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**Email:** info@worldbladdercancer.org

#### World Bladder Cancer Patient Coalition aisbl

Square de Meeûs 38–40 1000 – Brussels Belgium

#### Secretariat

E: info@worldbladdercancer.org

Reg. Number: 0720.618.047 VAT ID: BE 0720.618.047



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### Foreword from President and Executive Director

As we celebrate our fifth anniversary, it is remarkable to reflect on the path we have taken together. What began as a vision to unite patient organisations from around the world has blossomed into a strong coalition, now representing a diverse network of organisations across six continents. Our focus has remained clear through these years – ensuring that bladder cancer patients and their loved ones have access to the best care, information, and support, no matter where they live.

The year 2023 was significant for the World Bladder Cancer Patient Coalition, marked by the official launch of the Global Bladder Cancer Patient and Carer Survey – our largest project to date. Spanning 45 countries, the survey provided invaluable insights into the lived experiences of patients and carers. Published in *European Urology* and presented at major scientific congresses – including receiving awards at the European Association of Urology and the Société Internationale d'Urologie – the survey has highlighted the physical, psychological, and financial challenges faced by bladder cancer patients worldwide. These findings are already shaping efforts to improve patient care and enhance communication between patients and healthcare professionals.

For the first time we attended the AORTIC Cancer in Africa Congress, where we gained valuable insights into bladder cancer control efforts across the continent. Engaging with key figures in cancer care, including experts from Senegal, Malawi, and Nigeria, we deepened our understanding of local challenges, particularly the impact of schistosomiasis and smoking as major risk factors for bladder cancer in sub-Saharan Africa. These interactions continue to strengthen







We would like to express our gratitude to all of our member organisations, partners, and supporters who have contributed to the success of the WBCPC. Together, we can continue to build a global bladder cancer community, raise awareness, and advocate for better bladder cancer care.

our commitment to fostering collaboration and supporting local patient groups in underrepresented regions.

We are equally proud of the growth of the World Bladder Cancer Patient Forum, held this year in Madrid. This event brought together an even broader range of stakeholders, from patients and caregivers to healthcare professionals and industry representatives. The collaborative discussions addressed pressing challenges in bladder cancer careand developed actionable strategies for the future.

This year, we also introduced a unifying symbol for our community during Bladder Cancer Awareness Month in May – with the launch of the **Unsure Icon**. Designed to raise awareness of bladder cancer symptoms, this icon represents the uncertainty many feel when experiencing signs such as blood in the urine. It became the focal

point of our campaign, sparking conversations and increasing public awareness.

Our coalition continues to grow, welcoming new member organisations from Malawi and Argentina in 2023. These new additions reinforce our commitment to ensuring that no patient or family affected by bladder cancer is isolated. Through our expanding outreach, partnerships, and educational initiatives, we are building a global network that shares knowledge, offers support, and advocates for change.

As we look ahead, we remain inspired by the strength of our community. The past five years have laid a solid foundation, and together, we will continue to drive progress in bladder cancer care, making a lasting impact for patients, families, and advocates around the world.

### Our story

The World Bladder Cancer Patient Coalition (WBCPC) was established in January 2019 by dedicated patient advocates from three major national bladder cancer organisations that saw the need for a global bladder cancer coalition.

Our coalition now brings together 14 patient organisations from six continents, uniting the vision and goals of bladder cancer patient organisations to ensure the best possible outcomes for bladder cancer patients across the world. This coalition constitutes the first time that people affected by bladder cancer have had a force connecting bladder cancer patients, groups, and organisations worldwide. More than 610,000 people are newly diagnosed with bladder cancer worldwide each year. The need to elevate a global common voice for people affected by bladder cancer is critical.

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COMMUNITY ENGAGEMENT
COORDINATOR

### Our mission is to:



Foster an international community of people affected by bladder cancer



Advocate for access to the best bladder cancer information, support, and care



Build alliances with health professionals, policymakers, researchers, academics, and industry

Our vision is a world without bladder cancer

### 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 and partners, working together to improve the situation

We strive to grow our community and make sure that patients have access to the best support, treatment, information, and care no matter where they live. With 14 patient organisations as our members, we work closely on joint initiatives and collaborate on research, advocacy, and awareness-raising activities. We also develop multi-lingual information and resources for patient advocates. Our coalition shares tools, knowledge, and resources collectively and supports each other along the way. Below is the complete list of patient organisations that are members of our coalition.

### Our member organisations



**BEAT Bladder Cancer Australia** 



**Bladder Cancer Awareness** Australia



Bladder Cancer Canada



**Bladder Cancer Norway** 



Blåscancerförbundet - Sweden



Campaigning for Cancer -S. Africa





In 2023, we welcomed

One Community from Malawi

and VICARE from Argentina.



Fight Bladder Cancer - UK



Become a

Join our international

coalition, expand your

cancer patient support

and advocacy around

network, and share knowledge. Together, let's strengthen bladder

member

the world.

One Community Malawi



Norwegian Bladder Cancer Society



PaLiNUro - Italy



Patiëntenvereniging blaas-of nierkanker - Netherlands



Singapore Cancer Society



**VICARE** Argentina

HERE TO

JOIN

# 5-year reflection

Reflecting on our first five years

Over the past
five years, we have
dedicated ourselves to
supporting bladder cancer
patient organisations,
advocating for awareness, and
fostering a global community.
Our journey has been one of
growth, collaboration, and
unwavering commitment
to our mission.



# Biggest milestones over the last 5 years

2023 marks a significant milestone for our organisation as we celebrated our fifth year since establishment as a legal entity in Belgium.

Over the past five years, we have dedicated ourselves to supporting bladder cancer patients and patient support organisations, advocating for awareness, and fostering a global community. Our journey has been one of growth, collaboration, and unwavering commitment to our mission. We are proud to have active member organisations worldwide that share our cause and share their expertise. This global network has enabled us to share knowledge, resources, and support across borders, towards our joint efforts to ensure that bladder cancer patients have access to the best possible care, support and information no matter where they live in the world.

One of our notable achievements, is the Bladder Cancer Awareness Month (BCAM) marked each May in our community. Our joint annual campaign has reached more people each year and grown in size, with so many individuals and organisations joining our efforts to significantly increasing public awareness about bladder cancer. In just a few years, our BCAM activities and reach have grown more than ten-fold, inspiring further action to raise awareness in all corners of the world.



# Biggest milestones over the last 5 years

Our digital presence has also seen substantial growth. In 2020, we launched a new website which then attracted just around 5,000 visitors. Since then, the visitors count skyrocketed to over 150,000 people visiting our website in 2023, marking a 29x growth in this time frame. We have also launched startup guides in multiple languages and expanded our reach through social media, with our X/Twitter followers increasing by 200%. All our communication efforts add-up to help people affected by bladder cancer find information, support and a local group they can reach out, whilst also rallying up support for our cause.

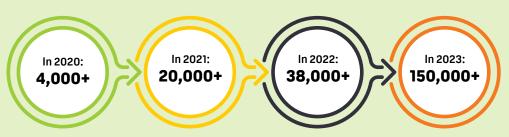
We went through a difficult period of a global pandemic in our first few years, where the patient support needs grew significantly.

