



World Bladder
Cancer Patient
COALITION

2022

Annual Report

worldbladdercancer.org

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Table of Contents

Message from President and the Executive Director	1
Our story	3
Our network	4
Bladder Cancer Awareness Month	5
World Bladder Cancer Patient Forum 2022	6
Fostering a global bladder cancer patient community	7
Our online hub	9
Bladder cancer newsletter	10
Advocacy & external engagement	11
WBCPC 4th General Assembly 2022	21
Balance Sheet	22
Financials	23
Our partners and sponsors	27

Message from President and the Executive Director

The year 2022 was filled with many significant milestones for the World Bladder Cancer Patient Coalition.

This year, we were able to meet again in person. For many of us, it was the first time seeing each other after years of online collaboration. For some, it was reconnecting with old friends face-to-face again. We know it was a special moment for our friends and colleagues in our community, and for us personally. We feel honoured to have been able to facilitate these connections during our first in-person event – World Bladder Cancer Patient Forum in Paris.

Our community's wealth of knowledge and inspiring dedication shines through every day, and we saw that in our workshops and discussions during the event. We strive to take those conversations and ideas forward, develop resources and initiatives that best respond to our members' needs and support the capacity building of all bladder cancer patient groups who need it.

Our Start-up guide for bladder cancer patient groups is now available in six languages. This community-developed resource is now accessible to millions who speak these languages, and we stand ready to support patients, carers and healthcare professionals in starting a local group to provide much-needed support for people affected by bladder cancer. We continue researching and connecting with aspiring advocates, fledgling groups and existing organisations.



Dr Lydia Makaroff, PhD
PRESIDENT



Alex Filicevas
EXECUTIVE DIRECTOR

A strong international community of bladder cancer patient advocates is what we are building and working towards every year. That's why it was so heartwarming to welcome four new organisations into our Coalition from Australia, The Netherlands, Singapore and Sweden. Our coalition now counts 15 organisations in 11 countries as our members.

Together, we worked on raising the profile and awareness of bladder cancer and its signs & symptoms to look out for. In 2022, our new campaign, "Don't go red. Go to a doctor", took bold action to capture the attention of the public in a creative way, helping us reach over 4 million people across WBCPC social channels alone.

This year we increased our efforts to connect with leading medical societies, cancer control organisations and advocates from around the world. We attended several congresses, where we presented early findings from the Bladder Cancer Patient and Carer Survey. Bringing attention to challenges faced in our community, our external engagements helped forge new connections and further our understanding of bladder cancer impact and advocacy challenges in underrepresented countries.

People affected by bladder cancer have the right to receive the best possible support, treatment and care and bladder cancer patient support groups, charities, and organisations are a fundamental part of that. Existing initiatives, passion for learning and sharing and big aspirations in the bladder cancer patient community inspire us so much. As we reflect on the many achievements of the past year in this Annual Report, we look forward with hope and enthusiasm to the years to come.



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 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 15 patient organisations from four 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 570,000 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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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 15 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 support each other along the way. Below is the complete list of patient organisations that are members of our coalition.



In 2022, we welcomed four new organisations to our coalition, **Leven met blaas- of nierkanker** from the Netherlands – **Beat Bladder Cancer Australia**, **Singapore Cancer Society** and **Blåscancerförbundet** from Sweden.

Become a member
Join our international coalition, expand your network, share knowledge and together, let's strengthen bladder cancer patient support and advocacy around the world.



Our member organisations

BCAN – United States

Bladder Cancer Canada

Action Bladder Cancer – UK

Fight Bladder Cancer – UK

Leven met blaas-of nierkanker - Netherlands

BEAT Bladder Cancer Australia

Bladder Cancer Awareness Australia

Singapore Cancer Society

Cancer Vessie France

Bladder Cancer Norway

Norwegian Bladder Cancer Society

Campaigning for Cancer – S. Africa

Blåscancerförbundet – Sweden

PaLiNUro – Italy

Bladder Cancer Awareness Month

In 2022, our organisation took bold action in raising awareness for bladder cancer with Bladder Cancer Awareness Month (BCAM) in May. With the support of our members and partners worldwide, we united communities to increase understanding of bladder cancer, empowering individuals to recognise the signs and symptoms and act on them.

We aimed to reach more people from all parts of the world, using the feeling of embarrassment, which everyone has experienced, as a hook to raise bladder cancer awareness. The campaign acknowledged the embarrassment associated with discussing intimate symptoms and urged people not to shy away from seeking help, with the motto: **Don't Go Red, Go to a Doctor.**

To achieve this, we launched a powerful campaign video featuring relatable and embarrassing affirmations to grab people's attention, followed by a surprising revelation

linking it to bladder cancer. This video was released in English, French, Spanish, and Italian and received an impressive 600,000 views on social media. We also challenged the public to share their own embarrassing affirmations with us, engaging with a wide range of audiences.

Our awareness-raising resources and engaging online social media messages contributed to a fourfold increase in website traffic compared to our previous BCAM 2021 campaign, with over 16,000 people from all over the world visiting our website to learn more about bladder cancer in May 2022.

Growing community
In just one month our online communities grew by



Learn more about our Bladder Cancer Awareness Month 2022 in the campaign report – [click here](#).

Multi-lingual Toolkits



We developed a Campaign Action Toolkit in English and Spanish, with a range of campaign resources also available in other languages, used by our members, individuals, supporters, and partners worldwide to participate in our BCAM activities. Additionally, we created virtual backgrounds, social media banners, and a Twibbon to provide as many possibilities as possible and resources for anyone willing to participate.

**I PRETEND I AM A JEDI
WHEN WALKING THROUGH
AUTOMATIC DOORS**

**SOME THINGS WE'RE EMBARRASSED
ABOUT ARE HARMLESS. SOME, MIGHT NOT BE.**
If you see blood in your urine, need to urinate on a more frequent basis, or have what you think could be a UTI...



**Reached over
4 million people
across our
social media
platforms**



**Over 600,000
people have
watched BCAM
campaign
video**



**#DontGoRed and
#BladderCancerMonth22
were used over
1,400 times**

World Bladder Cancer Patient Forum 2022

Changing bladder cancer patient care together.

We are proud to have hosted our 2nd World Bladder Cancer Patient Forum 2022, which brought together the global bladder cancer patient community for the first time in person in Paris, France. This annual event serves as the only international platform for exchanging knowledge, developing new ideas, and fostering collaboration within the bladder cancer patient community.

