, WBCPC & Executive Director, Bladder Cancer Canada*
- Christine La Rose – *Bladder cancer patient & Patient Support and Advisory Leader, BEAT Bladder Cancer Australia*
- Dr Stephanie Demkiw – *Co-chair, Bladder Cancer Awareness Australia*
- MEP Ondřej Dostál – *Non-attached, Czechia*
- Anita Eik Roald – *Bladder cancer patient & CEO, Norwegian Bladder Cancer Society*
- Dr Anke-Peggy Holtorf – *Board Member, HTAi*
- Fiorella Gagliardi – *President, VICARE GU*
- Benita Lipps – *CEO & Founder, Novya*
- Christopher McPherson – *Head of Global Oncology Policy & Advocacy, AstraZeneca*
- Annika Nowak – *Head of Sector, Cancer Mission Secretariat, Directorate-General for Research and Innovation, European Commission*
- Aysem Oeznel – *Patient Partnership Leader, Roche*
- Angela Pelletier – *Bladder cancer patient & Volunteer, Bladder Cancer Canada*
- Lauren Pretorius – *CEO, Campaigning for Cancer*
- Charles Ogada – *Team manager, Desert Scorpions F.C*
- Robert Sauermann – *Head of Pharmaceutical Department, Austrian Federation of Social Insurances*
- MEP Tomislav Sokol – *EPP, Croatia*
- Niccola Scocchi – *Head of Brussels Office, Fourtold*
- Julie Spony – *Project Officer, European Commission*
- Valentina Strammiello – *Interim CEO, European Patients' Forum*
- Carl-Henrik Sundin – *Founder, Swedish Bladder Cancer Society*
- Prof. Hendrik Van Poppel – *Policy Office Chair, European Association of Urology*
- Olivér Várhelyi – *European Commissioner for Health and Animal Welfare*
- Alex Filicevas – *Executive Director, WBCPC*
- Lori Funk-Cirefice – *President, WBCPC & President, Cancer Vessie France*
- Dr Ashish M. Kamat – *Endowed Professor of Urologic Oncology (Surgery) and Cancer Research, University of Texas MD Anderson Cancer Center & Chair, WBCPC Scientific Advisory Board*
- Alex King – *Head of Health, Fourtold*
- Oscar Rodriguez – *Bladder cancer patient & Founder, FUPROCER*
- Mihai Rotaru – *Associate Director, Market Access in the Economic and Social Affairs, EFPIA*
- Elisabetta Zanon – *CEO, European Cancer Organisation*
- Wisdom Zunguzungu – *Director of Programmes, One Community*

PROGRAMME COMMITTEE

- Sarah Coffey Dégrange – *Bladder cancer patient & advocate, Social Media Manager, Cancer Vessie France*
- Dr Stephanie Demkiw – *Co-chair, Bladder Cancer Awareness Australia*
- Lori Funk-Cirefice – *President, WBCPC & President, Cancer Vessie France*
- Adam Lynch – *Founder, BEAT Bladder Cancer Australia*
- Lauren Pretorius – *CEO, Campaigning for Cancer*
- Carl Henrik Sundin – *Founder, Swedish Bladder Cancer Society*

ORGANISING TEAM

- Alex Filicevas – *Executive Director, WBCPC*
- Marie Magenhann Cueto – *Community Engagement Coordinator, WBCPC*
- Theodoros Yfantis – *Project Coordinator, WBCPC*
- Angelina Kogur – *Programmes Support Trainee, WBCPC*

Brussels, Belgium | October 13–14, 2025 | worldbladdercancer.org

Importance of the Forum

The 5th Annual World Bladder Cancer Patient Forum took place on October 13–14, 2025 in Brussels, Belgium, marking an important moment for our growing global community. For the second time, the Forum featured two full days dedicated to learning, collaboration, and exchange, bringing together patients, patient advocates, healthcare professionals, researchers, policymakers, and partners from across the world.

The Forum matters because bladder cancer remains one of the most under-recognised cancers globally, despite its significant impact on patients and their families. By gathering in Brussels, at the heart of European policymaking, we reaffirmed our shared commitment to ensure that bladder cancer receives the recognition, policy and research prioritisation, and improvement of quality of care it deserves.

