



2020 Annual Report

worldbladdercancer.org

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Table of Contents

Message from Presidents and the Executive Director	1		
Our story	2		
Our network	3		
Bladder Cancer Awareness Month	4		
World Bladder Cancer Patient Coalitior Virtual Annual Meeting 2020	ו 5		
Start-up guide for bladder cancer patient groups	6		
Website – our brand-new home online	7		
Bladder Cancer Newsletter	8		
Advocacy & Capacity building			
Financials	12–15		
Our partners and sponsors	16		

Message from Presidents and the Executive Director

The year 2020 was an incredibly challenging time for the world, and our bladder cancer patient community was no exception. We were proud to see our member organisations rise to the challenge with resilience at a time of increased demand and limited resources. They continued to ensure that everyone affected by bladder cancer – patients, caregivers, family and friends – has a place to come to for support, information and advice.

Our office staff in Belgium found strength in the close community of our member organisations and new partnerships, which allowed us to connect, pool, and share knowledge. We are grateful to our industry partners who continued their support allowing the World Bladder Cancer Patient Coalition to continue working in line with our mission.

Our Board of Directors had to make a difficult decision to postpone the planned face-to-face WBCPC Annual Meeting in March 2020, as the pandemic took hold. Whilst meeting in person is an integral part of our community building, our Virtual Annual Meeting in September 2020 brought together over 100 participants from 26 countries for an inspiring discussion and renewed commitment to our mission.

Bladder Cancer Awareness Month in May took place virtually with a revised approach. Recognising the impact on cancer care services and uncertainty for bladder cancer patients, we focused the campaign to signpost patients to support and trusted information resources of our member bladder cancer patient organisations.

Our organisation was founded on the near-total absence of patientled support for most people affected by bladder cancer worldwide, and this unmet need is what drives our work every day. In 2020 we entered our second year, and our ambitions for impact have never been higher. We launched the *Start-up guide for bladder cancer patient groups* in several languages, an incredible member-led resource developed to help those ready to set up a bladder cancer patient group to get started. Our new website – launched in 2020 – was another milestone for the organisation. We are building a global bladder cancer hub where patients, caregivers, and partners can find trusted information, resources, inspiration, and a bladder cancer patient support group nearest to them.

We invite you to explore this Annual Report, showcasing our activities and impact in 2020. We hope it will inspire you to collaborate and connect with us and our bladder cancer patient community.

Thank you to our dedicated Board of Directors, member organisations, partners, and supporters – together, we lead forward for bladder cancer patients.

Ken Bagshaw FOUNDING PRESIDENT 2019–2021

Alex Filicevas EXECUTIVE DIRECTOR



PRESIDENT



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 11 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 a force connecting bladder cancer patients, groups, and organisations worldwide.

Approximately 500,000 people are newly diagnosed with bladder cancer around the world each year. The need to elevate a global common voice for people affected by bladder cancer is critical.

Our Board of Directors





PRESIDENT





Dr Stephanie Demkiw **BOARD MEMBER**



Lori Funk-Cirefice **BOARD MEMBER**



Ken Bagshaw BOARD MEMBER



Allen Knight **BOARD MEMBER**





Alex Filicevas EXECUTIVE DIRECTOR



Theodoros Yfantis PROJECT 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, researchers, policy makers, academics, and industry

Our network

The World Bladder Cancer Patient Coalition is a global community of bladder cancer patient organisations dedicated to improving the lives of people affected by bladder cancer. Our strength comes from our members, affiliates and partners.

We are continuously growing our global bladder cancer patient community and currently work together with 11 cancer patient organisations, all of whom are members. We work closely on joint initiatives and collaborate on advocacy and awareness-raising activities. We also share tools, information and resources collectively. Below is the complete list of patient organisations that are members of our coalition.

If you would like to become a member or would like to start a bladder cancer patient group in your country, visit our website to learn more and get in touch with us directly.

In 2020, we welcomed two new organisations to our coalition, Bladder Cancer Norway and Campaigning for Cancer from South Africa.







Cancer Vessie France



We encourage you to get in touch with us, so we can get to know each other and find ways to collaborate, exchange knowledge and for your organisation to join our international coalition.

