



**World Bladder
Cancer Patient
COALITION**

WBCPC 2020 –

Annual Meeting of the World
Bladder Cancer Patient Coalition

Putting bladder cancer on the global health policy agenda



**Toward a ‘network of networks’ serving
bladder cancer patient organisations**

World Bladder Cancer Patient Coalition 2020

Keynote speakers & panelists

Moderator: Dr Lydia Makaroff (UK)

Treasurer & Vice-President, WBCPC & CEO, Fight Bladder Cancer UK

Introduction: World Bladder Cancer Patient Coalition & our mission

Ken Bagshaw (Canada)

President, WBCPC & Board Member, Bladder Cancer Canada

Watch the
recording of
the meeting



SESSION 1:

How do we foster bladder cancer patient groups across the world?

PANEL DISCUSSION

Patient Perspective

Ferg Devins (Canada),
Chair, Bladder Cancer Canada

Medical Perspective

Dr Ashish Kamat (USA)
MD Anderson Cancer Center
Societe Internationale D'Urologie

International Group Perspective

Dr Rachel Giles (Netherlands)
Chair, International Kidney Cancer Coalition

Pharmaceutical Industry Perspective

Zsolia Bakonyi (Belgium)
Senior Manager – Partnerships, EFPIA

The bladder cancer world needs strong patient groups worldwide as the catalyst to place bladder cancer at the top of the global health policy agenda and ensure the best possible outcomes for patients.

A WBCPC priority is to encourage the creation of an international community of people affected by bladder cancer. It will be driven by enthusiastic national bladder cancer patient organisations in every country.

This session focused on how the WBCPC network can connect these communities and what resources and tools are needed to inform and inspire bladder cancer patient organisations worldwide.

SESSION 2:

Ensuring optimal treatment options for bladder cancer patients worldwide

From essential to innovative: access to bladder cancer treatment options

Dr Stephanie Chisolm (USA)
Director of Education and Research,
Bladder Cancer Advocacy Network

Patient & Public Involvement: setting the agenda for research on bladder cancer

Henry Scowcroft (UK)
Consumer Representative, National Cancer
Research Institute Bladder & Renal Group

By putting the concerns of the bladder cancer community on the table, patients' input helps develop solutions that help affect bladder cancer patients worldwide.

As the global voice of people affected by bladder cancer, WBCPC works to ensure that all patients worldwide can have access to the best possible information, support, treatment and care, when they need it.

This session explored pressing issues that the community faces – from medicines shortages to cancer research innovation. Patients' voices are a powerful force to shape bladder cancer research.

WBCPC 2020:

Ensuring bladder cancer is on the global health policy agenda

This report is a summary of the presentations and dialogue at WBCPC 2020, the Annual Meeting of the World Bladder Cancer Patient Coalition, held in September. This year's virtual global gathering brought together leaders in bladder cancer research, advocacy, patient organisations and the pharmaceutical industry from 25 countries worldwide to explore the topic:

What action is needed to place bladder cancer higher on the global health policy agenda?



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 little-known fact about the global landscape for cancer research, treatment and care is that bladder cancers are 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.

In the words of World Bladder Cancer Patient Coalition 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 to be one global voice for bladder cancer patients, linking national patient groups. In places where groups don't exist, we will facilitate their creation."

This report is organised around three themes that drive the WBCPC strategy: **Building Community, Raising Awareness, and Engaging in Advocacy**, with two objectives:

To be a resource that shares useful know-how, approaches, practices and ideas – to support all those building or strengthening bladder cancer patient groups in their country.

To inform discussions in the WBCPC network as we develop our action plan for the coming years.

We hope the exchanges summarised here inform and inspire you. We welcome your feedback, comments and questions.

World Bladder Cancer Patient Coalition:

A young organisation aiming for global support for bladder cancer patients.

Founded in 2019 by bladder cancer patient organisations from Canada, the UK and the USA, it aims to ensure that people with this condition in every country have access to a patient organisation.

11 national members
in N. America,
Europe, Africa and
Australia, and has
ambitious plans
for growth.

Alex Filicevas

Alex Filicevas
Executive Director

Building community:

how the patient voice adds value to the research-treatment-care pathway

For relevant research and optimal care for bladder cancer, the patient's voice needs to be at the centre of the conversation. Patient groups make this a reality.