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

Click **here** to watch the event highlights

The Forum opened with Advocates Day, focused on empowering patient organisations and strengthening their advocacy skills. Through interactive workshops and inspiring presentations, advocates shared initiatives that are transforming awareness and support in their countries, from nurse education and peer support programmes to national campaigns promoting early diagnosis. These sessions reminded us that local action can drive global change when supported by shared purpose and collaboration.

The Public Day continued with discussions that connected policy, research, and lived experience. The WBCPC Strategy 2030, presented for the very first time at the Forum, strengthening patient voices and empowering our memebr organisations, raising awareness and influencing decisions that impact people in our communities. European and international experts shared progress in research, policy, and access to innovation, while patients' personal testimonies reminded us of the human stories driving this movement forward.

This report presents the main themes, lessons, and reflections from the World Bladder Cancer Patient Forum 2025. It captures the spirit of collaboration, determination, and unity that defined this year's gathering, aiming to inspire continued action to improve the lives of everyone affected by bladder cancer worldwide.

Foreword

When the World Bladder Cancer Patient Coalition was established in 2019, we set out to connect people who shared a simple but powerful belief: those affected by bladder cancer deserve one united and strong voice.

Six years later, meeting together in Brussels for the World Bladder Cancer Patient Forum 2025, we felt how much that vision has grown. What began as a small network of dedicated advocates has evolved into a genuine global community, united by trust, shared purpose, and enduring friendships.

Each year that we come together, the bond within our community grows stronger. The Forum has become more than an event; it is a place where people listen, learn, and find understanding. The stories, ideas, and collaborations that start in these rooms continue long after the Forum ends. They are shaping how we support patients, influence policy, and advance research in every part of the world.

We are deeply grateful to everyone who has walked this path with us, including our members, speakers, partners, and friends. Your commitment and compassion have brought a vision to life. The connections we have built together remind us that progress in bladder cancer begins with people coming together. That sense of solidarity will continue to guide us in the years ahead.

Lori Funk-Cirefice
PRESIDENT
WBCPC

Alex Filicevas
EXECUTIVE DIRECTOR
WBCPC

Our mission

We unite and empower the global bladder cancer patient community by

Fostering collaboration

Amplifying advocacy

And taking collective action to drive better outcomes for all.

Outcomes

Empowering the global bladder cancer community

Sessions across the Forum highlighted the growing strength and reach of the global bladder cancer community. Speakers and patient advocates shared how collaboration, data, and lived experience are driving measurable progress in awareness, support, and advocacy worldwide. The discussions reinforced that empowerment happens when patients, professionals, and organisations unite around a shared goal: ensuring that no one faces bladder cancer alone.

A central theme was the power of community-led action. Through the Bladder Cancer Awareness Month (BCAM) Grant Programme, awardees demonstrated how small, targeted investments can deliver large-scale results. In Malawi, **Wisdom Zunguzungu**, from One Community, trained 120 volunteers and reached over 300 people through local awareness sessions. Meanwhile, in Kenya, **Charles Ogada's** Desert Scoprions F.C, football-based initiative utilised sport to disseminate information on prevention and early detection.

In Argentina, **Fiorella Gagliardi** from VICARE GU, brought together patients and professionals from across Latin America through a virtual congress that combined education with wellbeing activities, and in Colombia, **Oscar Rodriguez** from FUPROCER, built a digital storytelling campaign to give survivors a voice. These projects collectively expanded awareness in low- and middle-income countries and proved that small grants can spark lasting national movements.

> *"Our purpose is simple yet powerful, to make sure no one faces bladder cancer alone."*
>
> **Lori Funk-Cirefice**
> President
> WBCPC

Click here to explore all BCAM Grant awardees initiatives

Personal experience also emerged as a foundation for leadership. **Anita Eik Roald**, CEO of the Norwegian Bladder Cancer Society, shared how her experience as a clinical trial participant led to national advocacy for better access to trials and new treatments.

Alessandro Boni from Associazione PaLiNUro in Italy highlighted how patient associations can bridge gaps between science and lived experience through practical tools such as the Uro H Advisor app, which helps patients choose treatment centres based on transparent performance data. Both speakers showed how empowered patients can transform care systems by raising awareness, building trust with clinicians, and shaping national health agendas.