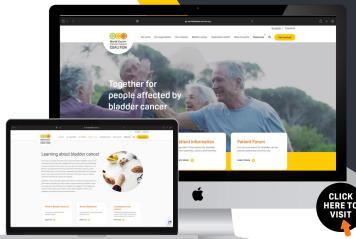
Our coalition worked together, sharing knowledge, experiences and ideas on how to best support the patient communities we serve. That's when in 2020, our first then-online meeting launched growing to become the World Bladder Cancer Patient Forum we now host annually. Since then, we brought together several hundred people online and in-person, at the Forum hosted in France and Spain.

Since the beginning, being the global voice of people affected by bladder cancer meant that we needed to give voice to patients and carers to share their experiences, generate evidence and use it as a catalyst for change. With 45 countries represented, the Global Bladder Cancer Patient & Carer Survey project which took several years to complete, meant that we were able for the first time to share data about the real life impact of bladder cancer on people affected by it.

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

The worldbladdercancer.org received 150,000 visitors in 2023, a staggering 38% growth over last year. Our visitors came from a wide range of countries, which showcases the broad global reach of WBCPC.





### Biggest milestones over the last 5 years

Our advocacy and capacity-building efforts have also been substantial, growing our partnerships around the world. We became a full member of the Union for International Cancer Control (UICC) and joined initiatives including All.Can International, WECAN and Global Cancer Coalitions Network, and partnered up with the Société International d'Urologie, European Association of Urology, European Cancer Organisation to further advance the voice of people affected by bladder cancer through these collective efforts driving policy and practice change.

We launched reports on the impact of COVID-19 on cancer patient organisations, participated in numerous international congresses, and collaborated with other cancer patient advocacy groups representing millions of patients worldwide.

As we reflect on the achievements of the past five years, we are inspired to continue our work with renewed energy and determination. The future holds many opportunities to further our mission, expand our reach, and deepen our impact. We are committed to supporting bladder cancer patients and their families, fostering bladder cancer patient support groups, advocating for better treatment and care, and raising awareness worldwide.

Thank you to all our members, partners, and supporters for being part of this journey. Together, we can make a difference in the lives of bladder cancer patients and their families around the world.

### **Milestones in numbers**

### Our membership growth



# Our membership has steadily grown since our establishment as we expand our reach and support establishment and growth of new bladder cancer patient groups around the world.

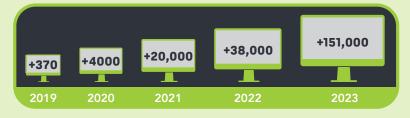
### Our funding growth



### Year-on-Year change



#### Our website visitor growth



Our website attracts visitors from around the world, seeking information and support. We guide them to our member organisations and many collective resources we have in our community.

### World Bladder Cancer Patient Forum

## Our key highlights

In 2020, during the height of the global pandemic, we held our first Annual Meeting virtually, bringing together the global bladder cancer patient community. Over 100 participants joined from 26 countries – which was then a two hour event. Its success led to our expansion of the event, which we now call the World Bladder Cancer Patient Forum in 2021, attracting over 150 participants from 35 countries.

The following year, we finally had an opportunity to meet in person, for our first full-day hybrid event in Paris, France. This was the moment the Forum was properly established, and in 2023 we brought the event to Madrid, Spain, for a full-day event featuring a diverse array of bladder cancer patient advocates and key stakeholders from around the world.

Each year, we aim to bring the most important topics up for a discussion to the Forum for a multistakeholder conversation that inspire collaborative action. Guided by the findings from the Global Bladder Cancer Patient & Carer Survey, it allows us to look deeper into the findings and hold conversations in the context of experiences of national bladder cancer patient groups. Our member organisations also embraced the opportunity to exchange knowledge, their own initiatives and share the learnings with each other, further growing the relationships within our coalition every year.



What our members say



"Our community at
Palinuro Association has
benefited greatly this year
from the resources and support
provided by WBCPC. Thanks
to the information we received
during one of the "Capacity
Building" meetings, we were
able to hold our first awareness
walk, informing people about
our disease and the main signs
to pay attention to for
early diagnosis."

Laura Magenta Associazione Pal iNUro

Fight Bladder Cancer's relationship with the World **Bladder Cancer Patient Coalition** has significantly benefited our organisation. We have been able to access their valuable resources, including information, support and awareness materials, to help and inform our patients and carers. We have become part of a global community where we can share knowledge, support, and collective advocacy efforts. It enables us to learn from diverse experiences and best practices, across different countries, in order for us to better help those hard to reach communities in our own multinational country."

**Melanie Costin**Fight Bladder Cancer
UK



"WBCPC has been instrumental in our efforts to campaign for better bladder cancer care and support in South Africa. Their expert content and patient-centered approach have provided us with the tools needed to advocate for policy changes and improve patient care standards."

Lauren Pretorius
Campaigning for Cancer



# Global Bladder Cancer Patient and Carer Experience Survey

In 2021, we launched our project of the first-ever Global Bladder Cancer Patient and Carer Survey, taking a significant step forward in evidence-generation for our community and better understanding the experiences of people affected by bladder cancer. It was a big milestone not only for the organisation, but for the entire bladder cancer patient community – bringing the insights and data from the very core of our communities, to inform and drive change globally and at local level.

In 2023, we officially launched the Global Bladder Cancer Patient and Carer Survey Report, with key data published in the European Urology, and presented at leading scientific congresses. Since its launch, we've had opportunities to share the findings with the medical communities, policymakers, industry partners and empower our member organisations with data to advocate for addressing the challenges faced by bladder cancer patients and carers.

Read on, to learn more about the Global Bladder Cancer Patient and Carer Survey and its results in this Annual Report.







Our 2023 activities

# **Building community:**World Bladder Cancer Patient Forum **2023**

The third annual World Bladder Cancer Patient Forum which was for the second time held in person, brought together people affected by and working with bladder cancer - patients, patient representatives, healthcare professionals, experts, and industry representatives, fostering knowledge sharing and inspiring conversations on addressing some of the most pressing challenges in our patient community worldwide. This time taking place in the capital city of Spain – Madrid, the event continues to be the only global bladder cancer advocacy platform for exchanging knowledge, fostering collaboration, and continuously developing strategies to support those affected by bladder cancer.

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

The workshops brought together bladder cancer patient advocates for an inspiring morning of working together. Our member organisations, seasoned and new bladder cancer patient advocates, people with bladder cancer and their loved ones engaged in focused collaborative workshop sessions. Together, we brainstormed and shared experiences on developing unique approaches to raising awareness and building locally impactful communities and a broader coalition with a global reach.

"The World Bladder
Cancer Patient Forum is
incredibly important. It's fantastic
to meet new people from around
the world, share experiences
between patients and doctors,
and connect on a human level.
This event allows us to discuss
how we can reach others globally
and raise more awareness
about bladder cancer."

**Krysta**Bladder cancer patient
and advocate







# **Building community:**World Bladder Cancer Patient Forum **2023**

"Bladder cancer
is often forgotten. This is
why awareness is a huge
tool regarding that disease.
We need to keep talking
about it and raise our voices
about the risk factors and
symptoms."

