



# WORLD BLADDER CANCER **Patient Forum 2021**

22 September 2021

## **Changing bladder cancer patient care together**

### **Speaker biographies**

**#BladderCancerForum**

[worldbladdercancer.org](http://worldbladdercancer.org)



World Bladder  
Cancer Patient  
**COALITION**



## Alex Filicevas

**Executive Director, World Bladder Cancer Patient Coalition (WBCPC)**

Alex Filicevas was appointed as the first-ever Executive Director of the World Bladder Cancer Patient Coalition (WBCPC) in October 2019. He has been leading the organisations' efforts to foster an international community of bladder cancer patient advocates. Alex brings with him great past experience in leading EU affairs work at Europe's largest cancer patient umbrella

organisation, the European Cancer Patient Coalition (ECPC).

Prior to this, he also worked as a consultant for many years, supporting a number of private and non-profit organisations in their EU policy and advocacy activities within healthcare. He has also been an active member of All.Can International, serving as a member of its Steering Committee since 2018, and was appointed President in 2020.



## Andrea Maddox-Smith

**Vice-President, WBCPC and Chief Executive Officer, Bladder Cancer Advocacy Network (BCAN)**

Andrea Maddox-Smith is the Vice President of the World Bladder Cancer Patient Coalition (WBCPC). She also currently serves as the CEO for the Bladder Cancer Advocacy Network (BCAN), the founding member of WBCPC. Andrea brings more than 20 years of experience within the voluntary sector.

Since joining BCAN in 2016, Andrea has transformed the organisation's approach, structure and focus and has helped to better the lives of bladder cancer patients. Prior to this, she served 16 years in various leadership roles for the American Diabetes Association (ADA), including her most recent of Senior Vice President.



## Dr Ashish Kamat

**Professor, Department of Urology,  
University of Texas MD Anderson Cancer Center**

Ashish M. Kamat is a Tenured Professor of Urology and Holder of the Wayne B. Duddleston Professorship in Cancer Research established in 2016 in his honor at M.D. Anderson Cancer Center in Houston, TX. Dr Kamat is also the Associate Head of the Cancer Center, Reliance Foundation Hospital in Mumbai, served as the Director of the MD Anderson Urologic Oncology Fellowship from

2005-2016 and is a graduate of the AUA Leadership Program, 2008.

Dr Kamat has made outstanding contributions in urologic oncology, research, education and training in not only in the United States but also globally. He is recognized internationally as an expert in urologic oncology with an emphasis on bladder cancer, immunotherapy, and organ-sparing techniques. Dr. Kamat maintains an active research portfolio in this area with a focus on efforts to develop novel therapies, and identifying predictors of response to therapy. He has initiated, led, and been active in several large studies including multinational trials in bladder cancer; these findings have been published in high impact journals and he is a co-PI on the MD Anderson GU SPORE (Bladder). He holds a patent for a predictive assay (CyPRIT) for intravesical therapy with BCG.

Dr Kamat is an exceptional educator and as Program Director grew the Urologic Oncology Fellowship into the premier program in the US and been nominated twice for the Robert M. Chamberlain Distinguished Mentor Award. He has trained numerous academic urologists who are currently in leadership positions in US, Canada, Chile, Brazil, Japan and India.

Dr Kamat has authored numerous editorials, book chapters, and over 350 publications in peer reviewed journals, and serves on the editorial board of high ranked journals including Journal of Urology and European Urology Oncology. He is listed in 'Who's Who in Medicine' and 'Best Doctors in America' and has won the 'Compassionate Doctor Award' from patient groups. He is recognized internationally for his efforts, been invited as a visiting professor to several universities in the US and elsewhere; to deliver invited plenary sessions nationally (AUA, ASCO, AACR); and internationally (e.g. EAU, JUA, SIU, USI); to chair related committees e.g. Society of Immunotherapy for Cancer (SITC); and as an AUA International Faculty. He developed and chaired special bladder cancer sessions at the EAU annual meeting and, in 2020, he was the only speaker to be asked to speak at two separate sessions at the AUA Plenary Program. He is also the lead for the BCG against COVID19 trial in the US.