The World Bladder Cancer Patient Coalition leadership also set a clear direction for the future. In their joint presentation, **Lori Funk-Cirefice**, **Alex Filicevas**, and **Michelle Colero** outlined how WBCPC is turning its 2030 Strategy into action. The focus now is on implementation: building stronger national advocacy networks, expanding membership in new regions, and supporting evidence-based campaigns that improve early diagnosis and equitable care.

Across all sessions, the message was consistent: empowered patients and advocates change outcomes. As **Lori Funk-Cirefice** affirmed, *"Our purpose is simple yet powerful, to make sure no one faces bladder cancer alone."* **Michelle Colero** added that WBCPC's strength lies in its ability *"to connect local realities with opportunities for global action."* These connections are transforming inspiration into measurable impact, from increased participation in clinical trials to the establishment of new patient support networks and policy engagement at national and European levels.

Collectively, the Forum demonstrated that empowerment is about personal resilience and about building structures that sustain advocacy. When patient leaders, healthcare professionals, and policymakers work together, they amplify each other's efforts. The initiatives shared this year show that a stronger, more inclusive global bladder cancer community is already reshaping what is possible for patients everywhere.

Advancing research, access, and patient partnership

Forum discussions on research, innovation, and equitable access underscored how meaningful collaboration between patients, clinicians, policymakers, and industry can close the gap between scientific discovery and real-world impact. Speakers explored how patient involvement is transforming Health Technology Assessments (HTA), clinical trial design, and access to medicines, ensuring that care reflects what truly matters to those affected by bladder cancer.

The session on the latest developments in bladder cancer research, led by **Prof. Hendrik Van Poppel** from the European Association of Urology (EAU) and Endowed **Prof. Ashish Kamat** from University of Texas MD Anderson Cancer Center, offered a comprehensive overview of advances in early detection and treatment.

Prof. Van Poppel emphasised the need to prioritise prevention and early diagnosis through better awareness of risk factors such as tobacco use and industrial exposure. He called for the centralisation of care and greater use of multidisciplinary teams to ensure consistent, high-quality treatment across Europe.

Prof. Kamat presented new data showing how immunotherapy and targeted combination treatments are improving survival for patients with muscle-invasive bladder cancer. Emerging evidence from trials such as CheckMate 274 and NIAGARA demonstrates that combining chemotherapy with immune checkpoint inhibitors can significantly improve outcomes and, in some cases, allow for bladder preservation.

Both experts stressed the importance of clinical trial participation and equal access to modern therapies, urging policymakers to ensure that innovation benefits patients everywhere, not only in high-resource settings.

Access was at the centre of the session, making sense of medicine access, moderated by **Lauren Pretorius**. **Mihai Rotaru** from European Federation of Pharmaceutical Industries and Associations (EFPIA) shared data revealing that delays in patient access to new medicines vary widely across Europe, with up to 69% of waiting times linked to lengthy national reimbursement processes.

Robert Sauermann, from the Austrian Federation of Social Insurance, outlined how payers balance innovation and affordability through managed entry agreements and outcome-based pricing. Both agreed that access must be a shared responsibility between industry, payers, and policymakers. From the patient perspective, **Lauren Pretorius** highlighted that "innovation means nothing if it doesn't reach the patient," reminding participants that transparency and collaboration are essential to fair access.

The discussion concluded that building trust, harmonising reimbursement procedures, and including patient voices in pricing debates are key to delivering timely and equitable care.

Patient involvement in decision-making was explored further in the session patient voice in Health Technology Assessments, moderated by **Dr Anke Peggy Holtorf**. **Valentina Strammiello** from the European Patients' Forum (EPF) highlighted how the EU HTA Regulation is making patient input mandatory in Joint Clinical Assessments (JCAs), ensuring that evidence reflects the lived experience of patients.

> *"Innovation means nothing if it doesn't reach the patient."*
>
> **Lauren Pretorius**
> CEO
> Campaigning for Cancer

Julie Spony from the European Commission noted that new frameworks are helping standardise patient engagement across Member States, while **Lori Funk-Cirefice** and **Lauren Pretorius** called for capacity-building initiatives to help advocates engage effectively. Speakers agreed that patient organisations need training, fair compensation, and clear guidance to contribute confidently. As Valentina stated, "The biggest barrier to patient involvement remains the conflict of interest issue," pointing to the need for balanced and transparent participation models.