Alex Filicevas EXECUTIVE DIRECTOR



Bladder Cancer Awareness Month

Each year, a core pillar of our advocacy and awareness-raising efforts is hosting the World Bladder Cancer Awareness Month in May, together with our members and partners worldwide.

Bladder Cancer Awareness Month in May 2020 was particularly important, as we were caught up in the early stages of the global pandemic. Despite the challenges presented, together with the community, we continued the conversation about bladder cancer. We helped to guide those affected to sources of support and information, such as our member organisations. We are proud of our collective achievements in 2020 through the awareness-raising activities and our campaign assets reaching audiences in Arabic, English, French and Spanish languages across the world.

Our online campaign reached over 1 million people

- Globally people and organisations joined the conversation using campaign hashtags, with a reach of over 16 million people;
- **Over 5,400** posts were shared on Twitter alone using the campaign hashtags;
- Our campaign was more global than ever reaching 18 countries in 5 world regions.

Our online campaign, The Bladder Cancer Digital World Tour, focused on bringing attention to the impact of bladder cancer in different countries across the world, sharing key data and signposting those affected to the support available in the country. We also encouraged the establishment of bladder cancer patient groups in countries where support was lacking or sometimes non-existent.

During this period, WBCPC Twitter followship grew 200%, and LinkedIn saw an increase by 36%, while a newly launched Facebook page grew exponentially, reaching the current number of 1,739 followers.

Globally people and organisations joined the conversation using campaign hashtags, reaching over 16 million people. Over 5,400 posts were shared on Twitter alone, using campaign hashtags **#BladderCancerAware** and **#BladderCancerAwarenessMonth**, including those in French, Spanish and Arabic languages. The World Bladder Cancer Patient Coalition campaign in 2020 was more global than ever – reaching 18 countries in 5 world regions.



We developed a **Campaign Action Toolkit** containing a range of campaign resources in Arabic, English, French and Spanish and were used by our members and partners worldwide.



World Bladder Cancer Patient Coalition Virtual Annual Meeting 2020

Putting bladder cancer on the global health policy agenda

The Annual Meeting of the World Bladder Cancer Patient Coalition is the only global gathering for the bladder cancer patient community. The meeting serves as a platform for exchanging knowledge, developing new ideas, and fostering collaboration. Whilst the global pandemic prevented our community from meeting in person, the WBCPC 2020 Virtual Annual meeting brought together over 100 participants from 25 countries on September 22nd.



Participants from the community explored the challenges of: including patients' voices in research design, how to best build communities across clinical, patient and industry groups, and how to encourage the creation of effective patient organisations in every country to support people affected by bladder cancer. For many, a littleknown fact about the global landscape for cancer research, treatment and care is that bladder cancer is one of the most common conditions. They are in the top 10 of the most frequently diagnosed cancers worldwide and rank 4th and 5th in North America and Europe.

While people living with breast, lung, colorectal and prostate cancers are supported by well-connected patient advocacy networks and global campaigns, it's curious to see that bladder cancer is not on many countries' public health radar. These patients generally have fewer options for support and advice. Despite the serious global incidence of this condition, most countries today do not have a bladder cancer patient organisation or support group.



Explore the event report, which is organised around three themes that drive the WBCPC strategy: Building Community, Raising Awareness, and Engaging in Advocacy. It ought to be a resource that shares practical know-how, approaches, practices,

and ideas to support those building or strengthen bladder cancer patient groups in their country.

In the words of World Bladder Cancer Patient Coalition Founding President **Ken Bagshaw**, the founders' motivation for creating our new international organisation in 2019 was driven by:

"... the near-total absence of support for most people affected by bladder cancer worldwide. The WBCPC aims





World Bladder Cancer Patient COAL LITION

WBCPC 2020 -

Annual Meeting of the World

utting bladder cancer

Start-up guide for bladder cancer patient groups

Bladder cancer patient groups, small and large, have an essential role in improving the situation for patients and their families. We have a vision for a bladder cancer patient group in every country, and we are here to support them every step of the way. Fostering a global community of strong patient advocates is what drives our work every day.