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

This session was a brilliant showcase of our community's collective vision and the transformative changes we strive to achieve to improve the lives of people with bladder cancer.

This was our biggest World Bladder Cancer Patient Forum to date, and this year's event saw expanded and more inclusive participation throughout the day. We welcomed over 100 attendees, over 50 in person and more online, joining us from 26 countries around the world. This diverse gathering included patients, patient representatives, healthcare professionals, academia, industry representatives, and other stakeholders.

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

Helen Lacy
Bladder cancer patient and
advocate, Australia

By uniting such a wide range of participants, we facilitated invaluable connections and knowledge sharing that otherwise would not have been possible. This blend of perspectives and experiences enriched the discussions and fostered a deeper understanding of the diverse aspects of bladder cancer care and research.



# **Building community:**World Bladder Cancer Patient Forum **2023**

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

As we move forward, the insights and strategies developed during the 2023 Forum will guide our collective efforts to enhance the lives of those affected by bladder cancer. This year's discussions have laid a strong foundation for continued growth and impact in our global and local advocacy efforts.

"Building alliances and partnerships is fundamental. Similar issues are being experienced by other cancer patients. Therefore the voice of patients must be prominent in networks and policy forums both nationally and internationally."

-ara Fernandez Rodriguez Psycho-oncologist at GEPAC, Spain

### **Audience feedback**





"When I was diagnosed with bladder cancer, I went into autopilot, focusing on the next steps and taking control where I could. The abrupt way my diagnosis was delivered was jarring, but it pushed me to be proactive about my treatment. I took meticulous notes during every conversation with my oncology team, researched ways to support my health through diet and exercise, and found solace in holistic practices like yoga and meditation. My advice to others is to stay informed, keep asking questions, and take one step at a time. Bladder cancer is treatable, and there is hope—focus on the things that uplift you and keep you strong."

Carole, from England. Diagnosis in 2021 at 50.

# Fostering a global bladder cancer patient community

One of the core commitments of the World Bladder Cancer Patient Coalition is to support the establishment and growth of bladder cancer patient groups, whether large or small, and working together to improve the lives of people affected by bladder cancer around the world. We strive to build a global community of strong patient advocates, and we believe that the the voice of our coalition is only as strong as the commitment of our members.

In 2023, we welcomed two new organisations to the Coalition. For

One kkkkikkhik

Community

the first time on the continent of South America, and only the second organization in Africa.

We aim to have a national bladder cancer patient organisation in every country – that's our long-term commitment. We work

to ensure these organisations are well equipped to provide support, increase awareness, and advocate for better diagnosis, access, and care. Recognising the challenges in establishing a bladder cancer patient group, we created the Startup Guide for Bladder Cancer Patient Groups as a priority. This guide, available in six languages, is based on the experiences of our members who have successfully established bladder cancer patient groups. It compiles their collective knowledge to help anyone interested in starting a patient organisation in their country, and the World Bladder Cancer Patient Coalition remains as a partner to guide them on their journey. Starting out is not easy, and we are proud to have supported bladder cancer patients in starting their own group, and

existing organisations in expanding their focus to support people affected by bladder cancer.

We are slowly starting to see the positive impact of our initiatives, and remain confident that new organisations will start and flourish in the coming years, by being connected to our coalition of extensive bladder cancer patient support and advocacy experience.

#### Available in:

- English
- French
- Spanish
- Portuguese
- Arabic
- Turkish

"I lead a women's support group. It has been so helpful to hear other women's experiences and to have people who truly understand what I have been and continue to go through. I love hearing feedback from the members on how the support group has made a positive change in their lives. I feel a sense of purpose knowing that I am helping other women with bladder cancer. We have created a community of women that is welcoming and full of knowledge with real-life experiences."

Angela Pelletier
diagnosed with bladder cancel
in 2019 aged 38, Canada



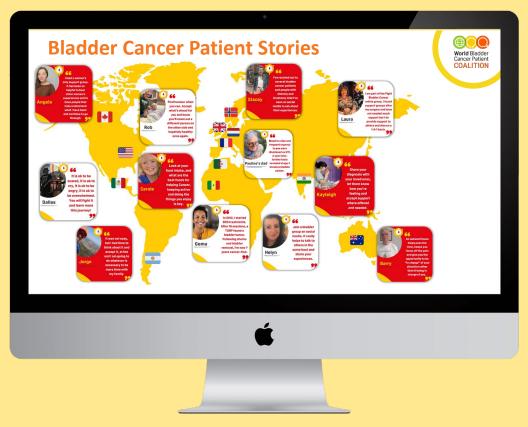
# Growing a community through real bladder cancer patient stories

Throughout 2023, we gathered 12 new inspiring stories from bladder cancer patients worldwide. Sharing these stories is important for our mission, particularly from countries without established bladder cancer patient groups. These stories not only raise awareness about the bladder cancer but also highlight the daily struggles and achievements of patients. They foster a sense of community, helping people feel less isolated during their often daunting and lonely journey. For those beginning treatment, these accounts provide valuable insights and reassurance, offering comfort and guidance.

In celebration of International Women's Day last year, we featured stories from two remarkable bladder cancer patients and advocates.

Amy from Senegal, diagnosed in 2022 at the age of 50, and Krysta from Canada, diagnosed in 2022 at the age of 37, shared their experiences and advice for other women facing bladder cancer.

By raising awareness and addressing the unique challenges women encounter, we aimed to improve care and foster positive change for female bladder cancer patients. Their stories not only inspire but also highlight the need for gender-sensitive approaches in bladder cancer treatment and advocacy.



# Knowledge hub

In 2023, we continued to build our website with the ambition of creating a knowledge hub as the global go-to resource for anyone affected by bladder cancer or seeking information about it. We created a space to showcase our community's impactful work and amplify the voice of bladder cancer patients, our members and our partners. As part of that is our ambition to ensure that people affected by bladder cancer do not feel alone, overwhelmed or unrepresented where there is lack of information and support available to them. This forms a part of our efforts to support the growth of capacities of existing and new bladder cancer patient support groups and organisations.

Our resource hub grew with new and updated resources for bladder cancer awareness-raising, which are available in a growing number of languages. These resources are available for anyone to download and use in their local communities, empowering them with the necessary knowledge, guidance and support. We are developing the hub will be a focal centre for our member organisations and aspiring bladder cancer patient advocates and supporters as we develop assets and materials for their use.

The worldbladdercancer.org received 151,000 visitors in 2023, showing 297% growth over the previous year, which we are very proud of. It helps us guide people affected by bladder cancer to the credible resources and information from our broader community.

Our visitors came from a wide range of countries, showcasing the broad global reach of the World Bladder Cancer Patient Coalition.



We continue to foster connections and build-up communities of bladder cancer patient advocates.

