



World Bladder
Cancer Patient
COALITION

Know the basics:

**A start-up guide for bladder
cancer patient groups**

Updated January 2025

Table of contents

Foreword	1
Our story	2
Bladder cancer facts	3
The importance of national bladder cancer patient groups	4
Steps for building up to a national bladder cancer patient group	12
Engaging with others to maximise your impact	16
Communicating about your group	18
Bladder cancer awareness month	20
How the world bladder cancer patient coalition can support you	22
Resources	23

Foreword

by Lori Cirefice

*Board of Directors at the World Bladder Cancer Patient Coalition;
and President of Cancer Vessie France*



On behalf of the World Bladder Cancer Patient Coalition, I'm excited to share this start-up guide with you which has been developed in collaboration with our members.

Bladder cancer groups across the globe, small and large, have an important role to play in improving the situation for patients and their families. It is our vision to establish a bladder cancer patient group in every country. We still have a long way to go, but we have started to make strides in the right direction.

There are so many things to consider when establishing a bladder cancer patient group, and it can be difficult to know where to start. Recognising this, we developed this guide for anyone with ambitions to start a bladder cancer patient group in their country. We have considered our own experiences in starting bladder cancer groups, and have combined our knowledge, tips and tricks for you in this guide.

We hope that this guide allows us 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

We sincerely hope that you are able to find helpful and practical information here to guide you on your way to establishing or growing a bladder cancer patient group in your country. Thank you for helping us win the fight against bladder cancer.

Sincerely,

Lori Cirefice

Our story

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

This coalition symbolizes the first time that people affected by bladder cancer have a force connecting bladder cancer patients, groups, and organisations worldwide.

The WBCPC now brings together a growing number of patient groups from all continents, uniting the vision and goals of bladder cancer patient groups to ensure the best possible outcomes for patients around the world.



“We hope that this guide will help kickstart bladder cancer patient groups, by providing them with the information we wish we had had when starting our own national groups. In addition, the people and resources of the World Bladder Cancer Patient Coalition will be there to help and guide you as needed.”

*Ken Bagshaw, Bladder Cancer Canada,
Founding President of the World Bladder
Cancer Patient Coalition*

Ultimately, our mission is to:



Foster an international community of people affected by bladder cancer



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



Build alliances with health professionals, policy makers, researchers, academics, and industry



Bladder cancer facts

Worldwide

Bladder cancer is the

9th most common cancer¹

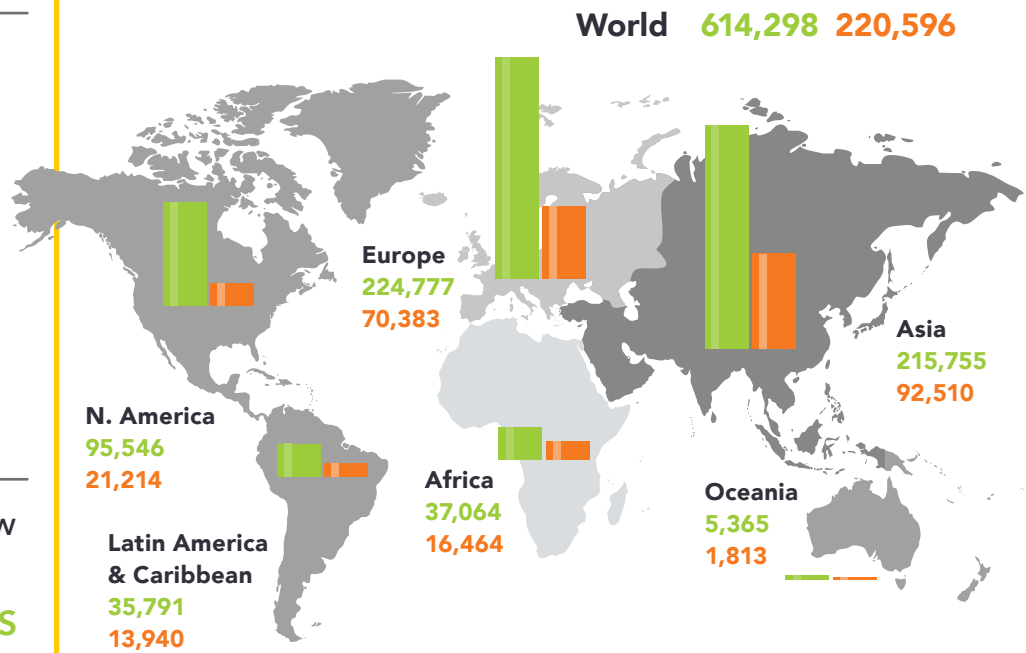
leading cancer-related cause of death¹
13th

