



World Bladder
Cancer Patient
COALITION

Know the basics:

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

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Foreword

by Lori Cirefice

*Board of Directors at the World Bladder Cancer Patient Coalition;
and Patient Coalition Delegate with Association Les Zuros (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 ten patient groups from three 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, President of the World Bladder Cancer Patient Coalition; and Board Member of Bladder Cancer Canada

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

10th most common cancer¹

It is the **leading** cancer-related cause of death¹

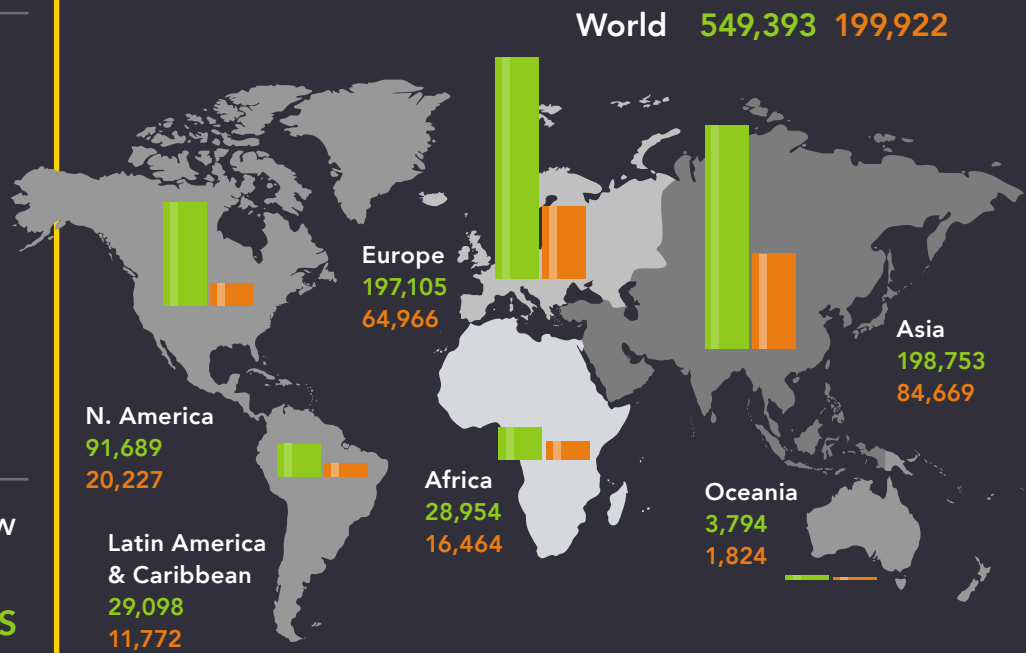
The latest figures show

549,393 NEW CASES

diagnosed and **199,922** DEATHS in 2018 alone¹

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

NEW CASES IN 2018¹ DEATHS IN 2018¹



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

REFERENCES:

1. International Agency for Research on Cancer (IARC). 2018. 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 study 1:

Creating a “Patient Guidebook” to help Australians access reliable information on bladder cancer

By **Tony Moore**, Co-Founder & Director of *BladderCancer.org.au*



When I was diagnosed with Bladder Cancer in late 2011, I was given a booklet with information about what I should know about this disease. It was good, but very basic so I turned to the internet for more information. I found some great resources online available for free in other countries like the UK, USA and Canada; however, Australian resources were virtually non-existent. The big things missing were information and statistics on recovery, continence, and erectile dysfunction – a reality for people who have had bladder cancer surgery.

After my own surgery and recovery, I went on a mission to collect data from Australian patients. I did a survey to understand the outcomes patients experienced and built a website to publicly showcase the results.