## Community capacity-building

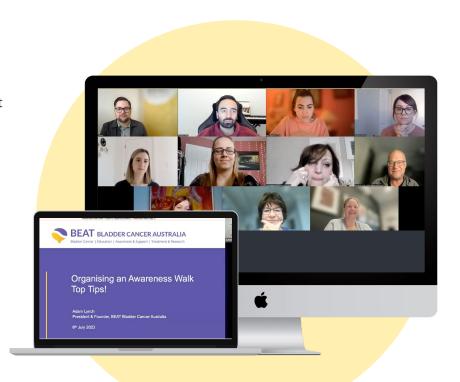
Capacity-building sessions hosted by WBCPC are an important element of our coalition's work with our global community. It provides members with the knowledge and tools to enhance their advocacy efforts and get inspired for new initiatives. In 2023, we hosted two capacity-building sessions for our member organisations.

Session on Awareness Walks – a session on organising bladder cancer awareness and fundraising walks, drawing from own experiences in the community to empower our members to make greater impact in their local communities.

Session on Fundraising – a session on exploring different avenues of fundraising, with examples and tips for effective approaches to empower our members to diversify and strengthen their financial sustainability.

We also hosted two video-interviews in conversation with our member organisations about their first steps starting out, to important areas of their work today. These inspirational conversations with Liesbeth de Boer-Ossterhuis, then-Chairwoman of Leven met blaasof nierkanker – kidney and bladder cancer patient organisation in the Netherlands and with Adam Lynch who has founded BEAT Bladder Cancer Australia serve as an extension of our capacity building programme. It also provides encouragement and inspiration for bladder cancer patients and families interested in bringing people together in their own community.

These sessions brought together global bladder cancer patient community to share insights and experiences on these relevant topics as well as to learn from external experts. Our members exchanged knowledge and learned valuable tips, strategies, and considerations for leading successful awareness walks in their regions and expanding their fundraising efforts.



# Raising awareness: Bladder Cancer Awareness Month 2023

A core pillar of our awareness-raising efforts each year is hosting the World Bladder Cancer Awareness Month in May to bring attention to the most common symptom of bladder cancer – blood in the urine, highlight information and facts about bladder cancer and call for greater attention and more investment in research, treatment and care.

In 2023, we launched our campaign with the motto "Feeling Unsure? Get Checked", part of our continued efforts for Bladder Cancer Awareness Month. This initiative was created to address the frequent misinterpretation of symptoms, urging individuals to question what they perceive as "normal" and to reassess their symptoms. After all, what may seem rather ordinary could indeed be a symptom of bladder cancer.

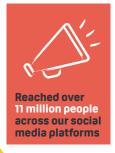
To capture attention and interest, the Campaign centered around the feeling of uncertainty. With this online-focused campaign, we created a visual element centred around this uncertainty. The Unsure Icon was specially designed by Noma Bar to be seen and interpreted in different ways, just like the symptoms of bladder cancer might be.

With the launch of the Unsure Icon, we need to have taken a step towards uniting the global bladder cancer community. This symbol, absent until now, offers a universally identifiable image that draws us together, filling the gap where a universally accepted icon for bladder cancer had previously been missing.

We have reached more people and had a much wider impact than ever before. Together, we brought the community together, helped bring attention to bladder cancer across online conversations, raised awareness about bladder cancer and guided people affected by it to a wealth of resources and support provided by our member organisations around the world.

2023 proved to be a breakthrough year for us! Our social media impact increased, reaching 175% growth compared to 2022.







Over 32,000
people have seen
our Unsure Icon
animation





**Twitter** 





Almost 30,000 profile visits on Facebook



Hashtags #BladderCancerMonth23 and #UnsureIcon were used over 2,500 times

\*The video animation with the Unsure Icon prompted viewers to pause and think twice about what they saw, which was the main driving force of this year's campaign. It was available in six languages: Arabic, English, French, Hindi, Italian and Hindi.

# Bladder Cancer Awareness Month Grants programme

This year, our Bladder Cancer Awareness Month Grants (BCAM Grants) programme for the second consecutive year offered support for increasing awareness in low resource settings. These grants enable patient organisations, support groups, or advocacy groups and communities in low and middle-income countries to raise awareness about bladder cancer in their communities.

In 2023, the BCAM Grants were awarded to four organisations, which have implemented fantastic initiatives to increase bladder cancer awareness in their communities.



### **\*\*Oncoguia** from Brazil:

Oncoguia launched a virtual patient education campaign, "Ame Sua Bexiga" (Love Your Bladder), focusing on preventing, diagnosing, and treating bladder cancer. Instituto Oncoguia collaborated with local institutions and produced educational videos with a uro-oncologist Dr. Fernando Korkes,

which gained over 10,000 impressions. Their live discussions and myth-debunking video series significantly engaged the community and improved public awareness of bladder cancer.



# Multi-lingual toolkits

The campaign this year was supported by the Campaign Action Toolkit which was available in English and Spanish. In addition to that, various campaign resources were made available in many other languages, used by our members, individuals, supporters, and partners worldwide to participate in our Bladder Cancer Awareness Month activities.

These resources included social media messages, symptoms cards, risk factors cards, virtual meeting backgrounds, social media banners, Twibbon and various other resources, some developed on demand, to provide as many opportunities to get involved as possible with resources that are useful for anyone who joins the awareness raising efforts.





DIFY conducted an awareness campaign in the rural Nkhata Bay district, engaging around 500 individuals through focus group discussions, health-awareness talks, and community sports activities. Their outreach extended to over 2,000

people, highlighting bladder cancer symptoms and the importance of early medical intervention. Collaborations with local organisations and creative engagement methods were critical to their campaign's success.

# MANSOURA TUNIVERSITY SAFETY SOCIETY



### Mansoura University Safety Society (MUSS) from Egypt:

MUSS increased bladder cancer awareness through surveys, educational materials, and interactive activities. They organised events at local clubs and hospitals, hosted a symposium, and conducted online sessions with medical professionals. Their campaign involved public competitions and community messages, enhancing knowledge about bladder cancer and encouraging proactive healthcare practices.







#### Women's Education and Economic Development Society (WEEDS) from India:



WEEDS targeted suburban and rural women in the Kancheepuram district. Collaborating with RMD Hospital, they conducted five informative sessions, both in-person and online, reaching over 930 women. The initiative raised awareness about bladder cancer symptoms and the importance of early medical consultations, resulting in 24 women seeking pre-consultations at RMD Hospital.

These organisations have made inspiring efforts to raise bladder cancer awareness in their communities, demonstrating the impactful role of the BCAM Grants in promoting early detection and better treatment outcomes in limited resource communities.

### Bladder cancer newsletter

Our monthly Bladder Cancer Newsletter goes to the inboxes of our members, partners, stakeholders, patients, and their families. It's a true and growing community at the forefront of bladder cancer patient advocacy and support. Since its launch in 2019, we have focused on bringing attention to the impactful work of our coalition members, broader community and of course the Coalition. The newsletter is a monthly resource for many, highlighting the most noteworthy news in patient advocacy and the bladder cancer landscape.



In 2023, we distributed 40 mailings, including our monthly newsletter and other communications to our audience, featuring an increasing number of original content and thought leadership developed with our community and partners. These include our monthly newsletter and more focused mailings for specific news or events throughout the year. Combined, our mailings were read over 7,000 times in 2023. Notably, our monthly newsletters alone were opened over 4,300 times, reflecting the growing interest and engagement within our community.