The latest figures show

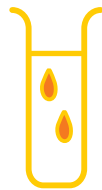
614,298 NEW CASES diagnosed and

220,596 DEATHS in 2022 alone¹

More than **60%** of cases and **50%** of all deaths occur in less developed countries²



Main symptoms



Blood in urine³



Frequent urination or pain when urinating^{3,4}



Abdominal, lower back & pelvic pain^{3,4}



Repeated urinary tract infections⁴



Incontinence⁴



Tiredness⁴



Weight loss⁴

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1. International Agency for Research on Cancer (IARC) 2022. Bladder. Online
2. Antoni S, Ferlay J, Soerjomataram I, et al. 2017. Bladder Cancer Incidence and Mortality: A Global Overview and Recent Trends. European Urology 71(1): 96-108
3. Mayo Clinic. 2019. Bladder cancer. Available from: <https://www.mayoclinic.org/diseases-conditions/bladder-cancer/symptoms-causes/syc-20356104>
4. Fight Bladder Cancer. 2020. Symptoms.

Main causes



Smoking and other tobacco use³



Past radiation exposure³



Chronic bladder inflammation³



Exposure to chemicals, especially at work³



Parasitic infections³

It is not always clear what causes bladder cancer, and some people can be diagnosed without having had exposure to any of the listed causes.



The importance of national bladder cancer patient groups

Patient groups have a unique and important role to play in the fight against bladder cancer. There are many different ways that patient groups can have a positive impact.

Advocate
for access to the best possible information, support, treatment & care

Raise awareness
about bladder cancer, its causes, & treatments

Contribute to preventing the disease (smoking, occupational exposure to toxins, etc)

Provide peer support or services through information provision, guidance, & facilitating contact with other bladder cancer patients & survivors



Advance and fund research into bladder cancer treatment & care

Participate in national HTA discussions and ensure patient perspective is included in decisions about reimbursement of diagnostics, treatments & care

Build strategic alliances with governments, policymakers, healthcare professionals, academics, researchers & industry

Advocate to national authorities for policy changes that are meaningful to patients & their families

Your role may include one, some or all of the above – it is important to find the role(s) that best support the bladder cancer patient community in your country.

On the next pages, we have gathered inspirational case studies from our member organisations to showcase the work that they have done around the world. We hope this will help to stimulate ideas about the kind of activities you can organise.

Case studies

Dive into 5 case studies from our global community. Learn from their challenges and triumphs to guide your journey. We hope their stories will inspire you as much as they have inspired us.



Creating an awareness-raising poster in France	7
Organising an annual bladder cancer walk in Canada	8
Setting up an online support forum for people affected by bladder cancer	9
Guiding patients to better care: The success of Uro H Advisor	10
How we built CANVES – Spain’s first bladder cancer support group	11



Case study 1:

Creating an awareness-raising poster in France

By **Lori Cirefice**, Cancer Vessie France, member of the World Bladder Cancer Patient Coalition



In May 2019, Cancer Vessie France developed an awareness poster about the signs and symptoms of bladder cancer, considering the surprising lack of awareness around bladder cancer compared to other common cancers in France.

Members volunteered to help develop the poster, and a small working group was created to manage the development and drafting of the awareness poster. Feedback was received on drafts from the larger membership, and once we had a final version, we also sense checked the content with our supporting urologists to ensure that our poster was scientifically sound.

We learned some interesting things along the way that may be helpful to other groups. First, we found out that it is not an easy task to manage photo rights, and we paid for the use of several images that we included on the poster (even the blood splatters!), but the payments were based on the number of printed copies and impressions we would get on the poster, and at that point in our poster development we had no idea how many we would print. The whole process was much more time-consuming and complicated than we anticipated.

Second, we also contacted different municipalities in France asking them to display our poster, either on their municipal website, or their municipal digital information boards. We were delighted to receive so many positive replies; however, it turned out that each municipality needed a different format of the poster, which ended up being very time consuming for our volunteers to create. We also hadn't set aside any budget to buy shipping supplies and postage to send paper copies across the country, so in the end the costs greatly surpassed our available funds for the project.

Creating the awareness raising poster was a great learning experience for us. In the end, we were very satisfied with the visual impact of the poster, and our social media campaign was a great success. Going forward, we will reuse this poster for our 2020 campaign, and we will know how to manage the budget much better this time. In hindsight, we would have started our project earlier, and better defined the budget and goals upfront.

You can download a copy of the awareness poster [here](#).



"Creating the awareness raising poster was a great learning experience for us. In the end, we were very satisfied with the visual impact of the poster, and our social media campaign was a great success."