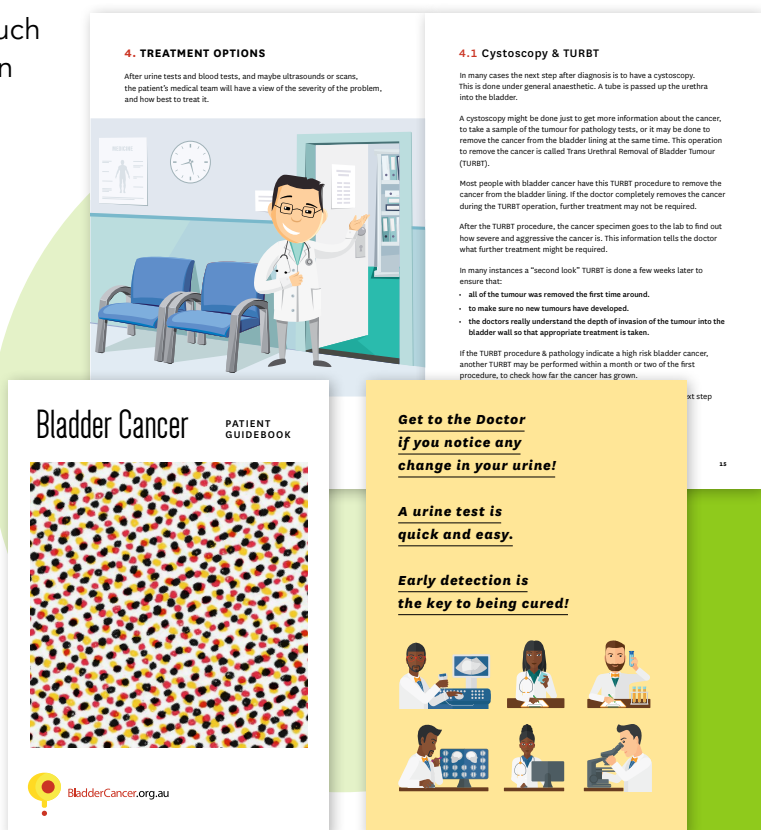
Once I completed the survey and knew more about the outcomes that could be expected for Australian bladder cancer patients and survivors, I began to work on an information booklet called the “Patient Guidebook” together with my medical team. We included information on what people could expect in terms of the main treatments and procedures, advice for families and loved ones on how to support and cope with bladder cancer, and findings from the survey that we did.

During this process, I learned just how much people needed more detailed information on the disease in Australia. The existing information was inadequate and patients all across Australia were lacking access to the information that they wanted and needed to take control of their disease and recovery.

We have launched the 4th edition of our Patient Guidebook in 2020. We have distributed over 5,000 copies and had more than 5,000 downloads since we launched it six years ago. It has become a vital resource for patients, their families, doctors, urologists and nurses across Australia.

You can download a copy of the Patient Guidebook [here](#).

“We have distributed over 5,000 copies and had more than 5,000 downloads since we launched it six years ago. It has become a vital resource for patients, their families, doctors, urologists and nurses across Australia.”



Case study 2:

Creating an awareness-raising poster in France

By **Lori Cirefice**, Board of Directors for the World Bladder Cancer Patient Coalition, and Patient Coalition Delegate with Association Les Zuros (France)



In May 2019, Association Les Zuros 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.

"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."

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

Case study 3:

Organising an annual bladder cancer walk in Canada



By **Ken Bagshaw**, President of the World Bladder Cancer Patient Coalition; and Board Member of Bladder Cancer Canada

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 4:

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



By **Lydia Makaroff**, Vice-President of the World Bladder Cancer Patient Coalition; Chief Executive Officer, Fight Bladder Cancer UK

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.



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'*.



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.

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,
World Bladder Cancer
Patient Coalition member;
Assistente alla Presidenza,
Association PaLiNUro (Italy)





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](#) 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.

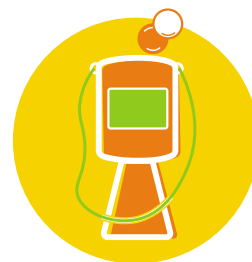
>> For more information, see '[Resources](#)'.