Our newsletter has featured compelling stories and impactful initiatives, such as the launch of new awareness campaigns, patient experience stories, and interviews with leading experts in the field. These pieces not only informed but also connected our readers, fostering a sense of community and support.

Following the success of our Member's Quarterly newsletter launched in 2022, we continued this effort in 2023. This newsletter, with its three editions annually, brings updates directly from our member organisations about their activities. Our member organisations work daily to provide

information, guidance, and support for people affected by bladder cancer in their countries.

Last year, we featured impactful initiatives such as successful fundraising walks in Canada, a significant awareness event in the Scottish Parliament, the Annual Congress in Italy, a new platform for patient advocates in South Africa, and many more. The growing engagement with our Member's Quarterly newsletter highlights the importance of showcasing the diverse and meaningful work of our members.

Bladder cancer knows no borders, and we strive to highlight the important work of our members and inspire those who may be thinking of or just starting with a bladder cancer group in their community.

We are confident that as we continue to improve our content, expand to new regions, and build new partnerships, our newsletters will continue this upward trend and play an even more significant role in inspiring our community, raising bladder cancer awareness, and strengthening support and advocacy efforts around the world.

### Bringing news, inspiration and awareness online

In 2023, over 150,000 people have visited the WBCPC Website at worldbladdercancer.org During this time, we published over 75 news articles on our website, available in both English and Spanish. We deliver a broad range of information and ideas – focused on the latest news and developments related to our work and the broader bladder cancer community. By featuring key initiatives and detailing the various events we represent at throughout the year, we aim to educate, engage, and empower bladder cancer patient advocates around the globe and inspire new partnerships with partners and a variety of stakeholders.

Our articles covered a range of topics, including new research, patient stories, advocacy efforts, and the different ways we are raising awareness, highlighting our commitment to our mission. For example, our most popular articles included the Bladder Cancer Awareness Month Press Release, new bladder cancer data published by the International Agency for Research on Cancer, patient stories, and insights from our Global Bladder Cancer Patient and Carer Experience Survey. These pieces not only informed but also connected our readers with the latest achievements and community support, reinforcing our mission to foster a well-informed community.



This strategic approach to sharing information plays a crucial role in advocating for access to the best bladder cancer information, support, and care. By building alliances with health professionals, policy makers, academics, researchers, and industry leaders, we continue to drive forward our mission to support those affected by bladder cancer on a global scale.

### Social media 2023

Our online presence through social media channels, including Twitter, Facebook, LinkedIn, Instagram, and YouTube, play a pivotal role in our communication strategy, enabling direct connection with our target audiences such as patients, healthcare professionals, patient advocates, and national organisations. This direct line of communication fosters immediate and personal interaction, building a strong sense of community and trust. Over the past year, we have seen a significant increase in both following and engagement across all platforms, bringing our total number of followers to over 8,300, compared to 7,000 at the end of 2022. This growth not only reflects the rising interest and support for our mission but also amplifies our reach and impact.

"Join a bladder support group on social media. It really helps to talk to others in the same boat and share your experiences."

> Helyn diagnosed with bladder cancer in 2021 at 55 years old (UK)





Our expanding social media presence enhances our ability to raise awareness, educate, and mobilise the bladder cancer community. It allows us to provide the latest news about bladder cancer, share stories, and engage in meaningful dialogue with our followers. This increased engagement strengthens our network, helping us influence public opinion, attract potential partners, and secure funding opportunities. Furthermore, our social media efforts contribute to community building by fostering connections among people, offering support, and creating a platform for shared experiences and mutual encouragement.

# **Engaging in advocacy**Global Bladder Cancer Patient And Carer Survey

In 2023, we published the results of the Global Bladder Cancer Patient and Carer Survey in the Report published in May. Since the beginning, being the global voice of people affected by bladder cancer meant that we urgently needed to give voice to patients and carers to share their experiences, generate evidence and use it as a catalyst for change. With 45 represented and with nearly 1200 responses, the Global Bladder Cancer Patient & Carer Survey project which took several years to complete, meant that we were able for the first time to share data about the daily impact of bladder cancer on people affected by it.

The key highlights of the survey results were published in the European Urology in May 2023, and we presented these findings at several international scientific and medical congresses, partner events and to policymakers.

The Global Bladder Cancer Patient and Carer Survey results were presented at the European Association of Urology Congress Patient Day, where it served as an insightful point for a discussion and was awarded the 2<sup>nd</sup> place as part of the three Best Patient Poster of the Congress.



The World Bladder Cancer Patient Coalition (WBCPC) was featured at the 43rd Congress of the Société Internationale d'Urologie (SIU) in Istanbul, Türkiye.

WBCPC President Dr Lydia Makaroff presented the latest research findings from the Global Bladder Cancer Patient & Carer Experience Survey. Our research poster was



awarded the best ePoster of the session.

The SIU Congress also allowed us opportunities to highlight the perspectives of bladder cancer patients and caregivers, advocating for better awareness, support, and care practices globally. This presentation underscored our commitment to ensuring that patient voices are central to bladder cancer care and policy discussions.

# 12%

wanted to be more involved in making decisions about their care and treatment

most respondents did not have barriers to accessing treatment



**27**%

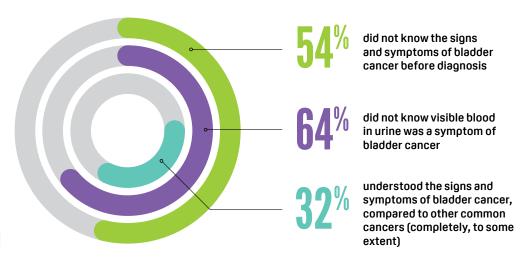
Over a quarter of the total survey respondents had a radical cystectomy



nearly half were not counselled before radical cystectomy on the possible sexual side effects

# Experts Discuss Findings from Global Bladder Cancer Patient & Carer Survey

Findings: awareness and diagnosis



The World Bladder Cancer Patient Coalition (WBCPC) partnered with UroToday.com for a four-part video series to discuss the findings of the WBCPC Global Bladder Cancer Patient and Carer Experience Survey.

WBCPC participated to highlight patient and carer experiences, aiming to improve bladder cancer care and support. The series, chaired by Dr Ashish Kamat, covered themes such as diagnosis, treatment access, supportive care needs, and the impact on daily life and carers.

# **Episode Treatment Access and Experience**

Dr Ashish Kamat, Dr Pat Hensley, and Dr Lydia Makaroff discussed patient experiences with care and treatment

access, highlighting disparities in preoperative counselling about sexual side effects post-radical cystectomy and the need for better patient education and shared decision-making.



# **Episode 3 Supportive and Complementary Care Needs**

Dr Ashish Kamat, Dr Bente Jensen, and Alex Filicevas explored supportive care needs, emphasising gender disparities, the importance of prehabilitation, and the role of patient advocacy groups in fostering a supportive environment.



# Episode 2 Diagnosis Experience

Dr Ashish Kamat, Dr Stephanie Demkiw, and Dr Lydia Makaroff focused on diagnosis experiences, revealing low awareness of

bladder cancer symptoms and the need for early detection, clear referral guidelines, and strong support systems.