The theme of the World Bladder Cancer Patient Forum 2022 was **“Taking Bladder Cancer Patients’ Voice Forward”**, a stepping stone for action. This theme recognised the need for international multi-stakeholder collaboration to achieve the common goal of improving the lives of people



Watch the recording and see what was discussed at the forum.

CLICK HERE TO WATCH

affected by bladder cancer, no matter where they live in the world.

Shining a Light on Bladder Cancer Patients & Carer Experiences

The first session, “Shining a Light on Bladder Cancer Patients & Carer Experiences”, featured the headline results from the Bladder Cancer Patient and Carer Survey presented by Alex Filicevas, WBCPC Executive Director. It also featured a video interview with Dr Ashish Kamat, Chair of the Expert Advisory Committee.

Rising to the Challenge

– Examples from the Patient Community

The second session, “Rising to the Challenge – Examples from the Patient Community”, featured three projects from WBCPC member organisations in Australia, Canada, and Italy. These initiatives showcased the diversity of incredible efforts of patient organisations to support people affected by bladder cancer and drive much-needed change locally.

By bringing the bladder cancer community together, we made possible the sharing of information, ideas and connections that could have a tangible benefit for the millions of people affected by bladder cancer around the world.



Explore the full report, which dives deeper into the discussions held at the forum.



Fostering a global bladder cancer patient community

Patient groups focused on bladder cancer, whether they are large or small, are essential in improving the lives of patients and their families. The World Bladder Cancer Patient Coalition is dedicated to supporting the establishment of bladder cancer patient groups in every country and providing ongoing support to ensure that they are successful. Our mission is to build a global community of strong patient advocates, and we believe that the voice of our coalition is only as strong as the commitment of our members.

Our goal is to have a national bladder cancer patient organisation in every country. We work to make sure that these organisations are equipped to provide support, increase awareness, and advocate for better diagnosis, access, and care. We acknowledge that establishing a bladder cancer patient group can be challenging, which is why we have created a “Start-up guide for bladder cancer patient groups”.

This guide is now available in six languages, including Turkish and Arabic, which we added this year, to help people around the world to start a patient group. The guide is based on the experiences of our members who have successfully established bladder cancer groups. We have compiled their collective knowledge in the guide to help anyone interested in starting a patient organisation in their country.

In addition to supporting the establishment of bladder cancer patient groups around the world, the World Bladder Cancer Patient Coalition provides various resources to keep our members and the wider community informed and connected. We have a website that features important information about bladder cancer, capacity building

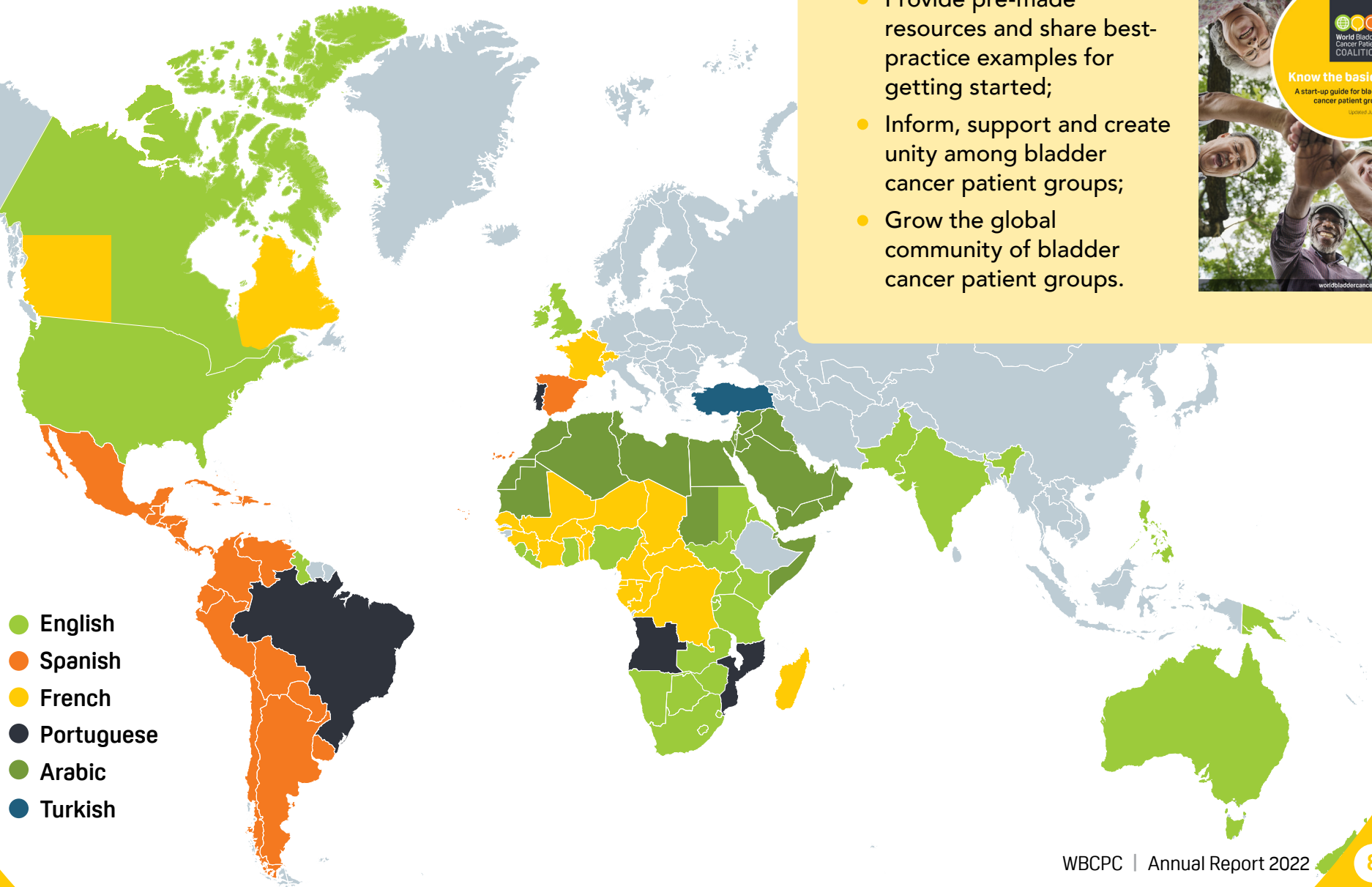
sessions, a newsletter that is sent out regularly, and active social media accounts that share patient stories and updates on our advocacy efforts. We also hold a general assembly each year, where members can connect and discuss important issues facing bladder cancer patients.