Vibrant patient communities are the platform needed to bring people's voices and experiences to the centre of the conversation that shapes bladder cancer policies, informs clinical practice and influences research. Patient organisations that the World Bladder Cancer Patient Coalition is working to support will be the force behind creating – and connecting – bladder cancer patient communities worldwide.

“The WBCPC is driven by the near-total absence of support for most bladder cancer sufferers worldwide. We aim to be one global voice for bladder cancer that links all national patient groups. In places where groups don't exist, we will facilitate their creation.”

Ken Bagshaw, President of the World Bladder Cancer Patient Coalition

Presenters and participants at the Annual Meeting discussed the challenge of creating communities, and exchanged examples of effective approaches by some patient organisations. There is much work to be done. Discussants agreed that the patient's voice is lacking in many countries, and that this perspective is a critical missing link in the research-to-care pathway.

Bladder Cancer Canada is one of the world's pioneering bladder cancer patient groups. It serves a community of some 80,000 patients living across six time zones. Sharing his experience with colleagues, **Ferg Devins**, the organisation's Chair, stressed that a website offering clear and useful information to patients and their families is the most important first touch-point to support a geographically distributed patient population. This organisation complements its web information with a range of web and digital channels that it uses to reach out to Canada's bladder cancer patient population.

Dr Rachel Giles, Chair of the International Kidney Cancer Coalition, explained how this organisation grew from an informal network of national groups in 2009, to today's global community representing 1.3 million kidney cancer patients. The group's role and professional skills also evolved as it grew – from advocacy to being involved in the research process. Today the coalition works closely with the science community, to help shape the research agenda for kidney cancers and to provide expert input to clinical trials development.

From the clinician's perspective, **Dr Ashish Kamat** shared his advice on how patient communities add value to health care professionals in the bladder cancer care space. In his daily activities as a bladder cancer specialist, professor and researcher, he sees partnering with patients as an integral part of the research-to-treatment pathway.

“Clinicians provide critical ongoing support during patient care and post treatment, sharing knowledge and advice with family members. For some cancers, patient support means advising members to consider diagnosis to pinpoint genetic mutations that may affect the wider family.”

Dr Ashish Kamat, Professor of Urology and Director of Urologic Oncology at the University of Texas, MD Anderson Cancer Center

Action points:



Explore the Start-up guide for bladder cancer patient groups, we continue to add new languages!



Get in touch if you have the ambition to start a bladder cancer patient group in your country!



Resources

- **Start-up guide for bladder cancer patient groups** – World Bladder Cancer Patient Coalition
- **Patient Guidebooks** – Bladder Cancer Canada
- **EFPIA Patient Think-Tank** – Forum for exchange between patients' organisations and pharma industry
- **Health Collaboration Guide** – examples of innovative partnerships and campaigns between the industry and patients

In their community role clinicians act beyond care and post-treatment, by supporting family members with advice and useful knowledge. He stressed that a bladder cancer patient's family is part of the care pathway, especially where the patient experiences lifetime changes. For some cancers, patient support also means advising members to consider diagnosis to pinpoint genetic mutations that may affect the wider family.

Addressing patient-industry links, **Zsafia Bakonyi**, Senior Manager for Partnerships at the European Federation of Pharmaceutical Industries and Associations (EFPIA), said that credible and meaningful research cannot happen without close alignment between these communities.

“To be credible, close alignment is needed between patients and the research process. We invest in building capacity with patient groups and industry to improve the quality of their engagement.”

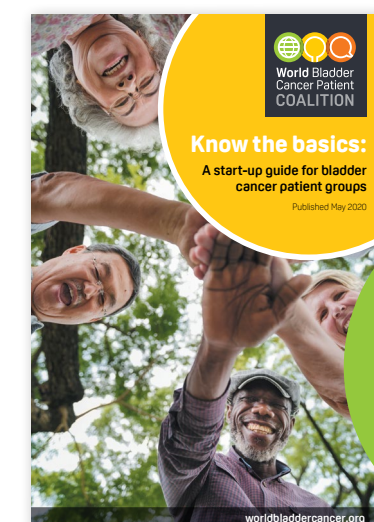
Zsafia Bakonyi, Senior Manager for Partnerships at the European Federation of pharmaceutical industries and associations

EFPIA has initiatives to building long-term relationships between the industry and patients. One of these is the *Patient Think Tank*, a forum for dialogue between patients and medicines developers. It recently co-created a white paper with patient groups. The report details how patients can be involved across the lifecycle of a medicine's development – from research priority setting, to determining the value of an innovation, and gathering outcome data to increase understanding of treatment outcomes in a real-world setting. EFPIA advocates for culture change in the industry,

calling on professionals at all levels of pharma companies to appreciate the value that the patient view brings to their work.