# **Episode** 4 **Impact on Daily Life and Carers**

Dr Ashish Kamat, Lori Cirefice, and Dr Lydia Makaroff discussed the impact on daily life and carers, highlighting financial and emotional strains and calling for community action to address these challenges.



# WBCPC & EAU Policy roundtable to launch EU White Paper on Bladder Cancer

At a pivotal moment in European legislation and ahead of the 2024 European Parliament Elections, the World Bladder Cancer Patient Coalition (WBCPC) and the European Association of Urology hosted a policy roundtable to launch the White Paper on Bladder Cancer. Held on September 25, 2023 at the European Parliament in Brussels, the event was hosted by MEP István Ujhelyi and brought together key stakeholders in cancer policy.

The launch event also saw intervention from our member community – bladder cancer patient and advocate Alessandro Boni, shared his personal story and work of our Italian member organisation – Associazione PaLiNUro. WBCPC Vice-President and Cancer Vessie France President Lori Cirefice also joined and co-Chaired this important policy event.

Bladder cancer is the fifth most common cancer in Europe. Despite having one of the highest lifetime costs among cancers, research funding remains amongst the lowest. The lack of awareness around bladder cancer hinders early detection, and the insufficient understanding of gender differences in symptoms further complicates outcomes, particularly for women.

The White Paper on Bladder Cancer, jointly published by WBCPC and the European Association of Urology, laid out ten key policy recommendations for leveraging legislative opportunities and enhancing support for patients and carers across Europe. It emphasised the urgent need to raise awareness, close research gaps, and ensure access to comprehensive care for people affected by bladder cancer

By facilitating a future-focused discussion with policymakers, healthcare professionals, and advocates, the roundtable provided a platform for aligning strategies and addressing the



bladder cancer patients.

The White Paper on
Bladder Cancer seeks to
inspire coordinated action,
ultimately improving the
lives of those affected by bladder cancer
across Europe – and inspire commitment
of the incoming policymakers to the EU
policymaking in 2024.



# Stigma: The Invisible Side of Bladder Cancer

In 2023, we published further editions of the advocacy infographic titled "Stigma: The Invisible Side of Bladder Cancer," highlighting the impact of stigma on people affected by bladder cancer. This initiative was conducted in collaboration with Grupo Español de Pacientes con Cáncer (GEPAC), Fight Bladder Cancer (UK), and Cancer Vessie France.

Based on the experiences of 312 patients and caregivers from France, Spain, Germany, the United Kingdom, and the United States, the infographic explores themes of disease disadvantage, internal stigma, and external stigma.

The primary goals of this research were to:

- Understand if and how stigma exists within the bladder cancer patient community.
- Explore what stigma is, how it manifests, and the different types experienced.
- Examine how reported stigma evolves over the course of the disease.

To support patient groups in their advocacy efforts, the infographic includes a one-page toolkit with practical suggestions for raising awareness in local settings with healthcare professionals, stakeholders, and the broader community. This resource has proven to be a valuable tool for addressing the stigma associated with bladder cancer, enabling patient groups to foster open discussions and reduce stigma within their communities.



### **EXTERNAL ENGAGEMENT**

### **European Cancer Summit 2023**

The European Cancer Summit, organised by the European Cancer Organisation (ECO), took place in November 2023 in Brussels, Belgium. This event brought together oncology experts, patient advocates, key opinion leaders, policymakers, and politicians to discuss critical issues in cancer care.

Executive Director Alex Filicevas represented the World Bladder Cancer Patient Coalition (WBCPC). During the panel "The Next Generation of Cancer Leaders," Alex emphasised the importance of incorporating patient perspectives in shaping cancer care policies. He highlighted the crucial role that cancer patients and survivors play in driving positive changes within the cancer care landscape.

Alex stressed the significance of patient advocacy education, citing initiatives such as EUPATI and WECAN. He also presented the Startup Guide for Bladder Cancer Patient Groups, a WBCPC initiative to support establishing and growing bladder cancer patient groups around the globe.

"Cancer patients and survivors are our future cancer leaders. Their voices are crucial in shaping cancer policies and care," stated Alex Filicevas. Referencing the WBCPC Bladder Cancer Patient & Carer Survey, which revealed that 73% of respondents were not guided to patient groups despite their presence, Alex underscored the need for young cancer professionals to engage with patient organisations early to improve care and support for people affected by bladder cancer and more broadly.





### **WBCPC at the EU Continence Health Summit 2023**

The World Bladder Cancer Patient Coalition (WBCPC) participated in the EU Continence Health Summit 2023, organised by the European Association of Urology, on November 8 in Brussels, Belgium. This policy-focused event brought together stakeholders to address continence health issues impacting patients, health systems, the economy, the environment, and society.

WBCPC joined the Summit to advocate for bladder cancer patients, whose continence health is a significant aspect of their overall well-being. By participating, WBCPC aimed to contribute to the dialogue on improving continence health policies and support systems, ensuring that the needs of bladder cancer patients are considered in broader health strategies.

The Summit united over 20 scientific, professional, patient, and non-profit organisations to emphasise the need for action to improve continence health.

WBCPC supported the launch of the Manifesto for Policy Reform on Continence Health in Europe, which calls for concrete policy changes to enhance patient-centred continence care.



# **WBCPC at SIU Congress**

At the 43rd Annual SIU
Congress, a prestigious
global event organised by
the Société Internationale
d'Urologie, the World
Bladder Cancer Patient
Coalition (WBCPC) proudly
hosted a booth in the exhibit
hall. This strategic presence
allowed us to engage directly
with urologists from around
the world, providing a
platform to introduce them
to the WBCPC and our
member organisations.

Our booth served as a valuable touchpoint where we could discuss the specific challenges faced by people affected by bladder cancer in different regions. Through these conversations, we gained insights into the unique local resource needs and highlighted the critical need for more bladder cancer patient organisations globally.

One of the key features we showcased was our Start-up Guide for bladder cancer patient groups. This guide has been instrumental in bridging the gap between physicians, patients, and caregivers, offering a comprehensive resource filled with innovative ideas and support from the WBCPC community. Our presence at the SIU Congress highlighted our commitment to expanding the reach and impact of bladder cancer patient advocacy worldwide.

We have also disseminated the Global Bladder Cancer Patient and Carer Survey report at our booth, in meetings with urologists and through poster presentation.



# Bladder Cancer Patient Day in France: Towards Better-Informed Patients

Cancer Vessie France, a WBCPC member, partnered with the French Association of Urology (AFU) to raise bladder cancer awareness in May. On May 24, a full day was dedicated to informing patients about bladder cancer in Paris.

The event focused on helping patients and their loved ones understand the bladder cancer care pathway. Urologists explained medical recommendations, treatment guidelines, and the standard of care in France. Experts provided research updates and answered questions from both in-person and online audiences.

Cancer Vessie France highlighted their work and how patients can find support and reliable information through advocacy organisations. The day also showcased the collaboration between Cancer Vessie France, AFU, and external stakeholders.

Executive Director Alex Filicevas and Communications & Community Engagement Assistant Marie Magenhann Cueto represented WBCPC. This event underscored the importance of raising awareness and ensuring patients are well-informed, given that bladder cancer affects 13,000 to 20,000 people annually in France and causes over 5,000 deaths.