The voice of the World Bladder Cancer Patient Coalition is only as strong as its members' commitment to the life of the association, and we foster our community so that:

- There is a national bladder cancer patient organisation in each country
- National bladder cancer patient organisations are strong enough to support people affected by bladder cancer, enhance awareness and advocate for better diagnosis, access and care

When establishing a bladder cancer patient group, there are so many things to consider, and it can be challenging to know where to start. Recognising this, we are proud to have launched a **Start-up guide for bladder cancer patient groups** in English and Spanish languages in 2020 for anyone with ambitions to start a bladder cancer patient group in their country.

WBCPC members considered their own experiences in starting bladder cancer groups and combined their collective knowledge in this guide.

We launched a promotional video shared across social media to reach target audiences, featuring Dr Peter Black, Dr Lydia Makaroff and Andrea Maddox-Smith, which was featured at the WBCPC Virtual Annual Meeting as well.

"It is critical that bladder cancer organisations mobilise to ensure better treatment outcomes for bladder cancer patients. Groups large and small have a role to play in driving change in their communities and the World Bladder Cancer Patient Coalition is here to help grow, connect, and support these groups with their journeys."



Andrea Maddox-Smith, Vice-President of the World Bladder Cancer Patient Coalition; and CEO of BCAN.

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.



Website - our brand-new home online

In November 2020, we launched the new World Bladder Cancer Patient Coalition website at worldbladdercancer.org

Our new home online is the first step towards our ambition to become a global go-to resource for people affected by bladder cancer, our members, partners and stakeholders. As a place where we can showcase our impactful work and strengthen bladder cancer patient voice, it is the first stop from which we hope to signpost bladder cancer patients to credible information and support groups closer to them. As we continue to develop the website content, we will also focus on providing information and education for unrepresented or under-represented countries where there are no established bladder cancer patient organisations on the ground right now.

The new website provides essential information about the organisation, our mission, vision and ambitions, and our commitment to transparency. Our resource hub will be a focal centre for our members as we develop assets and materials for their use at the national level, which we aim to provide in different languages. We developed educational web pages on bladder cancer patient information, supported by our member organisations' information. We will further expand the topics in this section as we move forward.

The worldbladdercancer.org

received 4,579 visitors in 2020, with a quarter of the visits since the new website's launch on November 18th, 2020. Our visitors came from a wide range of countries, which showcases a broad global reach of WBCPC.



Bladder cancer newsletter

The World Bladder Cancer Patient Coalition's monthly newsletter, launched in 2019, has steadily grown to become a trusted resource for our member organisations, stakeholders and other interested parties with information on bladder cancer awareness, advocacy and research at the international level.

Our highly engaged audience has more than doubled in the past year and continues to grow with an ever more global reach.

In 2020, we delivered 12 issues of the monthly newsletter, sending 2633 mailings to our audience, which has doubled over the course of the year to 303 subscribers. We are confident with our audience's steady growth and engagement with an average click-through rate of 30%. As we publish more content via the new World Bladder Cancer Patient Coalition website and expand into new regions and build new partnerships, the newsletter will continue to be an essential engagement platform for the organisation.





WBCPC 2nd General Assembly 2020

Despite the challenges and travel restrictions, our member organisations came together for the WBCPC 2nd General Assembly meeting online. We've reviewed the activities and performance of the World Bladder Cancer Patient Coalition in its first year. Looking ahead, our members discussed developing plans for 2020 and 2021 to support bladder cancer patients worldwide especially in light of the COVID-19 pandemic. We thank our member organisations for their active participation and commitment. The supportive and collaborative nature of our coalition inspired us and led us through the year 2020 with resilience and ambition to support and advocate for people affected by bladder cancer.



Advocacy & capacity building

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 at the policy level to drive concrete change.

The global pandemic has presented many challenges in undertaking advocacy activities in 2020, and we adapted in response. The World Bladder Cancer Patient Coalition has focused the strategy on establishing and building relationships with international organisations, which could elevate our advocacy priorities through collective activities.