Case study 2:

Organising an annual bladder cancer walk in Canada

By **Michelle Colero**, Bladder Cancer Canada, member of the World Bladder Cancer Patient Coalition



Each year at Bladder Cancer Canada (BCC) we organise a country-wide awareness raising walk for bladder cancer. Awareness walks are widely adopted by patient charities and they serve to bring people associated with the particular disease together; to encourage walkers to raise funds by collecting donations from family, friends and colleagues; and to raise awareness about the disease through media publicity about the walk and presence of walkers in the streets and parks.



"Today, there are 20 walk sites in different cities across Canada and each year we raise nearly \$600,000 to fund our activities."

BCC was founded in 2009 and held its first walk in May 2010 in the cities of Toronto and Calgary. We were able to gather 60

participants and raise \$25,000 through walkers' contributions and funds raised by them inviting close family and friends to sponsor them.

Before hosting our first walk, we moved quickly to get incorporated as a non-profit organisation in Canada and to obtain government accreditation as a charity. This enabled us to provide our donors with official tax receipts (for tax deductions) and can really make the difference between someone deciding to donate or not.

As BCC became better known over the years, the walks expanded and by 2013, our walks took place in 14 locations and raised \$400,000. Most of the funds came in through online donations driven by the walkers setting up their own personal fundraising pages (provided by BCC). Today, there are 20 walk sites in different cities across Canada and each year we raise nearly \$600,000 to fund our activities.

In the early years of organising the walks, BCC was largely dependent on the funds raised as our primary source of income. As we've grown and matured, our funding base has broadened significantly through corporate supporters, fundraising campaigns based on awareness month and year-end giving, sustaining donors and legacy giving. Nevertheless, the walk has been, and will continue to be, a very important annual activity for us!



Case study 3:

Setting up an online support forum for people affected by bladder cancer

By *Lydia Makaroff*, Fight Bladder Cancer, member of the World Bladder Cancer Patient Coalition



Fight Bladder Cancer UK started from a very personal battle. Andrew, one of our founders, was diagnosed with a Stage 4, G3 bladder cancer in summer 2009. He had been experiencing symptoms for over 18 months but was misdiagnosed with an enlarged prostate. Faced with a poor prognosis and immediate life-changing surgery, Andrew and his wife T made contact with a fellow bladder cancer patient and his partner who had recently undergone the same treatment.

“The group slowly grew from 40, to 400, to almost 5000 members. Now we have a team of 10 moderators from around the world who monitor the pages and provide support to everyone who posts.”

Just being able to talk to someone else who really understood what they were both going through helped them immensely. It also helped that the two carers could chat about what could be expected during surgery and recovery. It was these snippets of real information that made a difference in those early days. Despite the fact that bladder cancer was so common, they were amazed to find out that most people knew nothing about it, and there wasn't a dedicated bladder cancer charity in the UK yet.

Once Andrew was recovering from his surgery, they started the process of setting up what was to become the charity Fight Bladder Cancer UK.

Firstly, we set up a Facebook Page called Fight Bladder Cancer. Then on 2 June 2010 we used that page to set up a private group called “Fight Bladder Cancer: Support”. The group slowly grew from 40, to 400, to almost 5000 members. Now we have a team of 10 moderators from around the world who monitor the pages and provide support to everyone who posts.



It is a wonderful resource for anyone affected by bladder cancer. They can post trials and tribulations, and instantly receive support from others around the world who have gone through a similar experience.



Case study 4:

Guiding patients to better care: The success of Uro H Advisor



By **Eduardo Fiorini**, member of the World Bladder Cancer Patient Coalition

Three years ago, Associazione PaLiNUro created Uro H Advisor, a platform inspired by TripAdvisor, to guide bladder cancer patients in choosing the hospital that is best suited for them. For those recently diagnosed, making the right decision about care can be overwhelming, so we aimed to give patients access to practical information about hospitals known for their experience and reputation in bladder cancer treatment and care.

We faced several challenges in launching the project, particularly with funding and setup. Initially, our main issue was selecting a software company that failed to deliver on their promises. Eventually, we found the right support and secured funding from a pharmaceutical partner. Although building the platform took longer than anticipated, it has now become a valuable resource that meets our goals.

“We’re excited to see the reviews grow because each one helps one more patient to feel supported and informed. The more voices we collect, the stronger this tool becomes.”

Over the past two years, we have gathered more than 450 reviews of hospitals across Italy - each from a patient directly connected to PaLiNUro. We carefully check all reviews before publishing to ensure they reflect genuine patient experiences. This information is not only helpful for patients but also offers hospitals and doctors a useful tool to evaluate the quality of care they provide with a view of improving.