Join us in our mission to improve the lives of those affected by bladder cancer by becoming a member of our coalition today.



Increasing reach around the world

Countries and languages covered by the Start-up guides



The Start-up guide aims to:

- Promote the establishment of bladder cancer patient groups in different countries;
- Provide pre-made resources and share best-practice examples for getting started;
- Inform, support and create unity among bladder cancer patient groups;
- Grow the global community of bladder cancer patient groups.

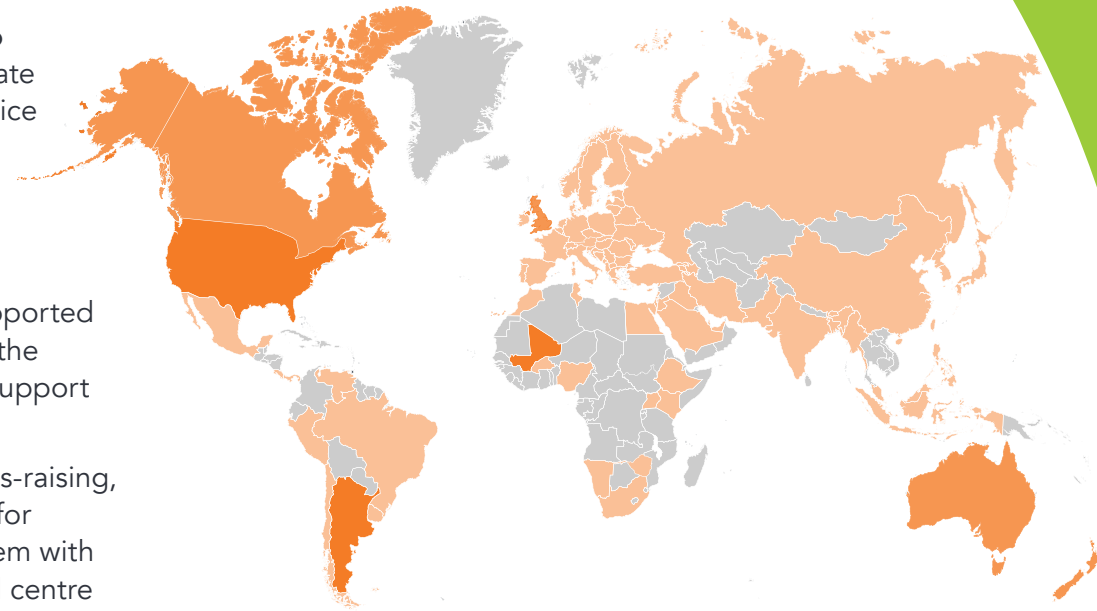


Our online hub

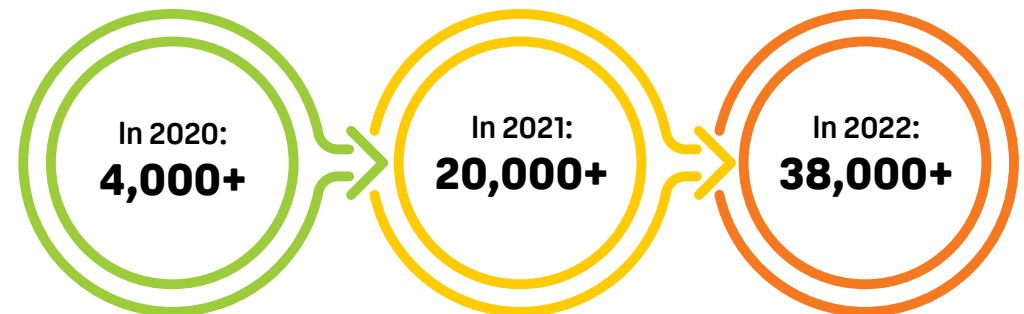
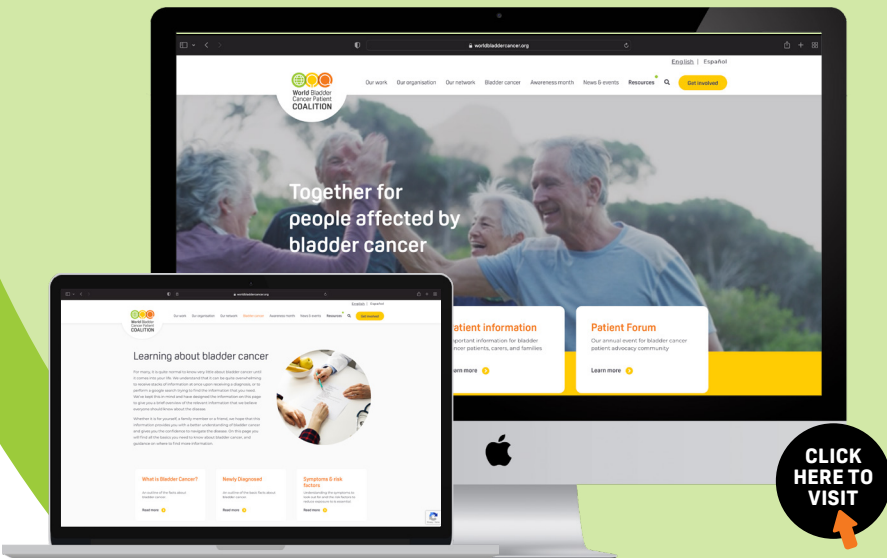
In 2022, we continued to build an online destination as the global go-to resource for anyone interested in or affected by bladder cancer. To create a space to showcase our community's impactful work and amplify the voice of bladder cancer patients, our members and our partners. We want to ensure that people affected by bladder cancer do not feel alone, overwhelmed or unrepresented due to a lack of patient-led information and support available to them.

We expanded our educational information pages on bladder cancer, supported by our member organisations' information. We will continue developing the information and resources in multiple languages about bladder cancer, support and advocacy.

Our resource hub grew with more materials for bladder cancer awareness-raising, which are available in multiple languages. These resources are available for anyone to download and use in their local communities, empowering them with the necessary knowledge, guidance and support. The hub will be a focal centre for our members as we develop assets and materials for their use.



The worldbladdercancer.org received **38,120** visitors in 2022, a staggering **38%** growth over last year. Our visitors came from a wide range of countries, which showcases the broad global reach of WBCPC.



Bladder cancer newsletter

Our monthly Bladder Cancer Newsletter goes out to the inboxes of our members, partners, stakeholders, patients and their families. Since its launch in 2019, we have focused on bringing attention to the impactful work of our community. The newsletter is a monthly resource for many, highlighting the most note-worthy news in patient advocacy and the bladder cancer landscape.



