## A New Global Voice for People Affected by Bladder Cancer

Feature from the European Association of Urology (EAU) Congress in Barcelona, Spain



**World Bladder Cancer Patient Coalition** 

**Authors:** \*Lydia E. Makaroff

World Bladder Cancer Patient Coalition, Brussels, Belgium

Fight Bladder Cancer, Chinnor, UK

\*Correspondence to info@worldbladdercancer.org

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For the first time ever, people affected by bladder cancer now have a global voice. The World Bladder Cancer Patient Coalition was officially launched on Monday 18<sup>th</sup> March 2019 at the European Association of Urology (EAU) Congress in Barcelona, Spain.

Approximately 430,000 people are diagnosed with invasive bladder cancer around the world each year.<sup>1</sup> Globally, there are 2.7 million people who are currently living with bladder cancer.<sup>2</sup> In the Western world, bladder cancer is the fourth most common malignancy in men and the eighth most common in women.<sup>3</sup> About 1 in 25 Western men and 1 in 80 Western women will be diagnosed with bladder cancer at some point in their lives.<sup>2</sup> Women are 23% more likely to die from the disease compared to men with bladder cancer.<sup>4</sup>

The Bladder Cancer Advocacy Network (USA), Fight Bladder Cancer (UK), and Bladder Cancer Canada worked together to establish the World Bladder Cancer Patient Coalition. Action Bladder Cancer UK, Bladder Cancer.org.au Australia, Blaerekreftforeningen Norway, Les Zuros France, and PaLiNUro Italy participated in the inaugural meeting and were invited to become full members. Other patient advocates, health professionals, academics, policy-makers, researchers, and representatives from the pharmaceutical and medical device industries also attended the launch.

Piyush Agarwal, Center for Cancer Research (U.S.) National Cancer Institute, Bethesda, Maryland, USA, spoke at the launch event. He said: "The World Bladder Cancer Patient Coalition unites patients around the world, giving them a powerful voice in the fight against a lethal disease that significantly impacts not only their survival but also their quality of life. The World Bladder Cancer Patient Coalition aims to create a global voice that hopes to alleviate much of the pain and suffering associated with bladder cancer."





"Treatment, research, and support for bladder cancer patients varies widely across the globe and even within countries," said Ken Bagshaw, bladder cancer patient and interim President of the World Bladder Cancer Patient Coalition. "It's critical that we mobilise bladder cancer patient organisations across the world to help ensure the best possible outcomes for patients."

The World Bladder Cancer Patient Coalition is governed by a board of directors. This board is composed of people diagnosed with bladder cancer, carers of bladder cancer patients, and those engaged with bladder cancer organisations at the national level.<sup>5</sup>

The missions of the World Bladder Cancer Patient Coalition are 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, academics, researchers, and industry.

In its first year of operation, the organisation will focus on Bladder Cancer Awareness Month in May, producing a regular newsletter for stakeholders, and developing a toolkit to help establish and build national bladder cancer patient organisations.

The World Bladder Cancer Patient Coalition welcomes other bladder cancer patient organisations to apply for membership. To be eligible for full membership, organisations must be (a) supporting or rendering services exclusively to bladder cancer patients and their caregivers; and/or (b) raising bladder cancer awareness, promoting bladder cancer research, and empowering organisations that support or render services to bladder cancer patients and their caregivers; and (c) a bladder cancer patient organisation.

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