



World Bladder  
Cancer Patient  
**COALITION**



# 2024

## Annual Report

[worldbladdercancer.org](http://worldbladdercancer.org)

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## Connect with us

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**Instagram:** @WorldBladderCancer  
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# Foreword from the President



# Reflecting on 2024

As I reflect on 2024, my heart is full. This has been a year of extraordinary progress for the World Bladder Cancer Patient Coalition and a deeply personal and emotional time for me. In June 2025, I will step down as board member when I reach the six-year term limit in our Articles of Association. While I know this is the right time to pass the torch, it is hard to put into words how difficult it is to say goodbye to a role and a community that have meant so much to me.

When we founded the World Bladder Cancer Patient Coalition in January 2019, we had a bold idea: to bring together people affected by bladder cancer from every corner of the world. We began as three organisations, and today, we stand as 16 member organisations across six continents.

This year, we expanded our Global Grant Programme, strengthened local organisations from Nigeria to Argentina, and delivered our most impactful Bladder Cancer Awareness Month yet. We gathered in Latin America at the World Bladder Cancer Patient Forum, where I felt once again the extraordinary strength, passion, and determination of this community.

Through these years, I have learned so much from the resilience of people affected by bladder cancer, the dedication of advocates, and the tireless commitment of our members and partners. I have had the privilege to work alongside brilliant, passionate people, and many of you have

become true friends. The memories we have made together, the moments of shared joy and even struggle, are what I will carry with me most.

I want to give my heartfelt thanks to Alex Filicevas, our first and best Executive Director. Alex has been an exceptional partner, bringing wisdom, skill, and compassion to every step of this journey. To my fellow Board members, the rest of the secretariat, and every member organisation, thank you for your trust and for making these years unforgettable.

Leaving this role is bittersweet. I am excited for the next chapter in the World Bladder Cancer Patient Coalition's journey, but parting also feels like leaving home. As I look to 2025, I do so with immense gratitude, knowing the coalition is in the best possible hands and will continue to thrive.

*With all my heart, thank you.*

*Warmly, Dr Lydia*

*“Through these years, I have learned so much from the resilience of people affected by bladder cancer, the dedication of advocates, and the tireless commitment of our members and partners.”*

**Dr Lydia Makaroff**  
WBCPC President

# 2024 at a glance

## Bladder Cancer Awareness Month


**12<sup>+</sup>** Million people reached

**100,000<sup>+</sup>** Social media interactions

**62** Countries used our campaign resources

Supported local initiatives in **Argentina**, **Kenya**, **Malawi** and **Nigeria** via BCAM Grants



**52,000<sup>+</sup>**  
People played the **Spot the Drop** campaign game in 12 languages



## World Bladder Cancer Patient Forum

**First two-day event** bringing the global bladder cancer patient community together in Punta Cana.

**23** Participants came from **23** countries

 Bilingual programme in **English** and **Spanish**

## Insights & impact



## New tools for connection



Launched **WBCPC Global Community Platform** on **Glue Up** to promote collaboration and knowledge sharing

## Speaking & representation

**3** **Posters presented**  
at major international  
events

**7** **Attended and spoke at**  
7 **major international**  
**events** and **congresses**



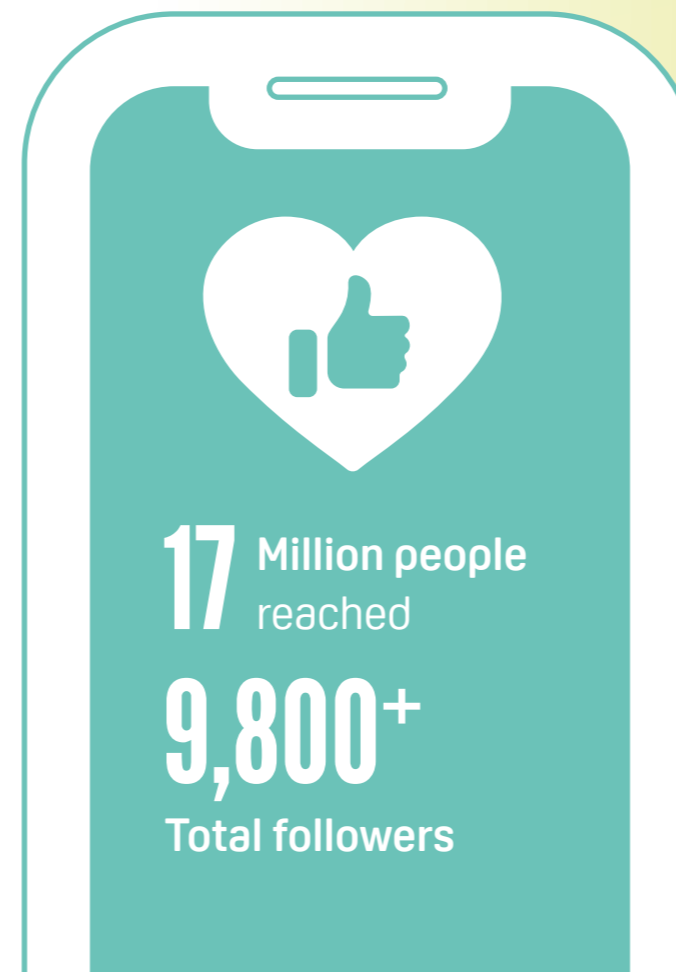
## Newsletters

**49** **mailings sent**  
Monthly and quarterly  
editions **shared globally**



**11,000+**  
**opens**

## Social media



*“Our coalition worked  
together, sharing  
knowledge, experiences  
and ideas how to best  
support the patient  
communities we serve.”*

**Theodoros Yfantis**  
WBCPC Project Coordinator

# About us

## Our story

The World Bladder Cancer Patient Coalition (WBCPC) was founded in January 2019 by passionate patient advocates from three national organisations who recognised a pressing need: a united, global voice for people affected by bladder cancer.

Today, our coalition brings together 16 patient organisations across six continents. We share one mission: to improve outcomes for everyone living with bladder cancer, wherever they are in the world. For the first time, people affected by this disease have a truly global community behind them, connecting patient groups and amplifying their voices internationally.

More than 610,000 people are diagnosed with bladder cancer each year. The need for strong, collective advocacy has never been greater. WBCPC is here to meet that need by championing patient voices, sharing knowledge, and working together to drive lasting change.

# Our network

The World Bladder Cancer Patient Coalition is a global network of patient organisations committed to improving the lives of those affected by bladder cancer. Our strength lies in the power of collaboration. By working together, our members and partners are making a real difference for patients and families around the world.

We are proud to grow our community and to support patient organisations in delivering the best possible care, information, and advocacy. With 16 member organisations across six continents, we collaborate on joint initiatives, drive forward advocacy efforts, and raise awareness through shared campaigns and resources.

We also develop multi-lingual tools and information to support patient advocates in their work. Our coalition shares knowledge, supports one another, and works collectively to ensure that every bladder cancer patient, wherever they live, has access to the support they need.