In 2022, we sent 30 mailings to our audience, featuring an increasing number of original content and thought-leadership which we develop 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 **10,000 times**. We are confident that as we continue to improve our content, expand to new regions and build new partnerships, our newsletter will continue this upwards trend and play an even more significant role in raising bladder cancer awareness, and strengthening bladder cancer support and advocacy community.



In 2022, we launched our **Member's Quarterly** newsletter which bring updates from the different initiatives and activities of our member organisations. Our member organisations work daily to provide information, guidance and support for people affected by bladder cancer in their countries. That is why we believe their work and impact deserve to be seen beyond the borders. Bladder cancer knows no borders, and with that, we wish to highlight the important work of our members and inspire those who may be thinking of or just starting out with a bladder cancer group in their community.

Advocacy & external engagement

As a global patient organisation, our mission is to foster an international community of people affected by bladder cancer. We help ensure that national bladder cancer patient organisations are strong enough to effectively support people affected by bladder cancer in their country, elevate awareness and advocate for better diagnosis, treatment and care.

Our goal is to bring bladder cancer to the top of the global health policy agenda. We do this by communicating the bladder cancer patient community's critical challenges to all relevant stakeholders and partners across the world, and working together to address them.

The 'P' Word: event on the challenge of urinary problems faced by people living with prostate and bladder cancer

On 7 December 2022, Alex Filicevas, Executive Director of the WBCPC, co-chaired a European Parliament session focused on the urinary challenges faced by bladder cancer and prostate cancer patients. This event was jointly organised by WBCPC, European Association of Urology and World Federation of Incontinence and Pelvic Problems.

This collaborative effort brought together leading organisations, including the European Cancer Organisation, European Association of Urology, and Eurocarers, among others. The session emphasised the EU's commitment to cancer care and the proposals under Europe's Beating Cancer Plan to address patients' needs.

Featuring insights from patient representatives, clinicians, and policymakers, the discussion focused on challenges and recommendations for European policies and programmes to find effective solutions for improving the lives of those affected by prostate and bladder cancer. Our member organisation from Italy, Associazione PaLiNUro, presented findings from their survey on continence challenges also sharing a personal bladder cancer patient experience.

We invite you to explore the recommendations on the WBCPC website aimed at enhancing the quality of life for prostate and bladder cancer patients while addressing urinary incontinence challenges and promoting environmental sustainability.



Advocacy & external engagement

Stigma: The invisible side of bladder cancer – new advocacy infographic

In 2022, WBCPC launched an insightful infographic, “Stigma: The Invisible Side of Bladder Cancer” highlighting the impact of stigma on bladder cancer patients and caregivers. This resource is based on the shared lived experiences of 312 patients and caregivers from France, Spain, Germany, the UK, and the USA who participated in targeted research through surveys and qualitative interviews.

The research aimed to improve understanding of patient experiences and perceptions of disease disadvantage and stigma by exploring its existence within the bladder cancer community, examining how it manifests, and investigating how reported stigma evolves over the course of the disease.

In addition to the international English infographic, we also created and launched infographics for France, Italy, Spain and the UK. The infographic came with a one-page toolkit to guide patient advocates on using the resource for advocacy and awareness.

Stigma: The invisible side of bladder cancer
 To understand the impact of stigma on people affected by bladder cancer, 312 patients or caregivers of which 69 from the United Kingdom have shared their experiences in a survey and qualitative interviews.

World Bladder Cancer Patient COALITION

1. Disease disadvantage 2. Self-stigma 3. External stigma

Bladder cancer patients are primarily worried about disease disadvantage, followed by self-stigma and external stigma.

1. What is disease disadvantage?

Delayed or misdiagnosis
 The diagnosis failures are Systemic Disadvantage. The system seems to be set up to let people down, with multiple delays, misdiagnosis and refusal to take symptoms seriously.

“Keep going to your GP. You have to shout loud.”

Lack of bladder cancer knowledge
 A natural reluctance to talk about private bodily functions in public. Bladders, urination, incontinence, sex organs are all intensely private. Men and older patients in particular, want to keep this to themselves – it’s not common to talk about such private things.

The choice to hide
 Some patients want to regain ownership of their lives and their bodies. They have a desire to portray normality to the world – to protect yourself and also save yourself from the awkwardness of others.

“No-one likes talking about their bits.”

Life on hold
Hamster wheel of treatments
 Life is effectively on hold as seemingly endless rounds of treatment, scans and retreatments become a reality. It is often impossible to commit to any plans or live a normal due to repeated, painful and uncomfortable hospital trips.

Scamxiety
 A big part of the trauma of this rollercoaster is the inevitable fear of recurrence – as the time for another scan comes round, patients are fearful and anxious – it’s another attack on their mental health, already vulnerable through self-stigma.

“Scamxiety, you know what’s coming, you get a bit more snappy, more anxious as the date gets closer.”

Peer support and information
 For some patients and caregivers there’s a lack of information about how life will be different afterwards. The value of patient support groups and networks is evident.

43% of international patients say their mental state has negatively impacted the relationship with their partner.

57% of international patients felt the opportunity to talk to other bladder cancer patients was important.

Making a difference for patients in the UK

56% of patients want a change in support and advice for carers

46% of patients want a change in the type of information

60% of patients want a change in emotional / psychological support

2. Experience of internal stigma
 A fear of being judged

Self-stigma is a significant issue for patients as they often anticipate and believe that others will judge them.