As Uro H Advisor grows, with more reviews and more hospitals throughout Italy, we see it becoming a comprehensive resource for patients and healthcare providers alike. The platform now includes details on hospital experience with bladder cancer surgeries (e.g. volume of bladder removal surgeries per year), lists of doctors, and soon, will include information on clinical trials. We’ve designed it so other organisations can adapt it for other medical conditions, extending this benefit to even more patients in need of guidance.

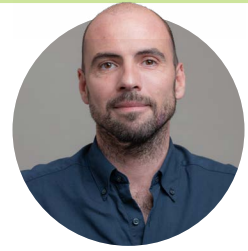
Although some voiced concerns that doctors might object to this tool, we’ve found that the response has been positive so far. The platform recognises those delivering high-quality care, which most doctors appreciate. Raising awareness about Uro H Advisor remains a challenge and we rely on hospital visits, social media, and direct patient outreach to get the word out.

Collaboration with doctors, hospitals, and pharmaceutical companies has been essential to our success. These partnerships provide us with up-to-date insights into treatment options, medical devices, and the latest therapies, all of which are vital for empowering patients to make informed decisions about their care. By working closely with healthcare providers and industry experts, we ensure that Uro H Advisor remains a reliable, comprehensive resource that reflects real advancements in bladder cancer treatment. This cooperation enriches our platform, ensuring patients are well-informed when choosing their care.



Case Study 5:

How we built CANVES – Spain’s first bladder cancer support group



By **Laurent Gemenick**, member of the World Bladder Cancer Patient Coalition

When I was first diagnosed with bladder cancer, I felt isolated and overwhelmed. There was so little information available, and I soon realised that there wasn't a dedicated support network for patients like me in Spain. It was a frightening time, but I knew I couldn't be the only one feeling this way. That is when the idea for CANVES (Alianza por el cancer de vejiga en España) was born - out of a need to connect patients, offer support, and raise awareness about bladder cancer.

Together with my husband, the first thing we did was reach out to other organisations for guidance. We connected with Cancer Vessie France and the World Bladder Cancer Patient Coalition (WBCPC), and that is when things started to take shape. WBCPC Start-Up Guide for bladder cancer patient groups was really helpful in outlining the steps to get CANVES started. It gave us a clear roadmap, from defining our vision, to gathering volunteers, to securing funding. This guide became our foundation, ensuring that we were building something helpful and impactful.

We knew we wanted CANVES to be a national organisation. Bladder cancer is the fourth most frequent cancer among men in Spain, with over 23,000 new cases diagnosed annually. The need was great, and we were determined to meet it. We decided early on that we wanted to provide more than just medical information, we wanted to offer emotional and practical support as well.

One of the key turning points for us was joining the World Bladder Cancer Patient Forum. Meeting other patient advocates and learning from their experiences was inspiring. We realised that we were part of a larger community and could build on what others had already done. The Forum allowed us to connect with experts like Dr. Ignacio Durán, whose collaboration was instrumental in establishing CANVES. The relationships we built at the Forum strengthened our resolve and gave us the tools we needed to succeed.

Launching CANVES came with its challenges, particularly in securing funding and raising awareness. However, we quickly learned that collaboration was essential. Building connections with doctors and healthcare professionals boosted our credibility, and partnering with organisations like WBCPC gave us access to valuable resources and expertise that we lacked.

Today, CANVES is a new and growing network, offering vital support to patients and their families, raising awareness, and working to improve outcomes for bladder cancer patients across Spain. If there's one thing I've learned from this journey, it's that you do not have to do it alone. The resources, connections, partnerships, and support are out there - you just have to reach out and take the first step.

“The Start-Up Guide showed us the way, but it was the support and encouragement from the global bladder cancer community that truly inspired us to push forward. We realised we were part of something bigger - a global effort to make a difference for bladder cancer patients around the world.”

Steps for building up to a national bladder cancer patient group

This section provides an overview of steps you should consider when setting up a bladder cancer patient group, growing an existing one, or seeking to become national in stature.

1. Define your vision

Define your vision early on.

This will help guide everything you do, from the projects you will take on, to the expertise you will need on your leadership team and the people you should work with along the way.

Before committing to your group's vision, research existing bladder cancer patient groups in your country, and region, and identify any unmet needs of patients that still remain. Brainstorm how you can meet the needs of patients in your country through your vision and try to avoid duplicating the valuable work of existing bladder cancer patient organisations.

>> For more guidance, see *'The importance of national bladder cancer patient groups'* and *'Resources'*.