The session concluded with a shared commitment to embed real-world data and patient experience evidence into future HTA processes.

The session meaningful patient engagement in action, moderated by **Alex Filicevas**, showcased practical examples of collaboration that are reshaping research and care. **Christine La Rose** from BEAT Bladder Cancer Australia described how her organisation's structured peer support and education programmes have empowered hundreds of patients to take active roles in their treatment decisions. **Aysem Oeznel** from Roche presented how patient engagement has evolved "from consultation to co-creation," with patients now contributing to clinical trial steering committees and protocol design.

> *"The biggest barrier to patient involvement remains the conflict of interest issue, pointing to the need for balanced and transparent participation models."*
>
> **Valentina Strammiello**
> Interim CEO
> European Patients' Forum

Maddalena Benevento from The Synergist shared global frameworks for ethical and measurable engagement, including the Patient Engagement Management Suite and Fair Compensation Tool, which help standardise practice across sectors. The session also introduced EU BCLEAR, a project co-funded by the European Union co-led by WBCPC & EAU amongst wider consortium, focusing on health literacy and shared decision-making in the EU and in particular in Poland, Greece, and Hungary. Together, these initiatives showed how patient involvement leads to more relevant research, more accessible information, and greater trust between communities and industry.

Across all discussions, one conclusion was clear: progress in research and access depends on partnership. Patients are no longer passive participants but equal collaborators shaping how evidence is generated and how new treatments reach those who need them. By aligning science, policy, and lived experience, the bladder cancer community is ensuring that innovation serves people first and that every breakthrough, from the laboratory to the clinic, translates into better outcomes for patients worldwide.

Shaping policy for a fairer future

The Forum concluded with a strong call to action: to turn collaboration into policy change that ensures equitable care for everyone affected by bladder cancer. Policymakers, clinicians, and advocates outlined how partnerships across sectors are reshaping the European and global policy landscape, from early detection to access to medicines and survivor rights.

The session driving policy progress in bladder cancer through collaboration, moderated by **Sarah Coffey Dégrange** from Cancer Vessie France, showcased how multi-stakeholder partnerships are delivering lasting influence. Building on the European White Paper on Bladder Cancer launched by WBCPC and the EAU, and the forthcoming Women Unseen report, panellists described how patient-led evidence is informing European cancer policy and closing persistent gaps in care. **Prof. Hendrik Van Poppel**, from the EAU Policy Office, detailed how collaboration between scientific societies and patient organisations is driving real change, from inclusion of patient representatives in guideline panels to joint advocacy in the European Parliament. He stressed the importance of addressing gender disparities, noting that "women are more likely to die from bladder cancer because they are diagnosed too late," and called for better training for primary care professionals to improve early detection.

Elisabetta Zanon, from the European Cancer Organisation (ECO), underlined that bladder cancer remains underrepresented in European cancer policy despite being the fifth leading cause of cancer mortality. She called for its inclusion in future screening recommendations and highlighted the need to address gender-specific barriers. Reflecting on WBCPC's Women Unseen initiative, she noted: "There is a huge unmet need for women with bladder cancer. Their symptoms are often dismissed, and their voices unheard. This must change."

Industry, research, and policy perspectives aligned on transparency and complementary roles. **Christopher McPherson** from AstraZeneca spoke about the industry's responsibility to utilise its data and resources to support advocacy, while allowing patient leaders to drive the public conversation. "*The most powerful voice in any room is the patient's,*" he said, citing the Lung Cancer Policy Network as an example of how shared evidence and unified messaging can accelerate policy adoption, offering a blueprint for bladder cancer advocacy.

> *“We cannot have first- and second-class citizens in the European Union.”*
>
> **MEP Tomislav Sokol**
> EPP, Croatia

Annika Nowak from the European Commission’s Directorate-General for Research and Innovation explained how the EU Cancer Mission and Europe’s Beating Cancer Plan connect research and policy. She described national “mission hubs” that bridge evidence and implementation, ensuring EU-level actions lead to national reforms. Over €500 million has been invested through the Cancer Mission, including projects requiring direct patient participation. She encouraged patient organisations to engage with mission hubs to strengthen bladder cancer’s visibility in future research and funding programmes.