## Our member organisations



Bladder Cancer Awareness Australia



Singapore Cancer Society



Associazione PaLiNUro



One Community



Bladder Cancer Norway



BEAT Bladder Cancer Australia



VICARE GU



Patient Association for Bladder or Kidney Cancer



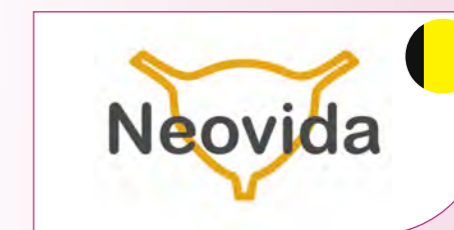
Cancer Vessie France



The Swedish Bladder Cancer Society



Bladder Cancer Canada



Neovida



Norwegian Bladder Cancer Society



Fight Bladder Cancer



Campaigning for Cancer



CANVES

# About us

## Our Board of Directors

Our Board of Directors brings together international expertise, leadership in patient advocacy, and lived experience of bladder cancer. Their diverse backgrounds guide the World Bladder Cancer Patient Coalition’s mission.

 PATIENT ADVOCATE

 CARER

 PATIENT

 HEALTHCARE PROFESSIONAL



**Dr Lydia Makaroff**  
PRESIDENT, WORLD BLADDER CANCER PATIENT COALITION  
FIGHT BLADDER CANCER, UNITED KINGDOM

**PATIENT ADVOCATE**



**Michelle Colero**  
VICE PRESIDENT AND TREASURER, WORLD BLADDER CANCER  
PATIENT COALITION  
BLADDER CANCER CANADA, CANADA

**PATIENT ADVOCATE AND CARER**



**Lauren Pretorius**

CAMPAIGNING FOR CANCER  
SOUTH AFRICA

**PATIENT ADVOCATE**



**Carl-Henrik Sundin**

SWEDISH BLADDER CANCER SOCIETY, SWEDEN

**BLADDER CANCER PATIENT AND  
HEALTHCARE PROFESSIONAL**



**Helen Lacy**

BLADDER CANCER AWARENESS AUSTRALIA &  
BEAT BLADDER CANCER AUSTRALIA, AUSTRALIA

**BLADDER CANCER PATIENT AND ADVOCATE**

Appointed  
**2024**



**Dr Stephanie Demkiw**

BLADDER CANCER AWARENESS AUSTRALIA  
AUSTRALIA

**HEALTHCARE PROFESSIONAL,  
PATIENT ADVOCATE AND CARER**



**Sarah Coffey Dégrange**

CANCER VESSIE FRANCE, FRANCE

**BLADDER CANCER PATIENT  
AND ADVOCATE**

Appointed  
**2024**

# Board of Directors biographies

## Dr Lydia Makaroff



President of the World Bladder Cancer Patient Coalition and Chief Executive of Fight Bladder Cancer.

She previously served as Executive Director of Europe’s largest federation of cancer patient organisations. Lydia holds a PhD in immunology from the Australian National University and a Master’s degree in Public Health from the University of Queensland. She has over a decade of international experience across academia, the pharmaceutical industry, and the non-profit sector.

## Michelle Colero



Vice-President and Treasurer of the World Bladder Cancer Patient Coalition and Executive Director of Bladder Cancer Canada.

With more than 20 years of leadership experience in the non-profit sector, she specialises in patient advocacy, awareness campaigns, and research funding initiatives supporting Canadians affected by bladder cancer.

## Lauren Pretorius



Chief Executive and co-founder of Campaigning for Cancer.

She has devoted her career to championing the rights of cancer patients. Her background spans corporate leadership and non-profit management, including senior roles at the Nelson Mandela Children’s Fund and the Breast Health Foundation. Lauren co-launched the Patient Advocacy Incubator and continues her academic development at the University of Adelaide.

## Dr Stephanie Demkiw



Primary care physician and co-chair of Bladder Cancer Awareness Australia.

Inspired by her father's experience with bladder cancer, she co-founded Australia's first bladder cancer charity. Stephanie has contributed to over ten published research projects, many focusing on bladder cancer, and is currently completing a Master of Public Health.

## Carl-Henrik Sundin



Founder of the Swedish Bladder Cancer Society.

With a background in medicine, technology, and patient advocacy, he focuses on improving information for patients and strengthening peer-to-peer support networks.

He is passionate about bridging gaps in healthcare systems and supporting the bladder cancer community in Sweden.

## Sarah Coffey Dégrange



Social Media Manager for Cancer Vessie France.

Originally from Ireland and fluent in English and French, she became active in advocacy following her diagnosis. Sarah's professional experience spans IT, project management, and education, and she volunteers her time with several organisations supporting cancer patients across France and Ireland.

## Helen Lacy



Board Member of WBCPC Patient Advisory Panel.

Diagnosed with bladder cancer in 2015, she volunteers extensively to support newly diagnosed patients through the Cancer Council and local initiatives. Professionally, she has held various operational management roles in the IT industry.

*“Collaboration drives progress. We are stronger when we work together.”*

**Helen Lacy**  
Bladder cancer patient  
WBCPC Board Member  
Australia

# About us

## Secretariat team



Alex Filicevas  
EXECUTIVE DIRECTOR



Marie Magenmann Cueto  
COMMUNICATIONS AND COMMUNITY  
ENGAGEMENT COORDINATOR



Theodoros Yfantis  
PROJECT COORDINATOR



Angelina Kogur  
PROGRAMMES SUPPORT TRAINEE

# Our work



# Building a community



## Welcoming new members

In 2024, we proudly welcomed two new organisations to our global community: **Neovida** from Belgium and **CANVES** from Spain.



**CANVES**

Alianza por el Cáncer de Vejiga en España

**CANVES** (Alianza por el cáncer de vejiga en España) was newly established this year with our support, using our Start-up guide for bladder cancer patient groups to help shape and launch their organisation. In response to Spain's lack of dedicated patient support, they are now working to provide emotional, practical, and medical support, raise national awareness, and build a strong community for patients and carers.



**Neovida**

**NEOVIDA**, based in Belgium, offers essential support to people living with bladder cancer and those who have undergone bladder removal surgery, with a special focus on individuals with a neobladder. Their mission is to improve patients' quality of life through peer support, information, and advocacy.

Become a member of our international community and help strengthen bladder cancer patient support and advocacy worldwide. Connect with others, share knowledge, and be part of a growing network working to improve outcomes for everyone affected by bladder cancer.

# World Bladder Cancer Patient Forum 2024

The 2024 World Bladder Cancer Patient Forum marked a significant milestone. Held in the Dominican Republic – it was our first two-day programme, allowing time for deeper conversations and a stronger drive for collaboration.

Participants included patients, advocates, clinicians, and industry partners from across the world. Together, they explored how to drive lasting change in bladder cancer care, support, and strengthen bladder cancer patient advocacy in all regions.

## Strengthening advocacy and awareness

Bladder cancer remains overlooked in many national health and cancer planning agendas. The Forum highlighted the urgent need to close gaps in care, focusing on South and Central America this year, where we had regional expertise from local healthcare professionals and advocates.

Our member organisations shared successful campaigns such as Italy's Stop at Red Walk and Canada's Light Up initiatives for Bladder Cancer Awareness Month. These efforts show the growing drive and creativity in our community to drive awareness about bladder cancer.

## Building a supportive community

Support extends beyond treatment. Patient-led initiatives showcased the power of peer networks and local patient support solutions.

Bladder Cancer Canada shared how it connects patients through its peer support programme. In Brazil, Instituto Oncoguia uses WhatsApp as a resource to guide patients through complex healthcare challenges.