TOP TIP:

"In my experience, it is extremely helpful to consider several questions before establishing a bladder cancer patient group. Ask yourself: **Who do you want to be? What will your main focus be** (i.e. information, support, etc)? **What is your mission? What activities will you do? What actions will you need to take to achieve your aims?"**

Laura Magenta,
Associazione PaLiNUro,
member of the World
Bladder Cancer
Patient Coalition



2. Gather volunteers

You will need to build a small team of supporters to get things off the ground. It is common for newly established groups to run solely based on volunteers in the beginning who are typically patients, caregivers to patients and others with a link to bladder cancer.



Further volunteers can be found through your doctor, hospital, clinic, online or national cancer charities. For example, we have seen cases where a urologist introduced two of his patients who then went on to become the founding partners of a vibrant national bladder cancer patient group in Canada.

Typically, some, or all of the group's founding volunteers will fill the board of directors' positions and guide the group's strategic decisions and direction. They will also take on the operational duties and carry out day-to-day activities.

As your group becomes more and more established, and can secure consistent funding, then you may want to consider hiring staff to take on the core management and administrative roles in place of volunteers. This typically comes at a much later stage of development.



3. Connect with your volunteers & members

Once you have an initial group of volunteers, consider creating an online platform for people to interact with each other, for example, on Facebook or WhatsApp, or your local equivalent if those are not popular or available in your country.



This will allow you to share important information, build a community, and keep people engaged in your vision and ongoing activities.

>> For more information, see [‘Communicating’](#).

“Consider creating and launching an online platform for people to interact with each other, for example, on Facebook or WhatsApp”

4. Organise your first meeting



Once you have successfully defined your vision, gathered a dedicated team of volunteers, and started communicating with your group, it is time to plan a first meeting to serve as a platform for exchanging knowledge, developing new ideas and fostering collaboration.

Consider hosting an in-person meeting offering your volunteers the chance to meet each other. You could meet in a local café, library or community centre which would not add to your costs. Reflect on your past activities, plan for the year ahead, gather input from your volunteers, ask for their opinion, and engage them in discussions. For those who cannot attend in person, consider hosting it virtually on a free conferencing service like [Zoom](#), [Skype](#), [Microsoft Teams](#) or [Google Hangouts](#).





5. Grow & formalise your membership



Initially, it is likely that your membership will consist of individual volunteers whom are dedicated to the cause and will help your group become more established.

Once you feel ready, you may wish to reach out to other organisations, policymakers, academics, etc, with an interest in bladder cancer and explore opportunities for collaborating. Aim to attract a wide array of different members who can bring unique perspectives to your discussions.

As your volunteer base grows, you may want to formalise your membership structure. Consider creating membership tiers, with varying levels of participation options and associated benefits.

However, in the start-up phase you will probably want a simple membership structure with only one class of members. It is also common for more established groups to consider a membership fee and formal application process for joining.

>> For more ideas, see *'Engaging with other to maximise your impact'*.

“Aim to attract a wide array of different members who can bring unique perspectives to your discussions.”



6. Create a legal organisation



After you have become more formalised and established, you may wish to legally register your organisation to get charitable status, to receive formal recognition for engagement with government bodies and other legal entities. This process will vary depending on your country, and we advise you to check the requirements locally, but it would typically include:

- **Register as an unincorporated or incorporated non-profit society or organisation**, whichever structure exists under domestic law in your country. For most countries, incorporating your non-profit is required for getting tax-exempt status, accepting donations, and having limited liability.
- **Create governing bylaws to guide your organisations operations.** These should outline your staff and leadership team roles, your mission statement, donations protocols, membership structure, decision-making process, procedures for amending bylaws, and financial reporting

One of the main advantages to legally incorporating your non-profit is that it helps with fundraising. A legally incorporated entity customarily is needed to allow for charitable donations and corporate funding.

>> For more information, see '[Resources](#)'.



HELPFUL HINT

Even without securing funding from one of the above sources, you can still accomplish quite a lot with no money at all. With just a computer and some time, you can successfully set up a Facebook group (or country equivalent), gather knowledge about bladder cancer groups and patients in your country, and/or host informal gatherings at a café. Do not get discouraged if you are not able to secure funding right away.

7. Funding your organisation



Often in the very early stages of development, volunteers will self-fund to carry out the activities. However, that model is not sustainable, and there are various avenues you can explore to secure funding externally. Try to combine funding from multiple sources. You can explore one, or all, of the below possibilities:

- **Fundraising activities** (ex: canvassing, events, and awareness walks or runs) - Facebook (in some countries) and some other online platforms allow organisations to collect charitable donations and host fundraisers on their page
- **Charitable donations** which may be generated by or in connection with an event
- **Government funding or grants**
- **Corporate grants or sponsorships** – by pharmaceutical or medical device companies, or with businesses who have employees affected by bladder cancer
- **Membership fees**

>> For further information on how build and establish your group, and take it to the next level, see '[Resources](#)' where we have linked to free helpful guides.