Patients in the UK resonated with the following statements:

- 16%** I don't think many people even know what bladder cancer is
- 14%** Society treats people with bladder cancer worse than people with other cancers
- 20%** Sometimes I feel ashamed
- 18%** I feel judged sometimes
- 16%** I sometimes blame myself for my illness

Stigma and disease have less impact on older patients in the surveyed countries:

- 71%** Aged 40-59
- 44%** Aged 60+

The percentage of patients from the surveyed countries who agree or disagree with the statement that stigma decreases over time

Patients diagnosed more than 2 years ago

Patients diagnosed 3 months to 2 years ago

External stigma

33% of young patients felt blamed by the doctor

31% of patients feel that they have embarrassed their family, friends or colleagues by their illness

23% of caregivers have been diagnosed with depression or anxiety

44% of caregivers from the surveyed countries: do not know how to talk to the doctor and what questions to ask

55% of caregivers from the surveyed countries: Training and advice in how to look after a cancer patient is general

33% of caregivers from the surveyed countries: Advice on how to keep them feeling positive and avoiding depression

40% of caregivers from the surveyed countries: More time to look after my partner / child / parent / friend / relative

44% of caregivers from the surveyed countries: do not know how to talk to the doctor and what questions to ask

31% of caregivers from the surveyed countries: Training and advice in how to look after a cancer patient is general

52% of caregivers from the surveyed countries: Advice on how to keep them feeling positive and avoiding depression

45% of caregivers from the surveyed countries: More time to look after my partner / child / parent / friend / relative

43% of caregivers from the surveyed countries: do not know how to talk to the doctor and what questions to ask

86% of caregivers from the surveyed countries: Training and advice in how to look after a cancer patient is general

86% of caregivers from the surveyed countries: Advice on how to keep them feeling positive and avoiding depression

85% of caregivers from the surveyed countries: More time to look after my partner / child / parent / friend / relative

83% of caregivers from the surveyed countries: do not know how to talk to the doctor and what questions to ask

DISCLAIMER:
 The infographic was developed by the World Bladder Cancer Patient Coalition with the financial support of Actavis Pharma Europe Ltd, using the data from the “Patient and caregiver survey on stigma and disease disadvantage in bladder cancer 2022” conducted by Real Key Planning for Actavis Pharma Europe Ltd. The survey received a total of 312 replies from bladder cancer patients or caregivers from France, Germany, Spain, the United Kingdom, the United States of America. Country-specific data is representative highlighting.

Legend:
 ● slightly agree
 ● strongly agree
 ● ALL agree

DOWNLOAD HERE

Advocacy & external engagement

Bladder Cancer Patient & Carer Survey

In 2022, we completed an important milestone in our multi-year project for evidence generation for effective support and advocacy - the first global Bladder Cancer Patient and Carer Experience Survey. It kicked off in October 2021 and ran through February 2022. The survey was available in 11 languages and was open to participants from all over the world. This survey aimed at filling the global evidence gap relating to the experience of bladder cancer patients and carers.

Collecting data on the patient and carers experience is fundamental as it allows us to identify what is important to the people affected by bladder cancer and drive patient-centred care and support improvements. Questions spanned the entire patient pathway, from symptom recognition and awareness to receiving a diagnosis, access to treatment and support, follow-up care and survivorship.

This study represents a genuinely collective effort among the bladder cancer community, including our patient organisations, patients, carers and experts in the field of bladder cancer treatment and research.



Some early results from the survey were presented at the European Association of Urology Congress 2022 Patient Day and the European Association of Urology Nurses Annual Meeting 2022 during a session dedicated to bladder cancer and the patient voice.

We were also proud to share the first insights from the findings with our community at the World Bladder Cancer Patient Forum 2022, held in Paris, France, on September 8. The findings offered insights into bladder cancer patient and carer experiences. They fuelled an active discussion on the way forward to address the unmet needs shared by the community.



We look forward to launching the full findings report in 2023, submitting an article to a peer-reviewed publication and engaging partners and stakeholders to drive meaningful change and improvements in care, support and information for people affected by bladder cancer.

EAU Patient Office Board

The WBCPC President, Dr Lydia Makaroff, was invited to join the newly formed European Association of Urology Patient Office Board.

Lydia's role and mission as a member of the Patient Office revolves around fostering collaborations between the EAU Patient Office and the European Patient Advisory Group (ePAG), ensuring that patients remain at the centre of all activities and decisions.

World Cancer Congress 2022

The World Cancer Congress 2022, organised by the Union for the International Cancer Control (UICC), took place in Geneva, Switzerland, in October.

The WBCPC delegation included President Dr Lydia Makaroff and Executive Director Alex Filicevas, focusing on connecting with patient advocates, civil society groups and cancer control leaders from around the world.



Advocacy & external engagement

WBCPC is committed to developing our collective knowledge of cancer control challenges, and patient needs worldwide, especially in low-resource settings. This will help us better respond to unmet needs, identify partners and work with the community to ensure that people affected by bladder cancer have access to the best available support and care no matter where they live.

At the World Cancer Congress, together with the European Association of Urology, we have co-developed a digital session empowering genitourinary cancer patients to become their own best advocates. The session featured speakers from the International Kidney Cancer Coalition (IKCC) and the European Cancer Leagues (ECL). Alex stressed the need for more bladder cancer support networks and organisations worldwide, sharing the Start-up guide for bladder cancer patient groups and the support frameworks that WBCPC has to support patient advocates starting a group in their community.

Dr Lydia Makaroff also made an audience contribution at the session "Redefining cancer research priorities in the emerging context of the COVID-19 pandemic", organised by the Institute of Cancer Policy, Kings College London. Lydia highlighted the need for professional organisations, UICC, and civil society to work together to improve treatment guidelines for constrained-resource areas, considering the availability of certain medications or resources and practice variations in different and remote regions of the world. Lydia also noted how cancer patient organisations can take global policy priorities locally to their local or national governments to drive change.



The 42nd SIU Congress

The World Bladder Cancer Patient Coalition team attended the 42nd Annual SIU Congress – a leading global event organised by Société Internationale d’Urologie (SIU) convening urologists worldwide. Our team included Dr Lydia Makaroff, President, Ken Bagshaw, Founding President and Alex Filicevas, Executive Director. This event marks the second-time participation for WBCPC at the SIU Congress.

The SIU Congress featured many insightful presentations and discussions about bladder cancer treatment and care today and in the future. Dr Lydia Makaroff joined the panel on Perioperative Immunotherapy Treatment of Localised Genitourinary Malignancies. The World Bladder Cancer Patient Coalition continues its collaboration with the SIU, which started with a Memorandum of Understanding in 2021.



Advocacy & external engagement



We continue to develop this important partnership to advance bladder cancer patient care worldwide.

We hosted a WBCPC booth in the exhibit area, where we invited urologists to learn more about the World Bladder Cancer Patient



Coalition and our member organisations. In conversations with booth visitors from various countries, we highlighted the need for more bladder cancer patient organisations around the world.

Stressing that, the Start-up guide for bladder cancer patient groups featured as a helpful tool to connect physicians, patients and caregivers with a wealth of ideas and resources from the WBCPC community.

The Start-up Guide for bladder cancer patient groups features tips and guidance on how to start a bladder cancer patient support group or organisation. Recently launched in Turkish and Arabic, the guide is available in English, French, Portuguese and Spanish.