New groups are forming, too. Inspired by the content of the Forum 2023 and connections made there, Spain's first bladder cancer patient organisation, CANVES, was launched with our support. At the Forum, they shared their journey from an idea to a reality, inspiring strength and commitment in our bladder cancer patient community.

*“The Forum gave us the push we needed to turn an idea into reality. Connecting with others who share our mission inspired us to take action and build something meaningful for bladder cancer patients in Spain.”*

**David Garrigues**  
CANVES  
Spain

## Driving progress in research and policy

Patients must be part of the research and policy conversation. Yet 84% of our Global Bladder Cancer & Carer Survey respondents said they were never informed about clinical trials.

Speakers called for better communication about and greater access to trials. Advances in imaging and therapies were also shared, drawing from the latest published bladder cancer research showing the potential to transform care pathways.

## The future of bladder cancer advocacy

As WBCPC marked our five-year anniversary, the Forum was a moment to reflect on our achievements and look forward with ambition. With 16 member organisations across 13 countries, our coalition is growing in reach and impact.

Initiatives from Bladder Cancer Awareness Month to the Global Patient and Carer Survey are shining the light on the challenges our patient community faces, shaping policy and healthcare decisions and amplifying patient voices globally.

*“We must design clinical trials around the real experiences of patients.”*

**Dr Stephanie Demkiw**  
WBCPC Board Member  
Bladder Cancer Awareness Australia



*“Together, we are building a world where every patient can access the care and support they deserve.”*

**Dr Lydia Makaroff**  
WBCPC President  
Fight Bladder Cancer  
UK





*“This platform makes it easier than ever to stay connected, exchange ideas, and grow stronger together.”*

**Amy Samuel**  
Bladder cancer patient  
Senegal

## A collective commitment to change

The 2024 Forum reinforced the power of a united bladder cancer patient community. Over two days, participants shared knowledge, built partnerships, and affirmed their commitment to improving patient outcomes. The Forum’s impact extends beyond the event itself, every connection made and insight shared contributes to lasting change and growing drive and inspiration.

As we look ahead, we remain dedicated to building a future where bladder cancer patients worldwide receive the best possible care and support. Through collaboration, advocacy, and innovation, we will continue to drive meaningful progress together.



## Connecting our global patient community

In 2024, we launched a new space for connection, collaboration, and conversation: the WBCPC Global Community Platform for our members and aspiring bladder cancer patient advocates on GlueUp.

For the first time, our member organisations have a dedicated, interactive space to engage directly with each other. Whether sharing updates, posting resources, asking questions, or seeking advice, members can now connect in real-time with peers from across the globe.

The platform was created in response to our members’ needs for more regular interaction, better access to shared materials, and a space to build deeper relationships between organisations. As our network continues to grow, Glue Up ensures that collaboration remains at the heart of everything we do.

# Engaging and building a community online

Our social media presence across X, Facebook, LinkedIn, Instagram, Bluesky and YouTube continues to play an important role in connecting directly with patients, healthcare professionals, advocates, and international and national organisations. These platforms enable real-time conversations, build trust, and foster a sense of belonging within the global bladder cancer community.

In 2024:



17,000,000+

Over 17 million people reached across platforms



125,000+

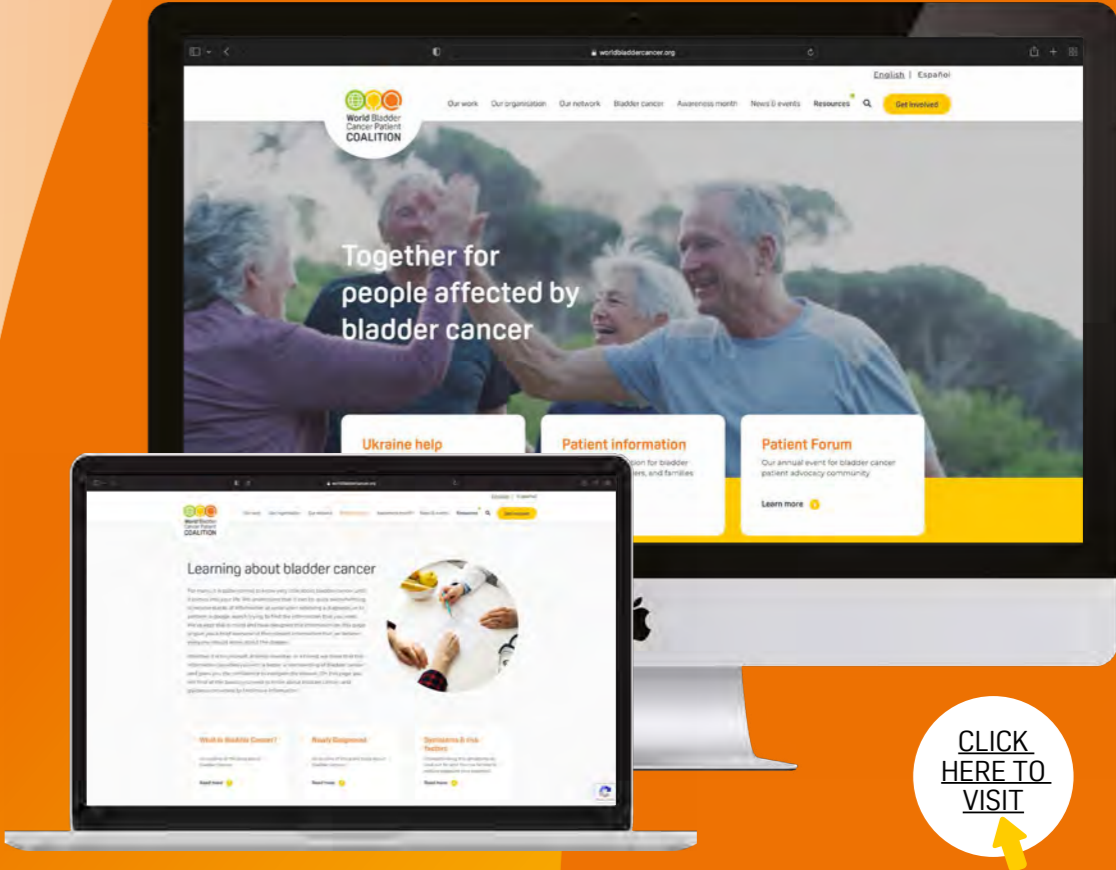
Visitors to our website



940

new followers across our social media channels, on **LinkedIn, X, Facebook** and **Instagram**, bringing our online community to more than **9,800** people by year-end

This growth reflects the increasing relevance of our mission as an organisation and as a community. It also expands our ability to raise broader awareness, share impactful stories whilst building a sense of a strong community, and drive action worldwide. Social media remains an important tool for amplifying patient voices, strengthening partnerships, and encouraging meaningful global dialogue.



*“Social media continues to be an essential tool to expand reach and foster community engagement.”*

Sarah Coffey Dégrange  
WBCPC Board Member  
Cancer Vessie France

# Raising awareness



# Bladder Cancer Awareness Month

Every May, our global community comes together to spotlight one of the most overlooked cancers. In 2024, Bladder Cancer Awareness Month (BCAM) reached more people than ever, building momentum, driving conversations, and encouraging early action.