RESOURCES FOR A BLADDER CANCER PATIENT GROUP IN EVERY COUNTRY

To drive its goal of having a bladder cancer patient group in every country worldwide, the WBCPC has created a start-up guide and toolkit designed for use by anyone interested in creating a local or national group. The guide was presented to participants in a video presentation, with comments by **Dr Peter Black**, Chair of the Bladder Cancer Canada Medical Advisory Board, and WBCPC Vice Presidents **Dr Lydia Makaroff** and **Andrea Maddox-Smith**. It offers practical, ready-to-use resources and shares best practices captured from the learnings of coalition members as they started their patient groups.



Download the Start-up guide for bladder cancer patient groups at worldbladdercancer.org

Click here to watch the video

Fostering an international community of people affected by bladder cancer

Raising awareness:

effective patient groups deliver high quality information: right materials, right channel, what patients and partners need

The real value of an effective bladder cancer patient group is its ability to provide clear, credible and useful information to patients and their families. Clinicians will also welcome well-presented bladder cancer information if they see that is helpful and relevant for use in their treatment pathways.

Telling a compelling bladder cancer story is the key to promoting a better understanding of the condition, increasing the appreciation of its importance and attracting more participation and investment in this field, said the World Bladder Cancer Patient Coalition President **Ken Bagshaw**.

Bladder Cancer Awareness Month, in May every year, is the flagship activity where WBCPC and its global community, amplify the bladder cancer messages and call to action. As the number of patient organisations grows, every year sees more activities globally – walks, events, information actions, medical-focused conferences and seminars. In the US, for example, the Bladder Cancer Advocacy Network has mobilised the support of members of Congress to call for specific funding for bladder cancer in national science and medical programs.

Bladder Cancer Canada Chair, **Ferg Devins**, advised that a robust website should be the core of a patient group's information ecosystem. The organisation can then build on this resource, harnessing the digital channels that connect best with the community. Bladder Cancer Canada engages with its members through a mix of digital channels: the website has discussion forums and learning resources such as patient guidebooks; Twitter, Facebook and LinkedIn to raise awareness and keep the community updated; and YouTube as the platform to broadcast webinars and learning events.

“A robust web resource is the key to supporting a widespread patient community. From here we engage with our partners through a range of digital and social media channels.”

Ferg Devins, Chair of Bladder Cancer Canada

“Telling a compelling bladder cancer story is the key to promoting a better understanding of the condition, increasing the appreciation of its importance and attracting more participation and investment in this field.”

Ken Bagshaw, President of the World Bladder Cancer Patient Coalition

Panelist **Dr Ashish Kamat**, Professor of Urology and Director of Urologic Oncology at the University of Texas, MD Anderson Cancer Center, said that a rich web resource can also be a strategic asset for clinicians and health care professionals. A website presenting substantive information on bladder cancer issues, solutions and experiences confirms the group's credibility. This sets a patient group apart from pundits and others using bladder cancer topics for ulterior motives. He sees many patient support groups popping up on social media whose intent is not honest.

Smaller medical centres with fewer resources are flooded with information and tasks and have little time to look into new topics. They will appreciate and use focused bladder cancer information that a patient group can offer. Here, he advises that it is important to understand clinicians' information needs and present them with information designed to help them in their work. If they find the resources useful, there is a good chance they will be integrated in the patient treatment workflow.

A useful example is the International Kidney Cancer Coalition's social media campaign 'Think Treatment; Think Trials!', created to encourage patients, patient organisations and clinicians to learn more about participating in clinical trials. It supports the coalition's strategy to boost diversity in trials, to make them more representative of the patient population – including broader ethnicity, stages of disease, and socio-economic situation. The

Action points:



Explore the resources and activities of the World Bladder Cancer Awareness Month 2020



Join us in raising awareness and get involved with the campaign in 2021. Get in touch!