Throughout the session, collaboration emerged as the strongest driver of influence. Shared advocacy between WBCPC, EAU, ECO, and partners has already yielded milestones, including the White Paper on Bladder Cancer, the EU-funded BCLEAR project on bladder cancer health literacy, and new European-level dialogues on gender equality in care. These efforts are ensuring that bladder cancer gains recognition within broader EU cancer priorities.

The Forum’s closing Policymaker Keynotes reinforced this momentum. **Tomislav Sokol**, a Member of the European Parliament (MEP), emphasised that *“we cannot have first- and second-class citizens in the European Union,”* advocating for equal access to treatments and joint procurement mechanisms to reduce inequalities. **Ondřej Dostál**, MEP from the Czech Republic, echoed this urgency, highlighting early diagnosis, reimbursement delays, and post-treatment support as key challenges. *“Innovation only matters if patients can reach it,”* he said, urging the EU to prioritise health in the next financial framework.

Video statements from European leaders echoed their messages. **Vytenis Andriukaitis**, MEP and former European Commissioner for Health and Food Safety, commended WBCPC for bringing bladder cancer to the forefront of European health policy debates. He called for its stronger integration within Europe's Beating Cancer Plan and urged action to improve early detection and access to innovation across all Member States. *"The visibility of bladder cancer must increase, because every delay in awareness costs lives,"* he stated.

European Commissioner for Health and Food Safety **Olivér Várhelyi** reaffirmed the European Commission's commitment to research, prevention, and collaboration. He highlighted bladder cancer as a disease where early diagnosis and equitable access can significantly improve survival rates, and praised WBCPC for uniting patients, clinicians, and policymakers around a common agenda. *"Bladder cancer deserves the same level of attention as other major cancers,"* he said, noting that European initiatives such as the EU Cancer Mission and Horizon Europe are helping translate research into tangible outcomes for patients.

These contributions reflected growing recognition of bladder cancer as a European health priority. By engaging directly with Members of the European Parliament, the European Commission, and institutional partners, the bladder cancer patient community is shaping the future of cancer policy across the continent.

The Forum confirmed that collaboration is not only improving awareness and care but also transforming how decisions are made. By uniting evidence, advocacy, and political will, the bladder cancer community is achieving lasting policy influence. The shared commitment of patients, healthcare professionals, and policymakers is paving the way towards a fairer future where every patient, regardless of geography or gender, can access timely diagnosis, effective treatment, and lifelong support.

> *"When we come together as a global community, we can achieve real change, from improving access to care to influencing national policies."*
>
> **Lori Funk-Cirefice**
> President
> WBCPC

Conclusion

The World Bladder Cancer Patient Forum 2025 demonstrated what can be achieved when our global community comes together with a shared purpose. Over the course of two days of discussion, learning, and collaboration, participants strengthened existing partnerships and forged new ones, uniting advocates, healthcare professionals, researchers, policymakers, and partners around a shared goal: improving the lives of those affected by bladder cancer.

We've come away from the Forum with a clear consensus that collaboration drives progress and we are collaborating across border more than ever before. Collaboration drives progress. From advocacy workshops to policy dialogues and patient testimonies, every session showed that meaningful change happens when patients, professionals, and policymakers work side by side to turn ideas into action.

As we look ahead, the Forum reaffirmed the importance of keeping patients at the centre of research, policy, and care delivery. The conversations in Brussels reminded us that lasting change begins when people listen, learn, and act together. Guided by the new WBCPC Strategy 2030, our community stands ready to continue working side by side to create a more equitable and supportive future for everyone living with bladder cancer.

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Useful links & resources

- WBCPC Start-up guide for bladder cancer patient groups
  https://worldbladdercancer.org/start-up-guide/
- Global Bladder Cancer Patient and Carer Survey
  https://worldbladdercancer.org/patient-and-carer-experiences-with-bladder-cancer/
- Factsheets
  https://worldbladdercancer.org/bladder-cancer-factsheets/
- White Paper on Bladder Cancer
  https://worldbladdercancer.org/white-paper-on-bladder-cancer/

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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 17 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. For the first time, people living with bladder cancer are connected through a truly global patient-led network.

World Bladder
Cancer Patient
COALITION

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 17 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.

WBCPC Board of Directors 2025

World Bladder
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COALITION

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