## Feeling Unsure? Get Checked

Continuing with the theme “Feeling Unsure? Get Checked”, this year’s campaign urged people to listen to their bodies and seek medical advice if something felt wrong. Early diagnosis can save lives, and our community has taken that message globally.

At the heart of the campaign was Spot the Drop, an interactive online game challenging players to spot symptoms quickly.

Available in 12 languages, over 52,000 people played it across the world.

## Campaigning at a glance:



62

**Countries participated**  
in the 2024 Bladder Cancer  
Awareness Month



1,000,000

Over 11 million **reached on**  
**social media**



100,000

More than 100,000 **interactions**  
**across platforms**



10

Resources  
**available in over**  
**10 languages**



**Posters, Videos, toolkits**  
shared in healthcare settings  
and online

*“When we work together,  
we make bladder cancer  
more visible not only in our  
communities but across  
the world.”*

**Alex Filicevas**  
WBCPC Executive Director

In 2024:

**49** mailings were sent, linking to key campaigns, new resources, and major events



**11,000+** Over 11,000 email opens showed strong and growing engagement. Monthly editions featured:

- News from the Coalition and members**
- Advocacy highlights**
- Personal stories and community voices**
- New tools, factsheets, and resources**

*“Our newsletter is more than updates. It is where the global bladder cancer community stays informed, connected, and inspired.”*

**Marie Magenhann Cueto**  
WBCPC Communications and Community Engagement Coordinator

## Global reach, local impact

Through the Bladder Cancer Awareness Month Grant Programme in 2024, we supported locally-driven awareness activities in Argentina, Kenya, Malawi, and Nigeria.

From awareness walks and radio shows to community workshops and outreach events, the collective message was strong around the fact that bladder cancer awareness saves lives.

## Bladder cancer newsletter

Our monthly newsletter continues to connect patients, families, advocates, and partners worldwide.

Since its launch in 2019, it has become a trusted space for sharing stories, updates, and opportunities for collective action.

## Members' Quarterly newsletter

In 2024, we continued to amplify the impact of local action through our **Members' Quarterly Newsletter**, a dedicated publication that shines a light on the inspiring work of our member organisations worldwide.

Each quarterly edition showcases member-led projects, awareness campaigns, events, and advocacy initiatives, highlighting the creativity and commitment of organisations working to improve the lives of those affected by bladder cancer. By sharing these stories, the newsletter fosters a sense of community, encourages idea-sharing, and helps spark new collaborations across borders.

Feedback from our members has been positive, with many expressing appreciation for the opportunity to learn from their peers and bring new ideas to their work. This newsletter continues to be a valuable tool for connection, recognition and shared growth across our global network.

## Bladder cancer information and resource hub on our website

Our website, [worldbladdercancer.org](https://worldbladdercancer.org), remains a central hub for people affected by bladder cancer and the broader community, offering timely, accessible, and relevant information.

It reflects the voice and vibrancy of our global Coalition, showcasing achievements, amplifying patient voices, and reporting on key developments across the world.

*“Every article published is another piece of a larger puzzle in making bladder cancer more visible globally.”*

**Lori Cirefire**  
WBCPC Board Member  
Cancer Vessie France

Our articles are always published in English and Spanish, helping us increase accessibility for our international audience. Whether highlighting a local activity or announcing new global initiative or research, each story continues to inform, connect, and strengthen our growing community.

In 2024:

74

74 **news articles** were published, covering **awareness campaigns, collaborations, advocacy** and **policy engagement, new resources, policy initiatives,** and **community events.**

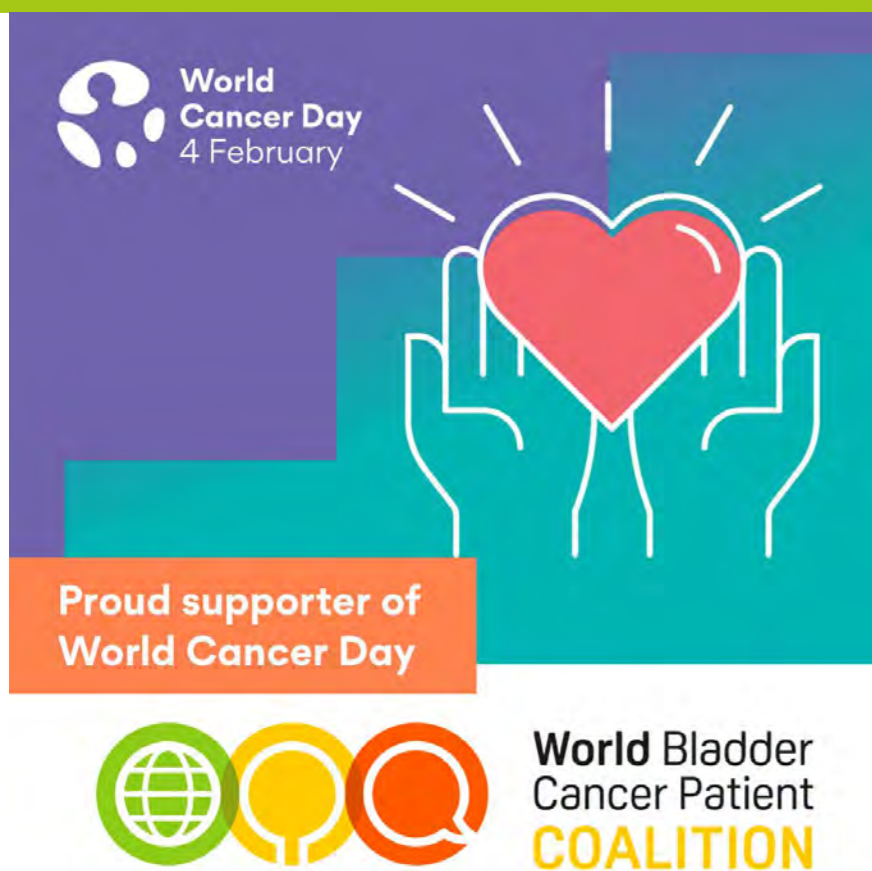
100

Readers from over **100 countries** engaged with our content, **showing our global reach and increasing interest in bladder cancer** and the work of our coalition and its members.



## Most read articles of 2024

- Launch of our **“Spot the Drop”** campaign game
- Highlights from Bladder Cancer Awareness Month 2024
- The World Bladder Cancer Patient Forum 2024 in Punta Cana
- Launch of our new **“What is Bladder Cancer?”** patient information factsheet
- Sharing bladder cancer stories from around the world



*“Every year, World Cancer Day shows the importance of collaboration in addressing inequalities in cancer care for all people affected by cancer.”*

Alex Filicevas  
WBCPC Executive Director

## #BladderCancerAware for World Cancer Day – Raising our voice to close the care gap

On February 4, 2024, we proudly joined the global cancer advocacy community to mark World Cancer Day, led by the Union for International Cancer Control (UICC). As a member of UICC, we seized this global moment to spotlight bladder cancer, one of the most under-recognised cancers, and call for greater equity in cancer care.

Through a dedicated social media campaign, we raised awareness about:

- The realities of living with bladder cancer
- The importance of early detection and informed care
- The power of strong patient advocacy
- The disparities in access to treatment worldwide

Using the hashtag #BladderCancerAware, we invited the community to share facts,

patient voices, and actionable ways to get involved. We also highlighted our **Start-up Guide for Bladder Cancer Patient Groups**, encouraging advocates, especially in countries without formal support systems, to take the first steps in building local movements.

