

Toward a 'network of networks' serving bladder cancer patient organisations

Highlights of the WBCPC 2020 Annual Meeting

The 2020 bladder cancer Annual Meeting explores the challenges of including the patient voice in research design, building communities across clinical, patient and industry groups, and encouraging the creation of patient organisations in every country.

A little-known fact about the global landscape for cancer research, treatment and care is that bladder cancer is one of the more common conditions. They are in the top 10 cancers worldwide and rank 4th and 5th in North America and Europe.

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

Against this background the World Bladder Cancer Patient Coalition (WBCPC) held its second Annual Meeting, that explored how to best place bladder cancer higher on the global health policy agenda. This virtual meeting brought together leaders in bladder cancer research, advocacy, patient organisations and the pharmaceutical industry to exchange views with participants from 25 countries worldwide.

Opening the meeting, WBCPC President Ken Bagshaw explains the founders' motivation for creating this new international organisation in 2019: "We are driven by the near-total absence of support for most bladder cancer sufferers worldwide. We aim to be one global voice for bladder cancer by linking all national patient groups. In places where groups don't exist, we will facilitate their creation."

Raising awareness – providing quality information drives credibility

Ferg Devins, Chair of Bladder Cancer Canada, shared the experience of how this national patient group, engages effectively with its network of 80,000 people across six time zones.

He stresses that a robust web resource is the key to supporting a widespread patient community. "This is the core of your information ecosystem. From here, you can decide how to best connect with your community." Bladder Cancer Canada offers its members a mix of digital resources: the website has discussion forums and learning resources such as patient guidebooks; Twitter, Facebook, LinkedIn keep the community updated; and YouTube is the platform to broadcast webinars.

Panelist Dr. Ashish Kamat, Professor of Urology and Director of Urologic Oncology at the University of Texas, MD Anderson Cancer Center and Board Member at Société Internationale d'Urologie, Montreal, agrees that a rich web resource ensures a patient group's value for patients and health care professionals.

Twitter: @WorldBladderCan

Email: info@worldbladdercancer.org

WBCPC: A young organisation aiming for global support for bladder cancer patients

The WBCPC was founded in 2019 by bladder cancer patient organizations from Canada, the UK and US.

It aims to ensure that people with this condition in every country have access to a patient organization.

To date the organization has attracted 11 national members in North America, Europe and Australia, and has ambitious plans for growth.

“A website offering substantive information on bladder cancer issues, solutions and experiences confirm your credibility. It sets you apart from pundits and others linking to bladder cancer topics for ulterior motives. We see too many patient support groups popping up on social media whose intent is not honest,” he says.

He says that quality web information helps patient organisations engage credibly with health professionals. “Smaller medical centres are flooded with information and issues to follow-up. If the clinical community sees that your bladder cancer resources are useful, they will integrate them into their patient treatment workflow.”

Engaging through advocacy – how the patient’s voice can shape the research agenda

As the bladder cancer community develops its patient organisations, it can learn from the experience of other groups who faced similar challenges in building their global networks. The International Kidney Cancer Coalition started in 2009 as an informal network of national groups. Today its global network represents some 1.3 million kidney cancer patients. Coalition Chair, Dr. Rachel Giles explained that its advocacy role has evolved into working with the science community, helping to shape the research agenda for kidney cancers and providing expert input to clinical trial development.

“We believe in evidence-based advocacy,” she says. “When we see a lack of evidence in specific areas, we encourage our research colleagues to focus on these topics. We organise groups of doctors to explore the best approach to a rare type of kidney cancer.”

This includes improving the diversity of clinical trials she says: “We know that most kidney cancer patients live outside Europe and North America. But the vast majority of people participating in current drug trials have demographic profiles from North America. So we are working to encourage more ethnically diverse trial groups, to generate data that are more relevant to patients in regions with the highest incidence of kidney cancers.”

The coalition’s social media campaign ‘*Think Treatment; Think Trials*’ aims to motivate every patient to ask their doctor about the possibility of being involved in trials; and every doctor to ask each patient if they are interested in participating. “Every patient needs to have this option. Diversity in trials includes a range of factors, including ethnicity, stages of the disease, and patients’ socio-economic situation,” she says.

Building community – patient-industry dialogue

Zsafia Bakonyi, Senior Manager for Partnerships at the European Federation of Pharmaceutical Industries and Associations (EFPIA) highlights her organisation’s approaches to building long-term relationships between the industry and patient groups.

One initiative is EFPIA’s Patient Think Tank, a forum created to understand patients’ needs better and inform EFPIA policy. Here, a white paper was recently co-created with partner patient groups. It specifies how patients can be involved across the lifecycle of a medicine’s development – from research priority setting to determining the value of innovation, and gathering outcome data to increase understanding of treatment outcomes in a real-world setting.

She sees close patient-industry engagement as an imperative to ensure that colleagues inside pharma companies are attuned to the patient’s world. “Pharmaceutical companies are big organisations. Every staff member is not necessarily close to the topic of patient engagement. Our role is to encourage cultural change, so professionals at all levels of companies appreciate the relevance that the patient view has for their work,” she says.

In his daily activities as a bladder cancer specialist, professor and researcher, Dr. Ashish Kamat, sees partnering with patients is as an integral part of the research-to-treatment pathway.

“Clinicians play an important role to provide ongoing support during patient care and post-treatment and sharing knowledge and advice with family members.”

He explains that a bladder cancer patient’s family is part of the care pathway, especially where the patient will experience life changes. “For some cancers, patient support also means advising members to consider diagnosis to pinpoint genetic mutations that may affect the wider family,” he says.

****This article is the first part of a two-article series which summarises the experiences shared at the WBCPC 2020 Virtual Annual Meeting.*