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, Primary Care Physician and Co-founder and Chair of Bladder Cancer Awareness Australia; Member of the World Bladder Cancer Patient Coalition



TOP TIP:

“I think the single **most important thing is to get the nurses on your side,** as they are the only ones who can tell newly diagnosed patients about your patient group.”

Allen Knight, Board Member of the World Bladder Cancer Patient Coalition; Chair of Action Bladder Cancer UK



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 A TWITTER ACCOUNT: you can use **Twitter** 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. Twitter 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

#bladdercanceraware

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.



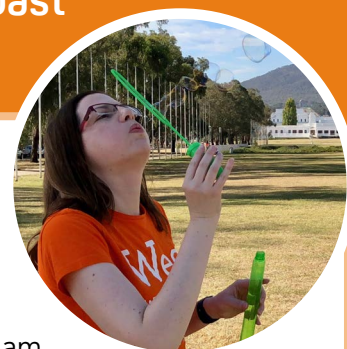
Here are some examples of activities World Bladder Cancer Patient Coalition members have organized in the past during Bladder Cancer Awareness Month in May:



Bubbles for Bladder Cancer:

Bubbles for Bladder Cancer began as a small fundraising event by Fight Bladder Cancer UK. Now, it is an annual event for people across the world affected by bladder cancer. During this special day in May, at 10 am local time, people across the world stand still for a moment and blow bubbles to honor those currently undergoing treatment, those lost to cancer, survivors, and anyone affected by bladder cancer in some way.

This event raises awareness of bladder cancer, and helps us to recognise people who have been affected by bladder cancer. Supporters of the event are asked to post pictures of themselves and their loved ones to social media and people are encouraged to make a donation to help fund Fight Bladder Cancer UK's work.



Wear the colour yellow or orange for bladder cancer awareness:

Yellow and orange are both globally recognised colours for bladder cancer. Encourage your members and supporters to wear orange or yellow throughout the month of May to bring greater awareness to bladder cancer and spark conversations with those who do not know about bladder cancer!

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, Vice President of the World Bladder Cancer Patient Coalition;
Chief Executive Officer of Fight Bladder Cancer UK*

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:

- **AUSTRALIA:** Beat Bladder Cancer Australia, online [here](#)
- **AUSTRALIA:** Bladder Cancer Australia Foundation, online [here](#)
- **AUSTRALIA:** Bladder Cancer Awareness Australia, online [here](#)
- **CANADA:** Bladder Cancer Canada, online [here](#)
- **DENMARK:** Danish Bladder Society, online [here](#)
- **FINLAND:** Timo Koponen, timokoponen@welho.com
- **FRANCE:** Les Zuros, online [here](#)
- **GERMANY:** Selbsthilfe-Bund Blasenkrebs e.V., online [here](#)
- **ITALY:** Association PaLiNUro, online [here](#)
- **NETHERLANDS:** Leven met blaas- of nierkanker, info@blaasofnierkanker.nl
- **NORWAY:** Blærekreftforeningen, online [here](#)
- **NORWAY:** Blærekreft Norge, online [here](#)
- **UK:** Action Bladder Cancer, online [here](#)
- **UK:** Fight Bladder Cancer, online [here](#)
- **USA:** American Bladder Cancer Society, online [here](#)
- **USA:** Bladder Cancer Advocacy Network, online [here](#)

BLADDER CANCER RESOURCES:

- Signs and symptoms factsheet, online [here](#)
- Awareness month communications toolkit, online [here](#)
- How to set up a support group, online [here](#)
- Bladder cancer patient guides, online [here](#)
- Awareness month social media toolkit, 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](#)
- Tips on how to effectively use twitter, online [here](#)
- Working with partners and stakeholders toolkit, online [here](#)
- Patient advocacy toolkit, online [here](#)



World Bladder Cancer Patient **COALITION**

You can find us here:

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Facebook: WorldBladderCan

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