World Cancer Day 2024 reminded us that change begins locally and that every voice, every story, and every effort helps close the care gap.

*“Providing clear and practical information empowers patients to participate more actively in their care and support the shared decision making in healthcare.”*

Adam Lynch  
BEAT Bladder Cancer Australia

Patient information resources – new factsheets to empower patient-doctor conversations about bladder cancer

Supporting patients, carers and healthcare professionals’ conversations about bladder cancer

In 2024, we expanded our library of patient education resources by introducing three new factsheets designed to support individuals diagnosed with bladder cancer. Developed in collaboration with medical experts and patients, these resources were published in English and Spanish, with more languages to be included.

New patient information factsheets launched in 2024:

1.

Understanding bladder cancer

A foundational guide covering key information on bladder cancer types, diagnosis, and treatment options. It is intended as a resource for patients and healthcare professionals as a conversation aid at the time of diagnosis.

2.

Understanding TURBT

A practical overview of the Transurethral Resection of Bladder Tumour (TURBT) procedure, including preparation and recovery guidance. It is intended as a resource for patients and healthcare professionals as a conversation aid at the time of diagnosis.

3.

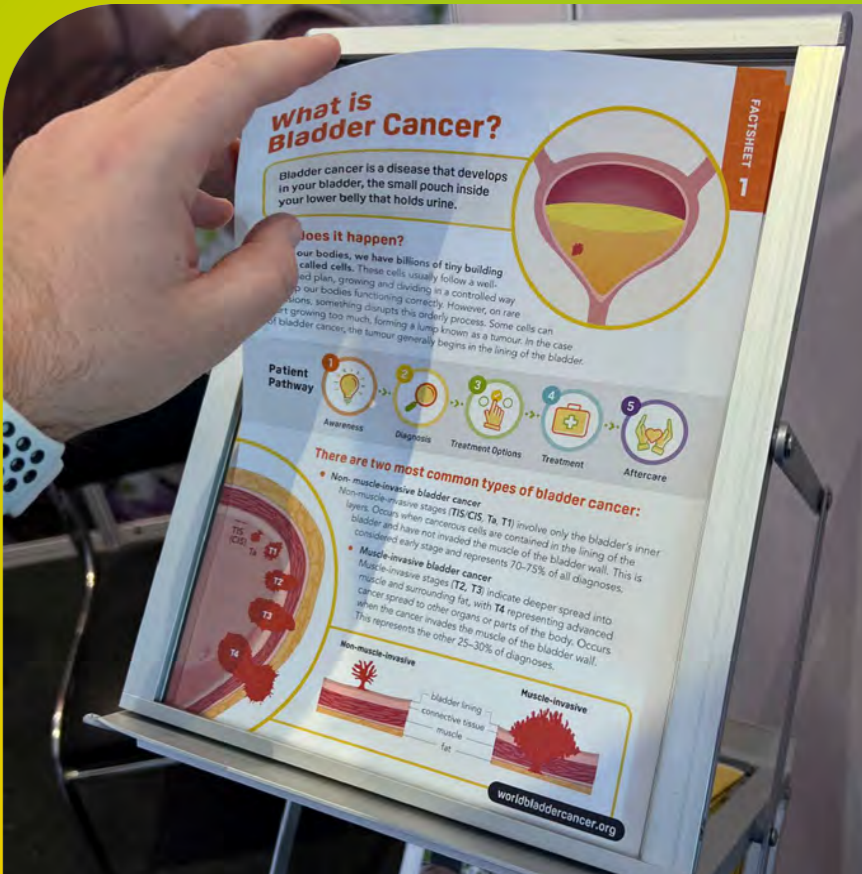
Key questions to ask your Doctor or Nurse

A resource designed to facilitate informed discussions between patients and healthcare professionals. It is intended for patients and carers as a guide on key questions to ask of the healthcare provider to support decision-making.



Downloads

These factsheets have been downloaded and shared across **more than 20 countries**, with active support from our national member organisations to promote them locally.



# Sharing 5 unique stories of women with bladder cancer

Five women. Five unique experiences. One shared message. Shining a light on women's experiences with bladder cancer

In 2024, we shared the personal journeys of five women affected by bladder cancer, helping to raise awareness of its impact on women and addressing the misconception that it only affects men.

Their stories shared throughout the year, helped spotlight the importance of recognising symptoms early and ensuring women's experiences are heard and validated within healthcare systems.

Their experiences launched on International Women's Day on March 8 were widely shared during Bladder Cancer Awareness Month and other key moments throughout the year, encouraging greater awareness and discussion about gender disparities in bladder cancer diagnosis and treatment.



## Claudia

**A 46-year-old mother from Rome, Italy**

Diagnosed with *upper tract urothelial cancer* that progressed to bladder cancer, Claudia underwent radical surgery to remove her bladder. A neobladder was created from her small intestine, allowing her to maintain continence and return to daily life with confidence.



## Angela

**A 42-year-old from Niverville, Canada.**

Diagnosed in 2020 after repeated misdiagnoses, Angela faced **muscle-invasive bladder cancer** and underwent chemotherapy followed by a radical cystectomy. She now lives with a urostomy bag named 'Peeatrice', symbolising strength, humour, and resilience.



## Fatima

**A 40-year-old from Mumbai, India.**

Her journey began in 2017 with blood in her urine, followed by the shock of discovering she was both pregnant and had **bladder cancer**. She underwent TURBT and BCG therapy, facing complications such as UTIs and reactive arthritis, but remained determined to fight for her health and her family.



## Vivian

**Aged 50 and based in Johannesburg, South Africa.**

After surviving cervical cancer in 2018, she was diagnosed with **bladder cancer** two years later, following severe abdominal pain. In 2023, she began chemotherapy, once again facing cancer with courage and determination.



## Ana Mariá

**Aged 79, living in Buenos Aires, Argentina.**

A **bladder cancer** diagnosis in 2022 was not her first encounter with cancer, she had previously overcome breast cancer. Ana Mariá is currently participating in a clinical trial for muscle-invasive bladder cancer, offering a perspective grounded in hope and science.

*“Enhancing visibility into women’s experiences with bladder cancer is critical for addressing diagnostic delays, improving the quality of care, and mitigating the disproportionately poor outcomes that women diagnosed with bladder cancer often face”.*

**Michelle Colero**  
WBCPC Vice-President  
Bladder Cancer Canada



## Leveraging patient and carer survey findings to improve bladder cancer care

The Global Bladder Cancer Patient & Carer Survey is a landmark initiative by the World Bladder Cancer Patient Coalition, bringing together the voices of nearly 1,200 respondents across 45 countries. It is the first international effort of its kind to gather patient and carer insights on the experience of living with and beyond bladder cancer.

The findings provide a comprehensive overview of the challenges faced by patients and carers – from delayed diagnosis and misdiagnosis to gaps in communication around treatment. These insights helped generate important evidence to inform our community

advocacy to improve care. The results, published in 2023, serve as a call to action for healthcare professionals, policymakers, and advocates to address long-standing unmet needs in bladder cancer care. In 2024, we continued dissemination through high-impact international forums, helping to raise awareness, promote patient-centred recommendations, and drive meaningful change in how bladder cancer is understood and managed worldwide.