European Association of Urology Congress 2022

We are proud to have co-developed a bladder cancer information session at the Patient Day of the European Association of Urology (EAU) Congress 2022, which took place in Amsterdam, the Netherlands. The WBCPC President, Dr Lydia Makaroff and Dr Eammon Rogers, Chair of the EAU Patient Information Office co-chaired the session.



We were delighted to welcome patient advocates and our bladder cancer patient group community to the session. The EAU Patient Day bladder cancer information session took place in-person for the first time. It brought together speakers from the WBCPC member organisations in Europe. Associazione PaLiNUro (Italy), Leven met blaas-of nierkanker (Netherlands), and Cancer Vessie

Advocacy & external engagement

France showcased examples of patient-led information resource development, scaling of patient groups and actively working to promote better care and better access to innovation for bladder cancer patients. It was also an opportunity for us to share critical early data from the WBCPC Bladder Cancer Patient and Carer Survey, presented by the WBCPC Executive Director Alex Filicevas.



European Association of Urology Nurses Annual Meeting 2022

The World Bladder Cancer Patient Coalition joined the European Association of Urology Nurses (EAUN) Annual Meeting 2022 in Amsterdam, The Netherlands. Alex Filicevas, WBCPC Executive Director, joined the Bladder Cancer: The Importance of the patient voice session, Chaired by Dr Bente Thoft Jensen.



Alex shared early insights from the WBCPC Bladder Cancer Patient and Carer Survey. The presentations and discussion focused on the importance of a meaningful patient-healthcare professional relationship with the ambition of improving patient outcomes and care experience. Speakers offered different views from their individual professional perspectives, helping to highlight the role of the patient voice in bladder cancer patient care and professional societies such as the EAU and EAUN.

Advocacy & external engagement

GO Norte International GU Debates 2022



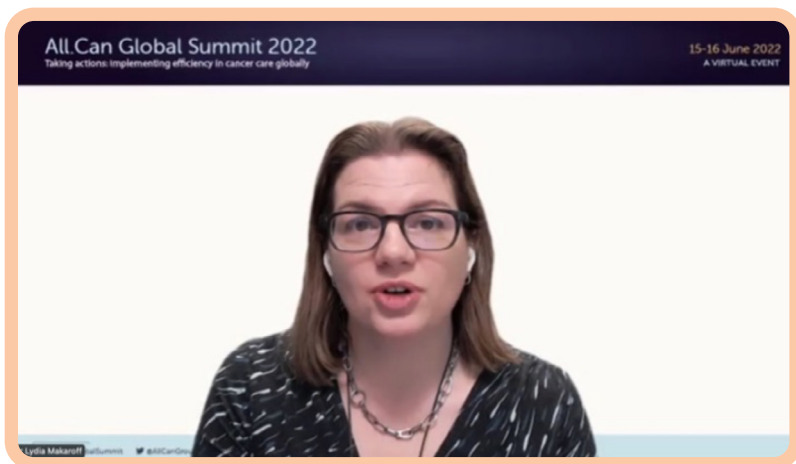
The WBCPC Executive Director Alex Filicevas joined the GO NORTE International GU Debates 2022, organised in the Spanish town of Limpias in October. With over 100+ attendees from all over Spain and international experts, the event featured discussions on advances in genitourinary cancers, challenges in care and approaches for better patient outcomes in bladder, kidney, and prostate cancer.

Alex Filicevas presented in the session focused on the patient's voice in bladder cancer. Addressing the audience, Alex focused on the role of patient organisations in strengthening patient-led support and information for people affected by bladder cancer. Patient organisations take different shapes in different settings based on local needs, including peer-to-peer support, patient-led and reliable information, awareness raising, advocacy and patient-focused research.

Currently, there is no patient-led network or patient organisation in Spain that focuses on and provides support for people affected by bladder cancer. Speaking at the GO NORTE International GU Debates, Alex Filicevas encouraged urologists and oncologists to identify patients and caregivers in their care to seek out those with a spark to do more. To connect them with resources and support from the World Bladder Cancer Patient Coalition.

All.Can Global Summit 2022

The World Bladder Cancer Patient Coalition (WBCPC) joined the virtual All.Can Global Summit in June sharing patient perspectives for a discussion focused on Supporting Healthcare Professionals.



“It is important to demonstrate early on the value and the right of patients to have a seat at the table. We need patient organisations represented whenever and wherever healthcare professionals are meeting for training, especially at medical congresses and their panels.”

Dr Lydia Makaroff, President of the World Bladder Cancer Patient Coalition

Advocacy & external engagement

The All.Can Global Summit, opened by WBCPC Executive Director and All.Can President Alex Filicevas explored concrete ways to overcome inefficiencies in cancer care by hearing from 26 panellists who provided concrete recommendations for practice changes around four key themes: empowering and partnering with people; supporting healthcare professionals; implementing a data-driven learning system; investing in efficient technologies. WBCPC President, Dr Lydia Makaroff, joined a session as a speaker and highlighted areas of patient expectations from healthcare professionals towards them.

Special peer-reviewed podcast with Dr Tom Powles

In this podcast, our Executive Director, Alex Filicevas, and Professor of Genitourinary Oncology, Dr Tom Powles, shared their perspective on the highlights from the European Society for Medical Oncology (ESMO) Congress 2021 by focusing on greater involvement and collaboration with patients and healthcare professionals in leading medical congresses.

Both discussants reflect on key challenges and opportunities in cancer care moving forward from the COVID-19 pandemic, including restoring and improving care and efficiency of cancer services. The podcast, also published as a peer-reviewed publication, points out the importance of working with healthcare professionals, research institutes and industry to better inform and educate the patient community around the world about the advances in cancer research and what it means for patient care in practice.

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The Economist 8th Annual World Cancer Series: Europe



In November, the Economist organised its 8th Annual World Cancer Series: Europe event in Brussels, Belgium.

The event focused on “innovation, equity and excellence”. The conversations explored different strategies to accelerate innovation, reduce inequities across cancer control in Europe, and what could be done to build towards universally excellent cancer control and cancer outcomes across the continent. WBCPC Executive Director Alex Filicevas discussed the importance of increasing the speed, accessibility, and effectiveness of screening programmes in Europe and beyond.

Advocacy & external engagement

“Extending the screening programmes to more cancer types, including bladder cancer, is crucial – collaboration to advance research is how we can make that happen. We also need to measure, evaluate and continuously learn about the efficiency of existing programmes and adapt in line with advancements in technology and research.”