Facing COVID-19 challenges

GCCN REPORT

In light of the pandemic, the World Bladder Cancer Patient Coalition joined forces with 8 other cancer patient advocacy groups, together representing over 750 cancer patient advocacy and support organisations working on behalf of over 14 million patients worldwide. The network, now called GCCN - Global Cancer Coalitions Network, came together to share experiences and best practice, a process they found invaluable during the pandemic and one they plan to continue.

Together we published a cancer patient advocacy organisation survey report on the COVID-19: Impact on Cancer Patient Organisations Worldwide in 2020 in June, and issued a joint statement on COVID-19 and cancer. A followup survey was conducted in December, with the results launch in 2021. Nearly six in ten organisations who provide support services for patients have seen an increase in the number of calls and emails, with an average increase of **44%**

Global Cancer Coalitions Network, 2021

ADVOCACY EXCHANGE

We joined the COVID Advocacy Exchange launched by GRYT Health with Bristol Myers Squibb – a platform to unite advocacy organisations, patients and industry in the exchange of information at a time of the global pandemic. The World Bladder Cancer Patient Coalition joined the weekly panel discussions with other advocates. In the virtual exhibition hall, amongst other global patient organisations, you can find the World Bladder Cancer Patient Coalition.

BLADDER CANCER & COVID

On our website, we've hosted the **Bladder Cancer & COVID-19 hub**, collecting information and resources from our member organisations, many of which addressed patients' questions on a regular basis. All the resources and the information was available to anyone who needs it, regardless of where they live.

SOCIAL MEDIA CAMPAIGN

In recognition of everyone fighting for our good health and keeping the world running, the World Bladder Cancer Patient Coalition launched a social media campaign in April in partnership with member organisations and in several languages. Sharing messages of support for healthcare and key workers, all those who #StayHome to protect themselves and those around them!

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EXPERT WEBINAR

In April, together with Bladder Cancer Advocacy Network (BCAN), we hosted a webinar with experts from MD Anderson discussing the BCG and COVID-19.

EUROPEAN COMMISSION

On February 4, the European Commission held a conference "Europe's Beating Cancer Plan: Let's Strive for More" to launch its commitment to cancer control. The meeting was attended by WBCPC Executive Director Alex Filicevas (seen in the photo below with a group of patient advocates & stakeholders).



UNION FOR INTERNATIONAL CANCER CONTROL

The World Bladder Cancer Patient Coalition became a full member of the Union for International Cancer Control (UICC), a strategic partnership for capacitybuilding, outreach and partnerships at international level.

ALL.CAN

The World Bladder Cancer Patient Coalition has joined the All.Can International initiative focused on reducing inefficiencies in cancer care across the world. The organisation is represented by Alex Filicevas, Executive Director, who also serves as the All. Can International President. A strategic partnership allows the World Bladder Cancer Patient Coalition to expand the stakeholder network internationally and contribute to the policy engagement at the EU level, bringing bladder cancer patient perspectives.

SIU PARTNERSHIP

The World Bladder Cancer Patient Coalition has signed a Memorandum of Understanding with the SIU - Société Internationale d'Urologie, paving the way for a formalised relationship. The World Bladder Cancer Patient Coalition for the first time had the virtual booth at the SIU40 congress. It was an opportunity to present the organisation to a global community of urologists, showcase our global mission and work to date. It followed by our participation at the SIU Bench2Bedside educational webinar series. In 2021, the partnership will extend into more areas, including Start-up guide dissemination, awareness month and education.



Bladder cancer facts



BLADDER CANCER INFOGRAPHIC

We published a Bladder Cancer Facts infographic. It highlights the key data from a global perspective and facts about bladder cancer. It is available to download for everyone and can be disseminated online, or be printed out.

Get your copy via this link.

CODE OF CANCER PRACTICE

The World Bladder Cancer Patient Coalition has also joined the Patient Advisory Committee of the European Cancer Organisation and has endorsed the European Code of Cancer Practice. This partnership allows us to feed into the strategic policy work of the European Cancer Organisation and represent bladder cancer patients' interests at the European Union level in collective policy activities.