We have also used the findings and the learnings from leading patient-led research at community training initiatives such as the WECAN Evidence-Based Advocacy Workshop.

# Engaging in advocacy

## ASCO GU Symposium 2024 San Francisco, USA

At the ASCO Genitourinary Cancers Symposium 2024, we presented a poster featuring key findings from the Global Bladder Cancer Patient & Carer Survey.

This marked our first appearance at this leading scientific meeting and an important step in integrating patient evidence into global research dialogues.



## World Cancer Congress 2024 Geneva, Switzerland

WBCPC presented its first poster at the World Cancer Congress 2024, highlighting findings from the Global Survey on diagnosis challenges and gender disparities.

This milestone marked growing engagement in global cancer policy and underscored our commitment to advancing equity in bladder cancer care.

## SIU Congress 2023 New Delhi, India

At the SIU 44 Congress, we shared a focused analysis of the experiences of patients with advanced and metastatic bladder cancer.

This engagement continues our valued collaboration with the Société Internationale d’Urologie and reinforces the importance of incorporating patient voices when shaping care pathways.



## Learning visit to understand bladder cancer impact in Malawi

Malawi faces one of the world's highest burdens of bladder cancer, ranking third globally in bladder cancer mortality among women. The country records an estimated 779 new bladder cancer cases and 466 deaths each year, with many more potentially unrecorded. Often, many bladder cancer cases in Malawi are linked to schistosomiasis—a preventable parasitic disease common around Lake Malawi and the Shire River.

In this context, our team travelled to Blantyre to meet with partners, understand local challenges, and explore collaborative opportunities to improve bladder cancer awareness and care in the country.

We met with Wisdom Zunguzungu from our affiliate member in Malawi – One Community, whose work focuses on empowering vulnerable communities through public health and awareness campaigns. Together, we discussed the development of awareness activities tailored to local populations.

At Queen Elizabeth Central Hospital, we held in-depth discussions with Prof Janelisa Musaya and her

research team on the role of mass drug administration for schistosomiasis prevention, including innovative community-led approaches in close collaboration with community leaders across the country. One of the most impactful moments of our visit was meeting with the surgeons at Queen Elizabeth Hospital. These dedicated professionals shared their experiences and the immense challenges they face daily.

Despite limited resources and outdated equipment, their commitment to patient care is unwavering. They discussed the difficulties in managing late-stage diagnoses due to a lack of early detection facilities. The surgeons also highlighted the importance of ongoing training and the need for better surgical tools and supplies.

This visit reaffirmed our commitment to fostering meaningful, community-driven partnerships and closer collaboration with partners in resource-constrained countries with high bladder cancer burden. By working together with local organisations and leaders, we can help raise awareness, improve early detection, and advocate for better outcomes for people affected by bladder cancer in Malawi.





## The role of the patient voice in Health Technology Assessment

Our HTA 101 workshop introduced patient advocates to the fundamentals of Health Technology Assessment (HTA) and its role in shaping healthcare decisions.

Expert speakers highlighted how HTA evaluates value of cost in patient outcomes and why patient input is essential in this process. Real-world examples from Bladder Cancer Canda and Cancer Vessie France demonstrated how patient data, experience and stories can influence decisions about access to treatment. As HTA frameworks evolve across Europe and the world, we focus on empowering our community to better engage in these processes and ensure that bladder cancer care reflects what truly matters to patients.

## Capacity-building workshops for our community

We hosted 2 in-person workshops developed to skill up our member organisations with the foundations to engage in policy discussions and assessments of new therapies.

Both workshops were incorporated into the World Bladder Cancer Patient Forum programme.



## Policy as a tool to advocate for bladder cancer patient needs

This capacity-building session, led by Eva María Ruiz de Castilla from the Latin America Patients Academy, introduced patient advocates to the fundamentals of using policy to drive change.

Our member organisations learned how patient organisations can influence laws, regulations, and healthcare access by engaging with decision-makers and building strategic partnerships. Drawing on real examples from Latin America and our own Coalition, the session provided a clear, step-by-step framework for developing effective policy advocacy strategies. It laid an important foundation for strengthening policy knowledge and equipping bladder cancer advocates with practical tools to advance patient-centred change in their own healthcare systems.



## WECAN Academy 2024

WECAN Academy 2024 welcomed 80+ cancer patient advocates for an intensive four-day learning programme. We were delighted to enable our largest bladder cancer patient community representation at the Academy to date, with representatives from Associazione PaLiNuRo, Cancer Vessie France and Fight Bladder Cancer.

We also had a role in the programme of the WE CAN Academy, where our Executive Director, Alex Filicevas, shared examples of WBCPC work and, together with our President, Lydia Makaroff, presented a session titled “The Power of Words: Elevating Patient Advocacy Through Communication.”

The session focused on the essentials of communication in patient advocacy, exploring why good communication is a critical component of our work. They shared strategic approaches to communications and real-life examples from the community and taught different ways to communicate effectively with various audiences to ensure messages resonate and make an impact.

Meeting with other patient advocates from across Europe was a wonderful experience. It allowed us to continue building our skills and expertise, ensuring we are better equipped to serve the needs of bladder cancer patients. This collaboration and knowledge exchange is crucial as we strive to enhance our advocacy efforts and support cancer patients more effectively.

## IBCG Annual Retreat Houston, USA

The World Bladder Cancer Patient Coalition was honoured to participate in the 2024 International Bladder Cancer Group (IBCG) Retreat in Houston, Texas, in the United States of America. This annual meeting brings together global experts to develop evidence-based recommendations that guide clinical decisions and improve the care of people affected by bladder cancer.

Representing WBCPC were President Dr Lydia Makaroff and Executive Director Alex Filicevas, who contributed to a dedicated session alongside US-based patient advocate colleagues to bring the patient voice into clinical discussions. This participation ensured that the needs, priorities, and lived experiences of patients were considered in shaping new international guidelines.

Throughout the retreat, discussions covered key challenges in bladder cancer care, including treatment approaches for variant histologies, improving surgical outcomes, and enhancing post-treatment support. Importantly, there was strong



support for making clinical research more inclusive by shifting away from age-based criteria towards assessments based on frailty and overall fitness. The group also emphasised the importance of survivorship care, ensuring patients receive continued support and monitoring beyond the acute treatment phase.

The retreat highlighted the value of multidisciplinary collaboration, where clinical experts and patient advocates work together to improve care standards. By contributing to this process, we continue to ensure that the patient perspective shapes the future of bladder cancer treatment and care globally.

## Our advisory and leadership roles

The World Bladder Cancer Patient Coalition is recognised as a valuable partner with many international organisations. We bring bladder cancer patient perspective into many collaborative initiatives which help advance meaningful change in cancer care and cancer policymaking. We've held leadership roles at All.Can International, Global Cancer Coalitions Network and actively participate in European Cancer Organisation Patient Advisory Committee and EFPIA Patient Think Tank and its Steering Committee.

## PRIME-ROSE Community Advisory Board in Oslo, Norway

Together with the Norwegian Bladder Cancer Society, we joined and actively contributed to the PRIME-ROSE project. It is an EU-funded initiative where we were representing bladder cancer patient perspectives in discussions on improving access to precision cancer medicine through the design of pragmatic clinical trials.