Resources

- **Bladder Cancer Awareness Month 2020 Campaign Toolkits**
- **Webinar Video Channel – Bladder Cancer Canada**
- **Advocacy campaign – ‘Think Treatment? Think Trials!’ – Advocacy campaign to boost patient diversity in kidney cancer trials**

campaign offers web and tweet-ready visuals for patients and health advocates, encouraging them to circulate this information to their social media communities. The goal, explained coalition Chair **Dr Rachel Giles**, is for every patient to know they can ask their doctor about the possibility of being involved in trials; and for every doctor to ask patients if they are interested in participating.

Engaging in advocacy:

How patients' voices can shape the research agenda

As the global bladder cancer community develops its patient organisations in countries, it can learn from the experience of other groups who faced similar challenges in building their networks. The advocacy approaches of the International Kidney Cancer Coalition, Bladder Cancer Advocacy Network (BCAN), and Cancer Research UK were presented and discussed.

The coalition actively promotes evidence-based advocacy to include patients input in the research agenda. Coalition Chair **Dr Rachel Giles** describes how the team looks for research areas where evidence is lacking and encourages research colleagues to focus on these new topics. For example, it may organise groups of doctors to explore the best approach to a rare type of kidney cancer.

Encouraging broader patient involvement in clinical trials is another area where the coalition applies its advocacy skills. Comparing the demographics of trials participants with locations of highest incidence of the disease, the team noted that most trials involve European and North American patients, while the majority of kidney cancer patients live on other continents. To correct this situation, the coalition works to encourage more ethnically diverse trial groups, which will generate data that is more relevant to patients in regions with the highest kidney cancer incidence.

Increased cooperation between medical centres worldwide also opens new opportunities to expand diversity, if trials from different parts of the world can be linked. This approach holds promise, said **Dr Ashish Kamat**, if current gaps in know-how and practice between regions can be overcome. He trains and mentors young clinicians in trial design and data interpretation in different countries, and works with the international bladder cancer group to identify centres of excellence worldwide.

When centres operate at the same levels of skill, know-how and processes, this creates the possibility to pool trial data from different locations, tapping into a more diverse patient base. Ultimately, he explained, the quality of trials depends on the quality of the investigators and the centre running the trials. The lack of common skills and approaches is the reason why trials were not previously possible in many parts of the world, as data they generate can be suspect. This situation is evolving.

“We believe in evidence-based advocacy. When we see an evidence gap, we encourage our research colleagues to focus on these topics.”

Dr Rachel Giles, Chair of the International Kidney Cancer Coalition

HOW ADVOCACY HELPS PROGRESS BLADDER CANCER RESEARCH IN THE US: AN EXAMPLE FOR INSPIRATION?

Even as the voice of bladder cancer patients is under-represented in many countries today, **Dr Stephanie Chisolm**, Director of Education and Research, Bladder Cancer Advocacy Network (BCAN), said that science and pharmaceutical innovation to control the disease have progressed steadily since 1900 – and patient perspectives have been present along this pathway.

Her overview charted the evolution of bladder cancer care – from discovering the link between Schistosomiasis and urinary bladder cancer in 1911, to the first chemotherapy drug in the 1970s, and today’s immune combination and targeted gene therapies.

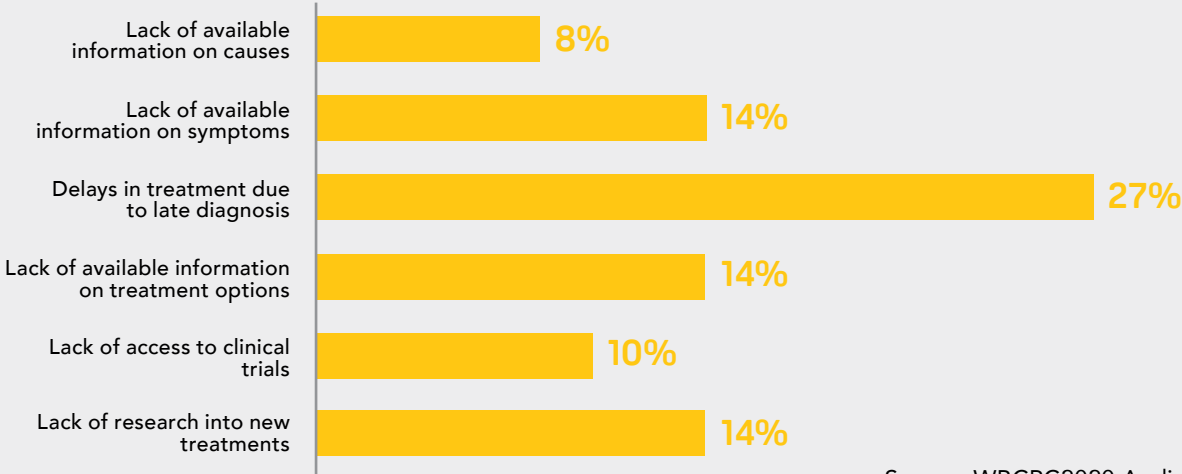
“Innovative new therapies and diagnostic tools will change the treatment landscape, but only if they are affordable and available. Our advocacy role can help improve access for the patient community.”