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ECONOMIST WORLD CANCER SERIES



In November, then WBCPC Vice-President (now President) Dr Lydia Makaroff joined the panel **How to achieve better outcomes** for patients at the Economist World Cancer Series Europe 2020 week of events. Speaking at the event, Lydia stressed the urgent need to focus health investments on what matters to patients and involve patients right from the start when conducting research and look to reduce inefficiencies in cancer care.

WORLD HEALTH ORGANISATION

The WBCPC has participated in the World Health Organisation (WHO) informal consultation on people living with NCDs in 2020, with WHO experts and over 100 participants from civil society organisations, patient groups and people living with NCDs. The collaborative meeting focused on creating meaningful engagement opportunities for PLWNCDs within the workstreams of the WHO. This was the first engagement with the WHO, and the WBCPC will build on this to expand collaboration opportunities. More information about the meeting is available via this link.

2020 CONGRESSES

In 2020, the WBCPC attended leading oncology and urology congresses, including ASCO20, EAU20, ESMO20, SIU40, IBCN Annual Meeting, European Cancer Forum, ESMO Asia 2020, UAA2020, European Multidisciplinary Congress on Urological Cancers, European Cancer Summit,



European Health Forum Gastein. These are particularly important, as it allows the organisation to stay up to date with the scientific developments in the field of bladder cancer, share and discuss it within the community. The World Bladder Cancer Patient Coalition has offered financial grants to cover the attendance fees for the EAU20 Virtual Congress to all its member organisations.

MAPPING BLADDER CANCER PATIENT ORGANISATIONS

In 2020, the WBCPC started the global mapping of bladder cancer patient organisations, completing an overview of Latin America, North Africa and Sub-Saharan Africa region, with Asia-Pacific, planned for 2021. This exercise has allowed the WBCPC to identify key focus countries in these regions, on which to focus outreach and stakeholder partnerships in addition to Europe, as part of our strategy of fostering bladder cancer patient communities and establishment of bladder cancer patient groups.

Financials

The 2020 unaudited financial results were approved by the Board of Directors and member organisations at the 3rd World Bladder Cancer Patient Coalition General Assembly, which took place on June 8th, 2021.

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

Summary of revenue and expenses for 2020

For the Financial Year 2020, the revenue of the World Bladder Cancer Patient Coalition aisbl (association internationale sans but lucratif) amounted to a total of €314.215,37.

The organisation's operating costs, including employee costs, office costs and the external costs related to the implementation of planned projects, amounted to a total of €216.165,75. Leaving a positive year-end balance of €98.079,62.

In 2020, all the funding received was in the form of sponsorship, grant, engagement specific remuneration and reimbursements from industry partners.

	2020 (AMOUNT IN €)	2019 (AMOUNT IN €)
SOURCE OF REVENUE		
Industry sponsorship	€ 307.622,00	€ 215.618,50
Other income	€ 6.593,37	€ 842,49
TOTAL REVENUE	€ 314.215,37	€ 216.460,99
OPERATING EXPENSES		
Staff costs	€ 84.616,05	€ 17.893,09
Management & running costs	€ 32.937,14	€ 30.154,00
Board expenses	€ 793,93	€ 2.416,83
Project costs	€ 97.848,63	€ 36.253,66
TOTAL EXPENDITURE	€ 216.195,75	€ 86.717,58
BALANCE	€ 98.019,62	€ 129.743,41

Industry support contributions received in 2020

Industry support consisted of Premier Partnerships with Ferring and Astellas – Seagen Alliance towards the support of the overall mission of the organisation and project-specific sponsorship and grants from other sponsors to directly support the implementation of various projects.