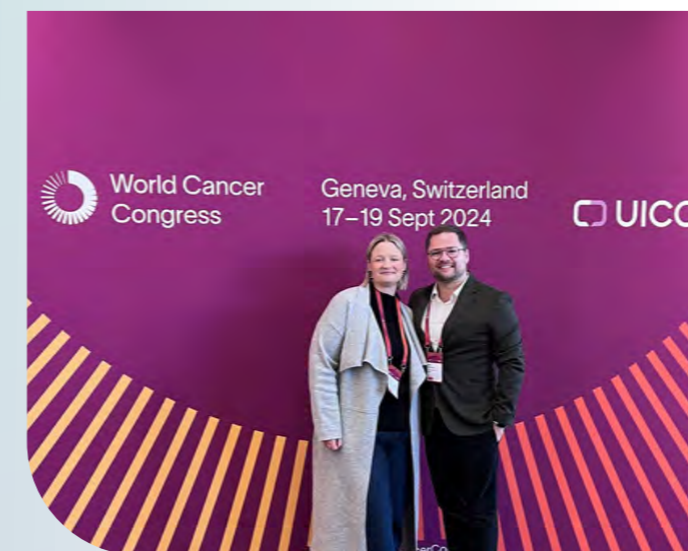


# Representing our community at global events

## World Cancer Congress 2024 Geneva, Switzerland

For the first time, we presented a research poster at the World Cancer Congress, organised by the Union for International Cancer Control (UICC). The poster shared key findings from our Global Bladder Cancer Patient & Carer Survey, representing voices from 45 countries.

Our participation brought bladder cancer into vital global policy discussions whilst also allowing us to connect with advocates and leaders in cancer control from all across the world.



## Global Cancer Coalitions Network (GCCN) Annual Meeting Toronto, Canada

As Co-Chair of the Global Cancer Coalitions Network, Executive Director Alex Filicevas helped lead discussions on strengthening collaboration across global patient advocacy organisations, joined by the WBCPC Vice-President Michelle Colero from Bladder Cancer Canada.

## SIU Congress New Delhi, India

At the 44th Annual Congress of the Société Internationale d’Urologie (SIU), we presented our second abstract poster, focusing on the experiences of patients diagnosed with advanced and metastatic bladder cancer. We engaged directly with urologists from around the world, highlighting the importance of early patient support and promoting the Start-up Guide for bladder cancer patient groups and newly launched patient information factsheets.



## EAU Congress Paris, France

At the European Association of Urology Congress (EAU24), our engagement included:

- A presentation by President Dr Lydia Makaroff on empowering patient care through AI and digital health.
- An exhibition booth sharing resources with healthcare professionals and advocates.
- Participation in the inaugural EAU Fun Run to support research initiatives.

## WECAN Academy Frankfurt, Germany

Our team participated in two days of intensive, evidence-based advocacy training, strengthening the Coalition’s ability to lead patient-centred research and initiatives.



## Cancer Patient Day Paris, France

We participated in the Bladder Cancer Patient Day, organised by the French Association of Urology and our French member, Cancer Vessie France.

The event featured expert insights, a moderated Q&A, and research and clinical trial access updates.



## WBCPC 6th General Assembly 2024

On June 13, 2024, the World Bladder Cancer Patient Coalition gathered virtually for the 6th General Assembly. The meeting brought together our member organisations to review achievements over the past year and discuss work priorities.

The discussions reflected the growing strength and reach of our coalition, with members highlighting the impact of joint initiatives and identifying new areas for collaboration and growth.

Throughout the meeting, we reviewed the key activities and milestones from 2023. These included the success of Bladder Cancer Awareness Month, which engaged more than 12 million people around the world, and the 3rd World Bladder Cancer Patient Forum, which welcomed participants from 23 countries. We also celebrated using the Global Bladder Cancer Patient and Carer Experience Survey to support advocacy efforts and influence national health policy discussions in several countries.

The Assembly marked a further step in expanding our global reach as we welcomed new member organisations from Argentina and Malawi.



Their addition strengthens our community and reinforces our commitment to representing people affected by bladder cancer on all continents.

Looking to the future, members discussed priorities for the coming year, including enhancing engagement in Health Technology Assessment processes, supporting the creation of new bladder cancer patient groups, and ensuring that patient perspectives continue to drive national and international advocacy efforts.

The 6th General Assembly reaffirmed our shared commitment to strengthening bladder cancer patient advocacy worldwide and ensuring that everyone affected by bladder cancer has access to better care, support, and information.

# Financial report



## Balance sheet

Financial statements for the year ended 31 December 2024, in euros.

These figures, as presented, represent a summary of audited financial statements of the World Bladder Cancer Patient Coalition. Appointed statutory auditor for financial years 2024–2027 is Mazars Belgium. Audited financial statements and auditors report are available on the organisation's website at [worldbladdercancer.org](https://worldbladdercancer.org)

ASSETS	2024 (AMOUNT IN €)	2023 (AMOUNT IN €)
<b>Fixed assets</b>	€ 5.064	€ 10. 556
Intangible assets	€ 2.770	€ 7.295
Tangible assets	€ 2.294	€ 3.261
<b>Current assets</b>	€ 416.170	€ 497.871
Amounts receivable within one year	€ 10.763	€ 99.162
Current accounts	€ 371.939	€ 389.714
Deferred charges	€ 33.467	€ 8.995
<b>TOTAL</b>	<b>€ 421.234</b>	<b>€ 508.427</b>
<b>Capital &amp; reserves</b>	€ 329.622	€ 345.762
Profit carried forward	€ 329.622	€ 345.762
Balance	-€ 16.140	€ 71.546
<b>Amounts payable</b>	€ 91.612	€ 162.666
Amounts payable within one year	€ 59.369	€ 39.323
Accrued charges & deferred income	€ 32.243	€ 123.343
<b>TOTAL</b>	<b>€ 421.234</b>	<b>€ 508.427</b>

## Financials

The board of directors approved the 2024 audited financial results and subsequently approved by the 7th World Bladder Cancer Patient Coalition General Assembly, which took place on June 12, 2025.

The World Bladder Cancer Patient Coalition is an international non-profit organisation registered in Belgium, registration number 0720.618.047 and VAT ID: BE0720618047.

Revenue and expenses for 2024 For the Financial year 2024, ended 31 December 2024, the revenue of the World Bladder Cancer Patient Coalition aisbl amounted to a total of **€ 523.978**.

The organisation’s operating costs, including applicable taxes, employee costs, office costs and external costs related to the implementation of planned projects, amounted to a total of **€ 540.117**. Leaving a negative net year-end balance of **€ 16.140**.