Dr Stephanie Chisolm, Director of Education and Research, Bladder Cancer Advocacy Network (BCAN)

Thanks to the efforts of US bladder cancer advocacy groups, she said, the condition is becoming recognised by science funders and public health policymakers in the United States. But there are many more patients who can be reached and involved. For example, some 1200 bladder cancer trials are listed in the Centres for Disease Control database, but only 3% of the eligible population participate in trials. This means it is difficult to have broad enough patient samples to have scientific significance. Also, BCAN and partners’ advocacy efforts have succeeded in listing bladder cancer as a priority topic for the US Department of Defense federal research funding.

She commented that innovative new therapies and diagnostic tools have the potential to change the treatment landscape. But they have limited value unless they are affordable and widely available to the bladder cancer patient community. Looking at availability even among well-established treatments, one example is BCG medicine. It is effective for many non-muscle-invasive bladder cancers, but is in increasingly short supply. BCAN is advocating with producers and the regulators to encourage prompt approval of other strains and look at the accessibility of alternative treatment options.

What are the 3 biggest major challenges in your country?



Source: WBCPC2020 Audience Poll

Action points:



What are the biggest challenges bladder cancer patients face in your country? Let us know!



Get in touch if you are looking to engage in bladder cancer advocacy in your country, we can match you with someone who can share their experience!



Resources

- **Stories that make cancer research understandable to the public** – Cancer Research UK Blog
- **Bladder Cancer Advocacy Network** – a community of patients, caregivers, survivors, advocates, medical and research professionals united in support of people touched by bladder cancer.
- **Bladder cancer clinical trials dashboard the USA**
- **Bladder cancer clinical trials dashboard the UK**

PATIENT INVOLVEMENT IN CANCER RESEARCH: WHAT DOES IT MEAN?

Henry Scowcroft is a consumer member of the Bladder and Renal Group and the UK National Cancer Research Institute. His presentation and the resulting discussion argued that clear and compelling advocacy messages are the force needed to involve patients more deeply in bladder cancer research.

He described the current state of bladder cancer in the UK through his personal story of his partner’s fatal bladder cancer journey, and showed how patients can participate in making this research more effective.

Exploring the UK’s bladder cancer research landscape, he found talented scientists doing important work. But he also observes that this research community is fragmented, and can benefit

“Patient advocacy is at its weakest when the patient voice is at the second step – where the research community develops the hypotheses and brings it to us. It’s most powerful when we are in the room, involved in the discussion as the research is being designed.”

Henry Scowcroft, Consumer Representative, National Cancer Research Institute Bladder & Renal Group

from better coordination between researchers and clinical centres. Compared to other cancers, he said that much work is needed to improve the understanding of these bladder conditions.

Today there are significant knowledge gaps on the biology of bladder cancers, on cancer types and their behaviour.

In this light, he discussed the important input that patients can make to improve the quality of bladder cancer research – explaining that ‘patient involvement’ goes beyond participating in clinical trials. Faced with a research base for bladder cancers that is not deep, researchers and clinicians need more data on tumour types and how they behave. By donating tissue, patients can make a direct contribution to improving the quality of science. For this science to progress, he said that the current lack of tissue and blood samples needs to be reversed.

Here advocacy can help, he said, as a catalyst that will encourage the patient involvement needed to enrich bladder cancer research. To help make this happen, he works to mobilise patients’ voices, aiming to bring together the patient, academic and laboratory communities for clinical trials. The world he wants to see is one where everyone with bladder cancer knows they can share their experience, to participate in improving the understanding of the disease and the quality of research data. This, in turn, will bring a better quality of life for every bladder cancer patient.

Thank you!

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