# **British Association of Urological Nurses Conference 2023**

The British Association of Urological Nurses (BAUN) Annual Conference 2023 took place from 19 to 21 November in Liverpool, UK. The World Bladder Cancer Patient Coalition (WBCPC) joined the Fight Bladder Cancer (FBC) team at their booth to share their work on raising awareness, supporting patients, and improving bladder cancer care.

WBCPC attended to understand how Fight Bladder Cancer engages with the urological community and those affected by bladder cancer in the UK. This opportunity provided valuable insights into FBC's local needs and how WBCPC can further enhance their awareness efforts.

Engaging directly with patients, healthcare professionals, urological nurses, and doctors allows WBCPC to develop more impactful resources for our global community. By supporting and learning from our UK member, Fight Bladder Cancer, we aim to strengthen our efforts to improve bladder cancer care worldwide.

# WBCPC at Associazione PaLiNUro's 6th Annual Congress

On 11 November 2023, the Associazione PaLiNUro held its 6th Annual Congress in Milan, Italy, which the World Bladder Cancer Patient Coalition (WBCPC) attended in person.

Edoardo Fiorini, President of Associazione PaLiNUro, opened the Congress and presented the Italian data from WBCPC's Global Bladder Cancer Patient & Carer Survey. This presentation highlighted how Italy's bladder cancer care quality compares with that of the rest of the world WBCPC's participation allowed us to connect with the bladder cancer patient community in Italy, engage in meaningful conversations, and forge connections that contribute to supporting those affected by bladder cancer. We shared perspectives and disseminated knowledge from Italy to other countries through our growing coalition. The collaborative space created during the Congress reinforced the importance of a united global front in the fight against bladder cancer.





This collaboration allowed us to exchange knowledge and experiences with advocates from around the world. The WECAN Academy offers comprehensive training across three key pillars: "Advocacy Tools & Skills," "Healthcare Systems, Policy and Access," and "Research and Data," ensuring that advocates are well-equipped with the necessary skills and knowledge to make a meaningful impact.

### **WBCPC at the WECAN Events 2023**

On April 20–21, 2023, the World Bladder Cancer Patient Coalition (WBCPC) joined leaders from over 20 cancer patient advocacy organisations for the WECAN Retreat 2023 in Frankfurt, Germany.

This annual two-day meeting focused on collaboration, listening, discussions, and alignment within the community to improve the lives of people affected by cancer. Participants reflected on past achievements, ongoing initiatives, and potential collaborative research, education, and advocacy projects. Representing WBCPC were Lori Cirefice, WBCPC Vice-President and President of Cancer Vessie France, and Alex Filicevas, WBCPC Executive Director.

Organised by WECAN—Workgroup of European Cancer Patient Advocacy Networks—the retreat provided a platform for cancer patient organisations to collaborate, learn, and align to strengthen European patient advocacy. WBCPC, a member of WECAN since 2019, values these opportunities to drive forward collective efforts in cancer care and advocacy. The WBCPC team was also present for four full days at the WECAN Academy, held from July 1–4, 2023, in Frankfurt, Germany.

Alongside our member organisation, Fight Bladder Cancer, we participated in extensive training sessions that provided us with invaluable insights into patient advocacy.



## WBCPC at the 38th Annual EAU Congress 2023

The 38th Annual European Association of Urology (EAU) Congress, Europe's largest urology event, took place in Milan, Italy, from March 10–13, 2023. This Congress provided patient organisations and advocates a platform to voice their goals and objectives alongside breaking scientific updates.

The World Bladder Cancer Patient Coalition (WBCPC) was prominently featured, with President Dr Lydia Makaroff and Executive Director Alex Filicevas participating in key sessions. Their involvement underscored WBCPC's commitment to advocating for bladder cancer patients and ensuring their voices are heard.





- EAU Patient Day: Urological Patient Presentations Alex Filicevas presented a comprehensive summary of patient and caregiver experiences with bladder cancer based on survey results from 45 countries. This session highlighted patient needs for innovations in patient-centred care and amplified patient voices on treatment experiences.
- Pragmatic Solutions for Chronic Urological Disease Dr Lydia Makaroff participated in a roundtable addressing strategies to empower patients with chronic urological illnesses to manage their conditions in partnership with healthcare professionals.
- Locally Advanced Bladder Cancer: Misconceptions of Informed Consent
  Dr Makaroff also discussed the differences in quality of life for muscle-invasive
  bladder cancer (MIBC) patients treated with radical surgery versus bladder-sparing
  treatments.
- Clinical Leadership Development Workshop In this workshop, Dr Makaroff covered physician-patient communication and patient engagement, emphasising the importance of understanding patient needs.
- Industry Symposium: Bridging the Gap Alex Filicevas joined a panel discussion featuring physicians and patients, focusing on health equity challenges, elevating the patient perspective in research, and improving health literacy.

# WBCPC at the 14th AORTIC Conference

The World Bladder Cancer Patient Coalition (WBCPC) participated in the 14th Cancer in Africa conference held November 2–6, 2023, in Dakar, Senegal. Organised by the African Organisation for Research and Training in Cancer (AORTIC), the Conference brought together multidisciplinary specialists focused on reducing the impact of cancer in Africa.

WBCPC attended this Conference to understand better the realities of bladder cancer patient care in Africa. Our goal was to connect with people affected by bladder cancer in the region and to understand the unique circumstances influencing awareness, incidence, and treatment.



This engagement allows WBCPC to work effectively with local and regional partners to address the needs of bladder cancer patients, ensuring no one faces the diagnosis alone.

WBCPC's participation also allowed us to engage with the local community, share knowledge, and collaborate on raising awareness about bladder cancer. Dr Sine emphasised the importance of recognising blood in urine as a serious symptom and the need for timely medical consultation to improve outcomes.

Our involvement in the AORTIC Conference reinforced the importance of a united global front in the fight against bladder cancer. By understanding the challenges and realities faced in Africa, WBCPC aims to support and enhance bladder cancer care and awareness efforts in the region.

The WBCPC team has also attended in various capacity the following events, actively connecting with new stakeholders and strengthening partnership for the growth of our coalition and advocacy capabilities:

- ESMO 2023 European Association for Medical Oncology Congress 2023
- The Economist Annual World Cancer Series: Europe 2024
- Global Cancer Coalitions Network Annual Members Meeting 2024
- All.Can Roundtable 2024

## **WBCPC 5th General Assembly 2023**

On June 14, 2023, our member organisations convened virtually for the 5<sup>th</sup> WBCPC General Assembly. This assembly provided an opportunity to reflect on the significant progress made over the past year and to deliberate on our strategic plans alongside fulfilling the essential administrative formalities.

Dynamic discussions highlighted the need for enhanced cooperation, leveraging WBCPC's growing reputation, and planning an impactful Bladder Cancer Awareness Month campaign for 2024.

A comprehensive review of the key 2022 WBCPC activities focused on raising awareness and building community.

Our main activities in these areas are the Bladder Cancer Awareness Month and our World Bladder Cancer Patient Forum. During the General Assembly, we discussed our 2022 achievements, how best to leverage our experience, and our members' needs to go beyond what we had previously achieved. Efforts to build community continued with the Member Quarterly Newsletter launch, showcasing member organisations' work and highlighting national activities.