SOURCE OF REVENUE	2024 (AMOUNT IN €)	2023 (AMOUNT IN €)
Sponsorships and grants	€ 493.720	€ 600.579
Other income	€ 30.258	€ 19.798
VAT account	€ 0	€ 0
TOTAL REVENUE	€ 523.978	€ 620.377

OPERATING EXPENSES	2024 (AMOUNT IN €)	2023 (AMOUNT IN €)
Staff costs	€ 273.232	€ 239.270
Management & running costs	€ 75.417	€ 75.782
Board expenses	€ 4.657	€ 9.726
Project costs	€ 186.811	€ 224.054
TOTAL EXPENDITURE	€ 540.117	€ 548.831
BALANCE	– € 16.140	€ 71.546

## Sponsorship and grants received in 2024

REVENUES FROM CORPORATE SUPPORT	AMOUNT IN €	PERCENTAGE (%)
AstraZeneca	€ 60.000	12.15%
Daiichi Sankyo	€ 26.000	5.27%
Ferring	€ 70.000	14.18%
Johnson & Johnson IM	€ 100.000	20.25%
MSD	€ 30.000	6.08%
Merck KGaA	€ 80.000	16.20%
Roche	€ 65.000	13.17%
Seagen & Astellas alliance	€ 62.720	12.70%
<b>TOTAL CORPORATE SUPPORT CONTRIBUTIONS REVENUE</b>	<b>€ 493.720</b>	<b>100%</b>

*This table does not include any revenue corresponding to consulting or similar types of compensation from the industry on specific external projects, accounted for elsewhere as revenue.*



- 12.15% AstraZeneca
- 5.27% Daiichi Sankyo
- 14.18% Ferring
- 20.25% Johnson & Johnson IM
- 6.08% MSD
- 16.20% Merck KGaA
- 13.17% Roche
- 12.70% Seagen & Astellas alliance

Revenue and expenses for 2024

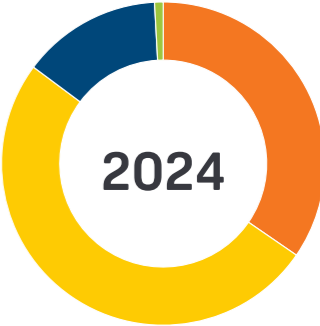
Source of Revenue 2024

94.23% Sponsorship and grants  
5.77% Other Income



Operating Costs 2024

34.59% Project Costs  
50.59% Staff Costs  
13.96% Management & Running Costs  
0.86% Board Expenses



Revenue and expenses for 2023

Source of Revenue 2023

96.81% Sponsorship and grants  
3.19% Other Income



Operating Costs 2023

40.82% Project Costs  
43.60% Staff Costs  
13.81% Management & Running Costs  
1.77% Board Expenses



## Operating costs and expenditures in 2024

OPERATING COSTS	2024 (AMOUNT IN €)	2023 (AMOUNT IN €)
<b>STAFF COSTS</b>	<b>€ 273.232</b>	<b>€ 239.270</b>
Remuneration	€ 203.554	€ 183.193
Social security contributions	€ 32.065	€ 18.939
Other employee costs	€ 38.524	€ 36.623
Tax provision for holiday pay	€ 1.955	€ 2.192
Recup. Withholding tax	– € 2.866	–€ 1.677
<b>MANAGEMENT &amp; RUNNING COSTS</b>	<b>€ 75.417</b>	<b>€ 75.782</b>
Office costs	€ 3.367	€ 7.759
Telephone/Internet	€ 2.568	€ 2.825
Depreciations on IT	€ 2.023	€ 1.304
IT maintenance	€ 4.066	€ 3.332
Insurance costs	€ 2.463	€ 1.361
Congress & Events	€ 4.640	€ 4.718
Subscription fees	€ 5.475	€ 5.145
Legal fees	€ 3.630	€ 3.020
Accountant & audit fees	€ 12.609	€ 11.440
Bank costs	€ 2.162	€ 4.553
Payroll services & fees	€ 6.423	€ 5.940
Advertising & Marketing	€ 4.867	€ 4.487

\*Previously title or grouped differently  
Advocacy & Capacity building

	2024 (AMOUNT IN €)	2023 (AMOUNT IN €)
Taxes & Fees	€ 85	€ 85
Training & Development	€ 7.436	€ 3.520
Team building	€ 1.336	€ 1.494
Travel	€ 12.269	€ 14.799
<b>BOARD EXPENSES</b>	<b>€ 4.657</b>	<b>€ 9.726</b>
Board related costs	€ 4.657	€ 9.726
<b>PROJECT RELATED COSTS</b>	<b>€ 186.811</b>	<b>€ 224.054</b>
Forum	€ 73.995	€ 68.696
Awareness Month	€ 44.593	€ 79.511
Patient Survey	€ 0	€ 7.972
Start-up & member support*	€ 2.719	€ 8.606
Communications & Newsletter	€ 6.718	€ 640
Special project: 5 Women	€ 38.329	€ 14.560
White paper	€ 0	€ 35.228
Resource library development	€ 2.987	
Low & middle income countries & bladder cancer impact	€ 11.547	
Other projects	€ 5.923	€ 8.841
<b>TOTAL OPERATING COSTS</b>	<b>€ 540.117</b>	<b>€ 548.831</b>

# Our partners



# Strengthening bladder cancer advocacy through collaboration

Working together with our partners and sponsors is vital to amplifying the patient voice and improving outcomes for people affected by bladder cancer around the world. We are proud to collaborate with leading global organisations who share our vision of patient-centred care, innovation, and advocacy.

## What our partners say:

### Société Internationale d'Urologie (SIU)



“Through our collaboration with the WBCPC, the SIU remains dedicated to better understanding and supporting the patient’s voice. Together, we are strengthening patient advocacy and improving bladder cancer care worldwide.”

**Professor Jean de la Rosette**  
President, SIU

### Union for International Cancer Control (UICC)



“By drawing attention to the experiences and priorities of people affected by bladder cancer, the World Bladder Cancer Patient Coalition helps ensure this often-overlooked disease is not left out of broader conversations on cancer care. As a UICC member, their work strengthens our collective efforts to ensure that the perspectives of people living with cancer inform national and global cancer control initiatives.”

**Muriel Auclair**  
Head of Membership, UICC

European  
Association of Urology (EAU)



“Through our collaboration with WBCPC, we are advancing patient engagement in urology and building stronger pathways for bladder cancer care and support across Europe and beyond.”

**Professor Eamonn Rogers**  
**Chairman, EAU Patient Office**

European Cancer  
Organisation (ECO)



“The voice of bladder cancer patients is essential to achieving equitable and patient-centred cancer care. We value WBCPC’s contributions to our shared mission of closing gaps and improving outcomes across Europe.”

**Dr Csaba Dégi**  
**President, ECO**

All.Can International



“WBCPC brings a critical perspective to the movement for more efficient, patient-focused cancer care. Our collaboration highlights the power of cross-sector partnerships in improving the entire patient journey.”

**Eduardo Pisani**  
**CEO, All.Can**

**WECAN**

“WBCPC exemplifies the strength of evidence-based patient advocacy. We are proud to work together to train, empower, and support patient leaders in bladder cancer advocacy and beyond.”

**Anita Kienesberger**  
Chair, WECAN

European Federation of  
Pharmaceutical Industries  
and Associations (EFPIA)



“Including patient insights is vital to shaping better healthcare solutions. We value WBCPC’s contributions in ensuring that the realities of people living with bladder cancer are heard at every level.”

**Mihai Rotaru**  
Director Market Access, EFPIA

**touchONCOLOGY**

“touchONCOLOGY is delighted to partner with the WBCPC to collaborate and raise awareness of bladder cancer and to advance the education and understanding of this often-overlooked disease.”

**Caroline Markham**  
Head of Strategic Partnerships  
Touch Medical Media

# Our sponsors

## Premier Partners



## Supporters





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Cancer Patient  
**COALITION**

Thank you to everyone who has  
taken a step with us toward creating  
a better world and future for people  
affected by bladder cancer.

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**Youtube:** @WorldBladderCancerPatient  
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