Engaging with others to maximise your impact

Try to join forces with different types of stakeholders locally, nationally, or globally, to maximise your impact by working towards a common goal. Expanding your network will help increase the visibility of your work, attract new donors and like-minded members. Some ideas of groups you could connect with are listed below.

Other cancer patient organisations

Look for patient organisations in your country that you could connect with on joint projects or initiatives or find out how they went about getting established. This could be other cancer patient organisations, particularly those connected with urological cancers (kidney, prostate, and testicular), or umbrella organisations representing all cancer types.

Academics and researchers

Search for well-known national academic medical centres and see if they have any research related to bladder cancer. Look online for a database of clinical trials in your country and consider reaching out to the relevant clinical trial coordinators.

Healthcare professionals

Pursue relationships with medical professionals and consider reaching out to the national associations of urological doctors, urological nurses (or local equivalents). Consider engaging with and gaining support from your own urologist.

The private sector

Reach out to pharmaceutical and medical device companies in your country to gauge their interest in building relationships with patient groups and enlist their support to publicise your initiative and their interest in funding some of your initiatives.



Policymakers

Identify key local, regional or national policymakers and decision-makers who can help you achieve your goals (politicians, civil servants, health authorities, etc). Reach out to those with an interest in health and aim to set up a meeting to educate him/her on bladder cancer in your country.

Global patient organisations

Consider joining an international patient organisation. Look for umbrella organisations or coalitions to do joint advocacy activities with or share communications resources. Some examples include: Union for International Cancer Control (UICC) or the World Bladder Cancer Patient Coalition.

Before reaching out to potential partners, it is a good idea to have some initial communications materials developed. These are described on the next page.

TOP TIP:

“You don’t have to reinvent the wheel. Outside of passion, the **key to establishing a successful patient advocacy group is collaboration.** There are individuals and existing groups all over the globe who are keen to help you spread the word on bladder cancer and increase quality supports to patients and families in your country.”

Dr Stephanie Demkiw MD, Bladder Cancer Awareness Australia, member of the World Bladder Cancer Patient Coalition



TOP TIP:

“One key strategy is to **build strong relationships with healthcare professionals, especially nurses.** They’re often the first point of contact for newly diagnosed patients and can significantly help in raising awareness about your support group.”

Adam Lynch, BEAT Bladder Cancer Awareness Australia, member of the World Bladder Cancer Patient Coalition



Communicating about your group

Establishing an online presence is important to help your group gain supporters, and to connect with patients and families who may need your services.

Consider the following:

DEVELOP YOUR BRAND: your brand is your identity. As a starting point you should look to develop a company logo, company name and branding guidelines. You can find reasonably priced designers online to develop these for you. Try [Fiverr](#), or [Canva](#), for example, or ask for recommendations from other patient groups and the WBCPC.

SET UP A FACEBOOK PAGE OR SIMILAR SOCIAL MEDIA PLATFORM: if available in your country, **Facebook** is the first social media channel you should consider setting up. It provides a great way to build an online community, gather initial supporters, and engage in discussions about bladder cancer. If you live in a country where Facebook is not a preferred social media network, seek out a locally available alternative with messaging features, such as **WeChat** or **WhatsApp**.



HELPFUL HINT

If you are using Facebook, make sure that your Facebook group is private, so members have to be vetted before they join. Clearly define the rules of your group to avoid spam and to deter anyone from posting inappropriate content.

SET UP AN X ACCOUNT: you can use **X** reactively by responding to and sharing the latest news in bladder cancer (by retweeting and adding your voice), promoting your activities and updating people on the latest information about your group. X provides a great way to interact with your followers and supporters on a regular basis.





DEVELOP A WEBSITE: consider developing a website to host all of your group's information. [WordPress](#) or [Wix](#) both provide a free and easy to use service.

LOOK INTO FREE GOOGLE ADVERTISING: in some cases, **Google** will grant non-profit organisations with free access to promoting their organisation or website on google search to increase your online visibility. You can find out more [here](#).

ESTABLISH A REGULAR NEWSLETTER: use an email newsletter to keep people updated on your activities, progress, and latest news. Try using [Mailchimp](#).

CREATE PRINTED AND DIGITAL MATERIALS: printed and digital materials can help your members communicate easily about your group. Consider developing an infographic, a poster, or digital materials, a standard PowerPoint presentation all containing basic information about bladder cancer and your group's vision or activities. Before developing these materials, contact the WBCPC, who can share pre-existing templates for adapting.