Alex Filicevas, Executive Director of the World Bladder Cancer Patient Coalition

Responding to the crisis in Ukraine

As the humanitarian crisis in Ukraine unfolded, the World Bladder Cancer Patient Coalition joined efforts with the European Cancer Organisation and American Society of Clinical Oncology and their members, partners and patient groups to share experience, contacts and intelligence in support of cancer patients affected by the war in Ukraine in early 2022. We have also closely monitored the experiences of the cancer patient community in Europe through the WECAN initiative.

We have created a dedicated page on the WBCPC website to guide bladder cancer patients to credible additional information and resources across many organisations in Europe for affected people in Ukraine and countries across Europe.

Advocacy & external engagement

GCCN Coalition Connection 3

The Global Cancer Coalitions Network (GCCN), of which WBCPC is a proud and active member, organised its 3rd online event Coalition Connection 3: Sustaining Patient Advocacy Post-Covid.

Many patient advocacy organisations faced extraordinary challenges during the COVID-19 pandemic, from loss of crucial funding to significant reductions in human resources, both paid and unpaid. The Coalition Connection series focused on sharing insights, learnings and support for cancer patient advocacy groups around the world.

WHO Consultation on People with NCDs

The WBCPC President, Dr Lydia Makaroff, represented the organisation at the World Health Organisation's Informal consultation with people living with non-communicable diseases and mental health conditions to highlight the importance of including people with lived experiences in co-designing policies, programs, and principles.



World Cancer Day

We were proud to join the international cancer community efforts in support of World Cancer Day on February 4, 2022. The new theme, Close the Care Gap marked the start of a new 3-year campaign for one of the most important health awareness days in the year led by the Union for International Cancer Control (UICC).

World Cancer Day is an opportunity to raise awareness about inequities in bladder cancer too. That's why our support efforts focus on informed and empowered patients who can demand better care alongside strong bladder cancer patient groups in their community.

“Strong, empowered patient groups are essential to close the care gap in bladder cancer care. That’s why we focus on supporting patient advocates in starting a group in their communities.”

Alex Filicevas, Executive Director of the World Bladder Cancer Patient Coalition



WBCPC 4th General Assembly 2022

On June 16, 2022, our member organisations convened virtually for the 4th WBCPC General Assembly. Together, our members reviewed the organisation's achievements of the past year and exchanged views on plans for 2022 – amongst the necessary administrative formalities of the General Assembly.

The new WBCPC Board of Directors was confirmed for 2022 – 2025. The new Board officially started the term on June 23, 2022.

The General Assembly acknowledged the immense contributions of the outgoing Board of Directors, who have fully or partially served on the Board during 2019-2022 since the organisations inception. Their dedication was instrumental in the success of the establishment and subsequent growth of the World Bladder Cancer Patient Coalition.

The WBCPC member organisations brainstormed and expressed their desire for increased collaboration, better use of WBCPC awareness and reputation, a robust Bladder Cancer Awareness Month campaign 2023, and fostering new patient organisations worldwide in 2023. Our members highlighted the importance of raising awareness about risk factors specific to low-income countries and supporting efforts to connect with people affected by bladder cancer in these regions.

The unwavering support, dedication, and insights that our member organisations have demonstrated continue to play a crucial role in the success of our outreach activities. Together, we amplify our collective impact, bolstering support and advocacy for those affected by bladder cancer around the globe.

Thank you to all Board Members



Andrew Winterbottom
FOUNDING BOARD
MEMBER 2019



Andrea Maddox-Smith
FOUNDING BOARD
MEMBER 2019 – 2022



Tammy Northam
FOUNDING BOARD
MEMBER 2019

Outgoing Board of Directors 2019 - 2022



Dr Lydia Makaroff
PRESIDENT



Ken Bagshaw
TREASURER /
FOUNDING PRESIDENT



Lori Funk-Cirefice
VICE-PRESIDENT



Allen Knight
BOARD MEMBER



Dr Stephanie Demkiw
BOARD MEMBER



Dr Stephanie Chisolm
BOARD MEMBER

Board composition as on December 31, 2022.

Balance sheet

Financial statements for the year ended 31 December 2022, 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	2022 (AMOUNT IN €)	2021 (AMOUNT IN €)
Fixed assets	€ 13.600	€ 19.305
Intangible assets	€ 11.820	€ 16.346
Tangible assets	€ 1.780	€ 2.960
Current assets	€ 354.134	€ 328.386
Amounts receivable within one year	€ 43.769	€ 27.576
Current accounts	€ 307.253	€ 299.773
Deferred charges	€ 3.111	€ 1.038
TOTAL	€ 367.734	€ 347.691
Capital & reserves	€ 274.207	€ 321.585
Profit carried forward	€ 274.207	€ 227.763
Balance	- € 47.378	€ 93.822
Amounts payable	€ 93.527	€ 26.106
Amounts payable within one year	€ 44.446	€ 26.106
Accrued charges & deferred income	€ 49.081	€ 0
TOTAL	€ 367.734	€ 347.691

Financials

The board of directors approved the 2022 audited financial results and subsequently approved by the 5th World Bladder Cancer Patient Coalition General Assembly, which took place on June 14, 2023.

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 2022

For the Financial Year 2022, the revenue of the World Bladder Cancer Patient Coalition aisbl amounted to a total of **€ 433.991**.

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 **€ 481.370**. Leaving a negative net year-end balance of **€ 47.378**.

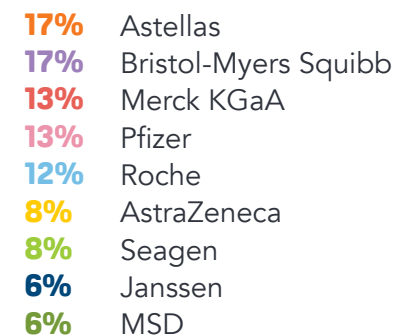
To be noted that the negative balance was accounted for in the Budget for FY 2022. The portion of the **€ 93.822** carry-over from the Financial Year 2021 at **€ 85.505**, were allocated towards the completion of the Patient Survey project, which were unexpended in 2021. Additionally, WBCPC aisbl registered as a VAT liable organisation in 2022, and due to regularisation of the VAT receipts from 2019-2022, **€ 37.541** was received in additional revenue as VAT refund.