The inspiring support, dedication, and insights of our member organisations continued to drive the success of our initiatives. Together, we were able to pool our forces, amplify our voices and advocate for better support for the people affected by bladder cancer around the world.















### **Balance sheet**

Financial statements for the year ended 31 December 2023, 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 2021–2023 is Mazars Belgium. Audited financial statements and auditors report are available on the organisation's website at worldbladdercancer.org

ASSETS	2023 (AMOUNT IN €)	2022 (AMOUNT IN €)
Fixed assets	€ 10.556	£ 12 400
		€ 13.600
Intangible assets	€ 7.295	€ 11.820
Tangible assets	€ 3.261	€ 1.780
Current assets	€ 497.871	€ 354.134
Amounts receivable within one year	€ 99.162	€ 43.769
Current accounts	€ 389.714	€ 307.253
Deferred charges	€ 8.995	€ 3.111
TOTAL	€ 508.427	€ 367.734
Capital & reserves	€ 345.762	€ 274.207
Profit carried forward	€ 345.762	€ 274.207
Balance	€ 71.546	- € 47.378
Amounts payable	€ 162.666	€ 93.527
Amounts payable within one year	€ 39.323	€ 44.446
Accrued charges & deferred income	€ 123.343	€ 49.081
TOTAL	€ 508.427	€ 367.734

### **Financials**

The board of directors approved the 2023 audited financial results and subsequently approved by the 6th World Bladder Cancer Patient Coalition General Assembly, which took place on June 13, 2024.

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 2023

For the Financial Year 2023, the revenue of the World Bladder Cancer Patient Coalition aisblamounted to a total of € 620.377.

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 € 548.831. Leaving a positive net year-end balance of € 71.546.

SOURCE OF REVENUE	2023 (AMOUNT IN €)	2022 (AMOUNT IN €)
Sponsorships and grants	€ 600.579	€ 393.900
Other income	€ 19.798	€ 2.550
VAT account	€ 0	€ 37.541
TOTAL REVENUE	€ 620.377	€ 433.991
OPERATING EXPENSES		
Staff costs	€ 239.270	€ 212.730
Management & running costs	€ 75.782	€ 65.927
Board expenses	€ 9.726	€ 15.280
Project costs	€ 224.054	€ 187.370
TOTAL EXPENDITURE	€ 548.831	€ 481.370
BALANCE	€ 71.546	(-) € 47.378

# Sponsorship and grants received in 2023

REVENUES FROM INDUSTRY SUPPORT	AMOUNT IN €	PERCENTAGE (%)
Astellas	€ 71.676	12%
AstraZeneca	€ 49.051	8.1%
Bristol-Myers Squibb	€ 65.000	10.9%
Ferring	€ 65.000	10.9%
Gilead	€ 30.000	5%
Janssen	€ 25.000	4.1%
MSD	€ 25.000	4.1%
Merck KGaA	€ 112.176	18.6%
Pfizer	€ 52.176	8.6%
Roche	€ 58.000	9.6%
Seagen	€ 47.500	8%
TOTAL INDUSTRY SUPPORT REVENUE	€ 600.579	100%

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.



18.6%	Merck KGaA
12%	Astellas
10.9%	Bristol-Myers Squibb
10.9%	Ferring
9.6%	Roche
8.6%	Pfizer
<b>8.1</b> %	Astra Zeneca
8%	Seagan
<b>5</b> %	Gilead
4.1%	Janssen
4.1%	MSD

### Revenue and expenses for 2023

### Revenue and expenses for 2022

#### Source of Revenue 2023

**96.81%** Sponsorship and grants VAT Account

3.19% Other Income



#### Source of Revenue 2022

90.77% Sponsorship and grants8.65 VAT Account0.58% Other Income



#### Operating Costs 2023

**40.82%** Project Costs **43.60%** Staff Costs

**13.81%** Management & Running Costs

**1.77%** Board Expenses



#### Operating Costs 2022

**38.95%** Project Costs **44.19%** Staff Costs

**13.69%** Management & Running Costs

**3.17%** Board Expenses



### Operating costs and expenditures in 2023

OPERATING COSTS	2023 (AMOUNT IN €)	2022 (AMOUNT IN €)
STAFF COSTS	€ 239.270	€ 212.730
Remuneration	€ 183.193	€ 162.897
Social security contributions	€ 18.939	€ 13.575
Other employee costs	€ 36.623	€ 27.326
Tax provision for holiday pay	€ 2.192	€ 10.021
Recup. Withholding tax	€ - 1.677	€ - 1.089
MANAGEMENT & RUNNING COSTS	€ 75.782	€ 65.927
Office costs	€ 7.759	€ 11.395
Telephone/Internet	€ 2.825	€ 2.559
Depreciations on IT	€ 1.304	€ 1.763
IT maintenance	€ 3.332	€ 3.048
Insurance costs	€ 1.361	€ 939
Congress & Events	€ 4.718	€ 4.408
Subscription fees	€ 5.145	€ 3.293
Legal fees	€ 3.020	€ 3.309
Accountant & audit fees	€ 11.440	€ 12.664
Bank costs	€ 4.553	€ 2.030
Payroll services & fees	€ 5.940	€ 4.621
Advertising & Marketing	€ 4.487	€ 2.461

	2023 (AMOUNT IN €)	2022 (AMOUNT IN €)
Taxes & Fees	€ 85	€ 76
Training & Development	€ 3.520	€ 1.185
Travel	€ 14.799	€ 11.902
BOARD EXPENSES	€ 9.726	€ 15.280
Board related costs	€ 9.726	€ 15.280
PROJECT RELATED COSTS	€ 224.054	€ 187.433
Forum	€ 68.696	€ 53.045
Awareness Month	€ 79.511	€ 56.520
Patient Survey	€ 7.972	€ 61.235
Advocacy & Capacity	€ 8.606	€ 10.665
Newsletter	€ 640	€ 1.473
Other Adhoc Projects	€ 8.841	€ 4.495
5 Women	€ 14.560	
White Paper	€ 35.228	
TOTAL OPERATING COSTS	€ 548.831	€ 481.370

# Our partners and sponsors

### Our partners

We are delighted to be working with a growing number of strategic partners across the globe. These organisations are committed to improving bladder cancer patient outcomes, survivorship and quality of life and form an essential part of our advocacy work. See a list of our partner organisations below.





















### Our sponsors

Thank you to our industry partners who have supported us throughout 2023.

#### **Premier Partners**







### **Supporters**











Thank you to our industry partners who have supported us throughout 2023.

#### You can find us here:

Twitter: @WorldBladderCan

Facebook: WorldBladderCan

Instagram: @WorldBladderCancer

LinkedIn: WorldBladderCan

Website: worldbladdercancer.org

Email: info@worldbladdercancer.org

YouTube: Search World Bladder Cancer

**Patient Coalition** 

World Bladder Cancer Patient Coalition aisbl

Square de Meeûs 38–40 1000 Brussels Belgium

Reg. Number: 0720.618.047 VAT ID: BE0720.618.047



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