“Establishing an online presence is important to help your group gain supporters, & to connect with patients and families who may need your services”

Bladder cancer awareness month

Join the bladder cancer awareness month activities throughout the month of May!

Each year in May we remember all those who have lost their fight with this disease, and it is also a time when bladder cancer patient organisations stand together to fight for those currently undergoing treatment and everyone who is affected by bladder cancer.

Bladder cancer is one of the most common cancers across the globe, yet many people are not aware of the risks or early warning signs to look out for. The World Bladder Cancer Awareness Month, aims to highlight the facts about bladder cancer, promote awareness of the symptoms and call for more investment in research. We want to end its status as a 'forgotten cancer'.

This presents a key opportunity for bladder cancer patient groups across the globe to collectively raise their voice and host events, activities, social media activity and connect with the media. You can join in the activities or organize your own.

It is common for patient groups to organise the below kinds of activities:

- **Sharing your personal journey** with bladder cancer to help others
- **Spreading awareness raising materials** with your community, such as posters and flyers
- Hosting awareness raising **information sessions** in your community
- Organising a **fundraising event** (e.g. walk or run)
- Engaging with your **local government** representatives
- **Making noise on social media** and adopting the hashtag which is used by WBCPC and all its members during Bladder Cancer Awareness Month, which is

#BladderCancerMonth

Before you get started, you should reach out to us at the World Bladder Cancer Patient Coalition and we will share awareness month ideas with you.

Bladder Cancer Awareness Month
May



FEELING UNSURE?
GET CHECKED.

Play Now!
Learn about the importance of early detection

Spot the Drop
Test your reactions. Fastest time wins!
START

5 FACTS ABOUT BLADDER CANCER

- SMOKING IS THE BIGGEST RISK FACTOR**
- BLOOD IN THE URINE IS THE MOST COMMON SYMPTOM**
- IT IS THE 9TH MOST DIAGNOSED CANCER IN THE WORLD**
- 1 IN 4 BLADDER CANCER PATIENTS ARE WOMEN**
- BLADDER CANCER IS HIGHLY TREATABLE WHEN CAUGHT EARLY**

BLOOD

FOUND IN THE URINE IS THE MOST COMMON SYMPTOM OF BLADDER CANCER

Here are some examples of activities World Bladder Cancer Patient Coalition members have organised in the past during Bladder Cancer Awareness Month in May:

Anna's Walk:

Anna's Walk is a meaningful way to take part in Bladder Cancer Awareness Month each May. Organised by BEAT Bladder Cancer Australia, this annual event honours Anna Lynch, who passed away from bladder cancer at the age of 45. What began as a tribute to Anna has grown into a nationwide initiative, bringing people together across Australia to raise awareness and support for those affected by bladder cancer.

During Awareness Month, participants in cities like Sydney, Perth, and Brisbane gather for scenic walks that not only pay tribute to Anna's memory but also highlight the importance of early detection and support for patients and



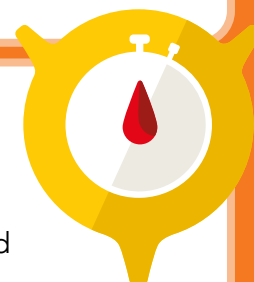
families. By sharing photos of their walk on social media and using hashtags tied to the campaign, supporters amplify the message of awareness and solidarity.

Anna's Walk is a powerful reminder of the strength in community and the impact we can make together during Bladder Cancer Awareness Month. It's also an opportunity to fundraise for BEAT Bladder Cancer Australia's vital work in advocacy, patient support, and education.

Wear and share the Unsure Icon:

Embracing the Unsure Icon. You can wear it on badges, shirts, or other materials to spark curiosity and start conversations about bladder cancer. Share the Unsure Icon visuals or video across your social media channels to amplify its message and encourage others to learn the signs and symptoms.

Using this symbol, we can highlight the uncertainty that often accompanies bladder cancer symptoms and inspire individuals to seek medical advice early. Together, we can create a global movement to improve understanding and outcomes for patients.



Organise an awareness-raising activity or campaign:

May is the opportune time to conduct an awareness raising activity or campaign for bladder cancer since this is Bladder Cancer Awareness Month. This can be a simple talk hosted at a local café or library, or a fully-fledged campaign with media attention to raise awareness of bladder cancer and its symptoms among the general public.

In Canada for example, the sophisticated 'See Red Campaign' was initiated to raise awareness about the signs and symptoms of bladder cancer, especially the most frequent one which is blood in urine. Bladder Cancer

Canada released a series of posters, and videos, and placed these all-over public areas in various metropolitan cities in Canada – including posters on bus stop shelters and on the back of washroom stalls or in front of urinals. The campaign was very successful in reaching a high number of people.