SOURCE OF REVENUE	2022 (AMOUNT IN €)	2021 (AMOUNT IN €)
Industry support	€ 393.900	€ 452.969
Other income	€ 2.550	€ 2.890
VAT account	€ 37.541	€ 0
TOTAL REVENUE	€ 433.991	€ 455.859
OPERATING EXPENSES		
Staff costs	€ 212.730	€ 134.765
Management & running costs	€ 65.927	€ 74.466
Board expenses	€ 15.280	€ 3.895
Project costs	€ 187.433	€ 148.910
TOTAL EXPENDITURE	€ 481.370	€ 363.037
BALANCE	- € 47.378	€ 93.822

Industry support contributions received in 2022

REVENUES FROM INDUSTRY SUPPORT	AMOUNT IN €	PERCENTAGE (%)
Astellas	€ 67.000	17%
AstraZeneca	€ 30.000	8%
Bristol-Myers Squibb	€ 65.000	17%
Janssen	€ 25.000	6%
MSD	€ 25.000	6%
Merck KGaA	€ 50.000	13%
Pfizer	€ 50.000	13%
Roche	€ 45.000	12%
Seagen	€ 32.000	8%
TOTAL INDUSTRY SUPPORT REVENUE	€ 389.000	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.



Revenue and expenses for 2022

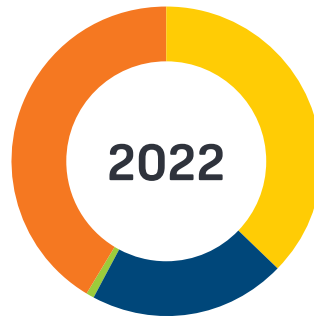
Source of Revenue 2022

90.77%	Industry Sponsorship
8.65	VAT Account
0.58%	Other Income



Operating Costs 2022

38.95%	Project Costs
44.19%	Staff Costs
13.69%	Management & Running Costs
3.17%	Board Expenses



Revenue and expenses for 2021

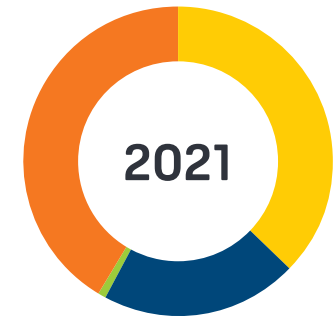
Source of Revenue 2021

99.37%	Industry Sponsorship
0.63%	Other Income



Operating Costs 2021

41.04%	Project Costs
37.14%	Staff Costs
20.52%	Management & Running Costs
1.07%	Board Expenses



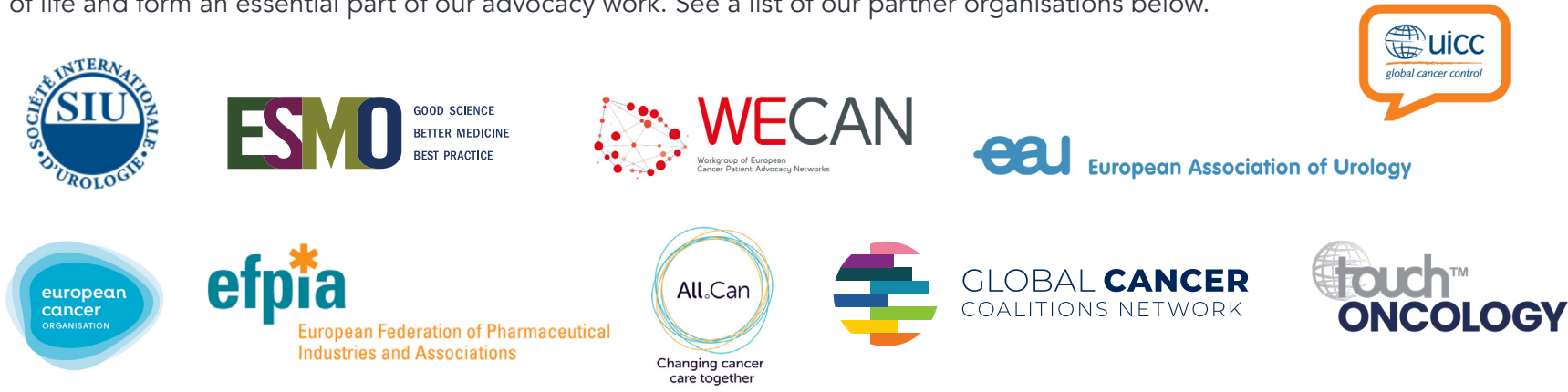
Operating costs and expenditures in 2022

OPERATING COSTS	2022 (AMOUNT IN €)	2021 (AMOUNT IN €)		2022 (AMOUNT IN €)	2021 (AMOUNT IN €)
STAFF COSTS	€ 212.730	€ 134.765			
Remuneration	€ 162.897	€ 106.501			
Social security contributions	€ 13.575	€ 3.988			
Other employee costs	€ 27.326	€ 20.077			
Tax provision for holiday pay	€ 10.021	€ 5.430			
Recup. Withholding tax	€ - 1.089	€ - 1.230			
MANAGEMENT & RUNNING COSTS	€ 65.927	€ 74.466			
Office costs	€ 11.395	€ 12.586			
Telephone/Internet	€ 2.559	€ 2.998			
Depreciations on IT	€ 1.763	€ 2.693			
IT maintenance	€ 3.048	€ 3.083			
Insurance costs	€ 939	€ 979			
Congress & Events	€ 4.408	€ 295			
Subscription fees	€ 3.293	€ 4.852			
Legal fees	€ 3.309	€ 21.911			
Accountant & audit fees	€ 12.664	€ 8.422			
Bank costs	€ 2.030	€ 1.332			
Payroll services & fees	€ 4.621	€ 6.157			
Advertising & Marketing	€ 2.461	€ 4.543			
			Taxes & Fees	€ 76	€ 660
			Training & Development	€ 1.185	€ 3.855
			Team Building	€ 273	€ 99
			Travel	€ 11.902	€ 0
			BOARD EXPENSES	€ 15.280	€ 3.895
			Board travel	€ 15.280	€ 3.895
			PROJECT RELATED COSTS	€ 187.433	€ 148.910
			Annual Meeting / Forum	€ 53.045	€ 6.298
			Awareness Month	€ 56.520	€ 56.317
			Website	€ 0	€ 22.990
			Start-up Guide	€ 0	€ 6.748
			Patient Survey	€ 61.235	€ 44.552
			Advocacy & Capacity	€ 10.665	€ 6.458
			Newsletter	€ 1.473	€ 307
			Other Adhoc Projects	€ 4.495	€ 5.240
			TOTAL OPERATING COSTS	€ 481.370	€ 362.037

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 2022.

Premier Partners



Supporters



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**

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VAT ID: BE0720.618.047



**World Bladder
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.**