	AMOUNT IN €	PERCENTAGE (%)
REVENUES FROM INDUSTRY SUPPORT		
Astellas / Seagen (Premier partnership)	€ 60.000,00	20%
AstraZeneca	€ 30.000,00	10%
Bayer	€ 10.000,00	3%
Bristol-Myers Squibb	€ 22.622,00	7%
Ferring (Premier partnership)	€ 60.000,00	20%
lpsen	€ 20.000,00	7%
Janssen	€ 20.000,00	7%
Merck Sharp & Dohme	€ 20.000,00	7%
Merck KGaA	€ 17.500,00	6%
Pfizer	€ 17.500,00	6%
Roche	€ 30.000,00	10%
TOTAL INDUSTRY SUPPORT REVENUE	€ 307.622,00	100%

Operating costs and expenditures in 2020

	2020 (AMOUNT IN €)	2019 (AMOUNT IN €)
STAFF COSTS	€ 84.616,05	€ 17.893,09
Remuneration	€ 67.155,80	€ 14.546,68
Social security contributions	€ 224,51	€ 50,99
Other employee costs	€ 9.098,35	€ 3.581,00
Tax provision for holiday pay	€ 8.912,24	_
Recup. Withholding tax	- € 774,85	- € 285,58
MANAGEMENT & RUNNING COSTS	€ 32.937,14	€ 30.154,00
Association Management	€ 0,00	€ 18.537,87
Office costs	€ 7.601,61	€ 1.367,91
Telephone/Internet	€ 1.245,25	€ 215,52
Depreciations on IT	€ 849,23	€ 849,23
IT maintenance	€ 0,00	€ 249,00
Insurance costs	€ 995,29	€21,85
Congress & Events	€ 180,00	€ 652,22
Subscription fees	€ 3.278,00	€ 208,45
Legal fees	€ 4.073,82	€ 1.146,20
Accountant fees	€ 5.505,50	€ 2.843,50
Bank costs	€ 793,80	€ 296,87
Payroll services & fees	€ 3.339,01	€ 2.423,33
Advertising & Marketing	€ 5.075,63	€ 1.342,05

	2020 (AMOUNT IN €)	2019 (AMOUNT IN €)
BOARD	€ 793,93	€ 2.416,83
Board travel	€ 793,93	€ 2.416,83
PROJECT COSTS	€ 97.848,63	€ 36.253,66
Annual Meeting	€ 30.387,34	€ 21.606,45
Awareness Month	€ 56.401,67	€ 7.253,13
Website	€ 6.256,71	€ 2.444,08
Toolkit	€ 4.669,29	€ 4.950,00
Newsletter	€ 133,62	-
TOTAL OPERATING COSTS	€ 216.195,75	€ 86.717,58

Balance sheet

on December 31st 2020, in euros.

These figures, as presented, represent a summary of financial statements of the World bladder Cancer Patient Coalition. A more detailed financial statements for 2020 are available in the Financial Report 2020 on the organisation's website at worldbladdercancer.org

	2020 (AMOUNT IN €)	2019 (AMOUNT IN €)
ASSETS		
Fixed assets	€ 21.720,72	€ 1.698,72
Intangible assets	€ 20.871,23	€ 0,00
Tangible assets	€ 849,49	€ 1.698,72
Current assets	€ 251.833,91	€ 130.511,88
Amounts receivable within one year	€ 339,19	€ 1.314,39
Current accounts	€ 251.402,65	€ 129.108,46
Deferred charges	€ 92,07	€ 89,03
TOTAL	€ 273.554,63	€ 132.210,60
Capital & reserves	€ 227.763,03	€ 129.743,41
Profit carried forward	€ 129.743,41	€ 129.743,41
Balance	€ 98.019,62	€ 0,00
Amounts payable	€ 45.791,60	€ 2.467,19
Amounts payable within one year	€ 20.791,60	€ 2.467,19
Accrued charges & deferred income	€ 25.000,00	€ 0,00
TOTAL	€ 273.554,63	€ 132.210,60

Our partners and sponsors

Our partners

We are delighted to be working with a 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 supported us throughout 2020.

You can find us here:

Twitter:	@WorldBladderCan
Facebook:	WorldBladderCan
Website:	worldbladdercancer.org
Email:	info@worldbladdercancer.org
YouTube:	Search World Bladder Cancer
	Patient Coalition

World Bladder Cancer Patient Coalition

Square de Meeûs 38-40 1000 Brussels Belgium Reg. Number: 0720.618.047



World Bladder Cancer Patient COALITION

Thank you to all our member organisations, partners, sponsors and supporters.