You can find the 'See Red' awareness raising video online [here](#) and [here](#).



How the World Bladder Cancer Patient Coalition can support you

“Our vision is to have a bladder cancer patient organisation established in each country, and that they are fully able to support people affected by bladder cancer. The World Bladder Cancer Patient Coalition is here to help grow, connect and support these groups on their journey.”



Lydia Makaroff, Fight Bladder Cancer, member of the World Bladder Cancer Patient Coalition

The World Bladder Cancer Patient Coalition’s vision is that there is a national bladder cancer patient organization in each country. It is an ambitious plan and it is people like you who can help make that happen! This toolkit is here to guide you with the first steps.

WBCPC wants to make sure that national bladder cancer patient organizations are strong enough to support people affected by bladder cancer, enhance awareness and advocate for better diagnosis, access and care. We are here to provide guidance, support and a helping hand to aid your work in your country to make a difference.

When you join WBCPC you may benefit from opportunities such as:

- **Network** with other like-minded bladder cancer patient organisations from your region or half-way across the world
- Learn from the **experiences** of already established organisations
- Use materials and informational **resources** and **seek assistance** in adapting these to your local needs
- **Educational and capacity building activities**, attending conferences and joining the WBCPC Annual Meeting
- Bring global attention to the needs of bladder cancer patients in your country and **contribute to the global voice** of people affected by bladder cancer
- **Stay informed** on developments in research, new treatment options and global challenges that may also affect your country
- **Exchange of useful resources and best practices** in cancer patient support and cancer care advocacy

“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,
World Bladder Cancer
Patient Coalition*



WBCPC is a growing international organisation connecting bladder cancer patient advocates like you!

For general information, membership inquiries or policy related information, please contact:

Alex Filicevas, Executive Director,
World Bladder Cancer Patient
Coalition Secretariat.

info@worldbladdercancer.org

Resources

In addition to this start-up guide, there are many different free resources available online to help you grow or establish your bladder cancer patient group in your country.

We have linked to the most helpful ones below.

BLADDER CANCER GROUPS:

- **ARGENTINA:** VICARE, online [here](#)
- **AUSTRALIA:** BEAT Bladder Cancer Australia, online [here](#)
- **AUSTRALIA:** Bladder Cancer Awareness Australia, online [here](#)
- **BELGIUM:** NEOVIDA, online [here](#)
- **CANADA:** Bladder Cancer Canada, online [here](#)
- **DENMARK:** Danish Bladder Society, online [here](#)
- **FINLAND:** Timo Koponen, timokoponen@welho.com
- **FRANCE:** Cancer Vessie France – Les Zuros, online [here](#)
- **GERMANY:** Selbsthilfe-Bund Blasenkrebs e.V., online [here](#)
- **ITALY:** Association PaLiNUro, online [here](#)
- **MALAWI:** One Community, online [here](#)
- **NETHERLANDS:** Patiëntenvereniging blaas- of nierkanker, online [here](#)
- **NORWAY:** Blærekreftforeningen, online [here](#)
- **NORWAY:** Blærekreft Norge, online [here](#)
- **SINGAPORE:** Singapore Cancer Society, online [here](#)
- **SOUTH AFRICA:** Campaigning 4 Cancer, online [here](#)
- **SPAIN:** CANVES, online [here](#)
- **SWEDEN:** The Swedish Bladder Cancer Society, online [here](#)
- **UK:** Fight Bladder Cancer, online [here](#)
- **USA:** American Bladder Cancer Society, online [here](#)

BLADDER CANCER RESOURCES:

- Bladder cancer knowledge hub, online [here](#)
- Signs and symptoms factsheet, online [here](#)
- Bladder cancer awareness month campaign resources, online [here](#)
- How to set up a support group, online [here](#)
- Bladder cancer patient guides, online [here](#)

OTHER HELPFUL GUIDES:

- Tips for writing a non-profit mission statement, online [here](#)
- Defining a mission and vision webinar, online [here](#)
- Non-profit bylaw template, online [here](#)
- What to consider when designing a logo, online [here](#)
- Checklist for starting a non-profit, online [here](#)
- Working with partners and stakeholders toolkit, online [here](#)
- Patient advocacy education and resources, online [here](#)



World Bladder Cancer Patient **COALITION**

You can find us here:

X: @WorldBladderCan

LinkedIn: WorldBladderCan

Instagram: WorldBladderCancer

Youtube: WorldBladder

Facebook: WorldBladderCan

Website: worldbladdercancer.org

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