Dr Kamat is President of the International Bladder Cancer Group (IBCG), Co-President of the International Bladder Cancer Network (IBCN), Chairs the Bladder Cancer Think Tank, actively participates in various Global urologic efforts (e.g. in setting up cancer centers overseas), serves on the board of regional and national societies for Urology (SCS AUA, Texas Urologic Society) & Urologic Oncology (SUO – CTC) and also in patient advocacy groups (MD Anderson Bladder Support Group, Bladder Cancer Advocacy Network, etc). He is a member of the AUA Guidelines Panel for Bladder Cancer.

He lives in Houston, Texas with his wife and 2 children.



## Dr Bente Thoft Jensen

**Chair, Bladder Cancer Group, European Association of Urology Nurses (EAUN)**

Dr Bente Thoft Jensen (BTJ) Works as Associate professor at Department of Urology, Aarhus University Hospital in Denmark. She has been involved in Urology for more than 25 years as a trained nurse and achieved a MPH as well as a Ph.D. degree in clinical medicine. She was first-mover in multimodal pre & rehabilitation in major uro-oncology surgery with specific emphasis

on exercises, nutrition and mental interventions to counteract the surgical stress response and reduce functional impairment after major bladder cancer surgery and improve patient involvement and supportive care.

BTJ has been involved in international urologic nursing for more than 15 years and chaired the European Association of Urology Nurses (EAUN) for 7 years. Currently she chairs the EAUN Bladder Cancer Group. Moreover, she is now serving as a member of the Scientific Committee and the Guideline-group in the EAUN and the EAU Patient Education Program.

She was one of the initiators of the European School of urology Nursing. Moreover she's the Chair of The European SIG Bladder Cancer Group and chairing the Danish National Nursing Research Counsel.

She has recently done a one year surgical fellowship at the Department of Urology at Memorial Sloan Kettering Cancer Center & MSK Research Laboratory in New York with specific focus on implementing multidisciplinary prehabilitation in uro-oncological pathways.



## Laura Magenta

**Associazione PaLiNuro**

Laura Magenta is a bladder cancer patient since 2016, when she had a radical cystectomy. Since February 2019 she is Assistant to the President of the PaLiNuro Association, the only Italian organization born to inform and support patients with bladder cancer and raise awareness about it. The experience of the disease generated her choice to fully dedicate her professional skill to patient advocacy.



## Lauren Pretorius

### Chief Executive Officer, Campaigning For Cancer

Lauren Pretorius is the CEO and co-founder of Campaigning for Cancer NPC, an advocacy patient group that lobbies for the promotion and protection of patients' rights with regards to policy, healthcare costs and healthcare delivery.

Pretorius has worked in the cancer civil society since 2005.

She was the chief operating officer of Breast Health Foundation, a co-founder of Bosom Buddies and a consultant to the Prostate Cancer Foundation of South Africa, as well as various other cancer charities. Pretorius managed the pilot LIVESTRONG/American Cancer Society's SEI Survivor Forum in South Africa and has represented South Africa as a Global Cancer Ambassador for the UN's Resolution for Non-Communicable Diseases. She chaired the Civil Society Commission at the National Department of Health's NCD Summit and was a member of National Cancer Registry implementation team as well as a founding member of the executive committee of the Cancer Alliance. She serves as a director to the Lymphoma Coalition, an international alliance of 75 lymphoma patient groups across 42 countries. Most recently she was a signatory to the Presidential Health Compact and sat on the Joint Technical Monitoring and Evaluation Committee for the Compact in her role as head of the Patient User Network, a network of 118 health-related patient groups.

As a specialist consultant, she assisted several non-profit organisations in applying business principles and marketing strategies to ensure their greater success and sustainability. From 2000 to 2003 she was contracted to the Nelson Mandela's Children Fund on brand governance and fundraising partner. She has conducted several stakeholder mapping research, developed patient advocacy and engagement strategies for a number of multi-national companies. She launched nine SETA accredited modules that cover various aspects of leading and managing a patient group with the aim to capacity builds patient into effective and professional leaders.

Pretorius has spoken and presented as a key opinion leader at numerous local and international speaking engagements and has published several papers on cancer control. Campaigning for Cancer is a member of multiple local and international coalitions; including the International Kidney Cancer Coalition (IKCC), African Organisation for Research and Training in Cancer (AORTIC); South African Health Technologies and Advocacy Coalition (SAHTAC); Lymphoma Coalition(LC); Childhood Cancer Network SA (CCNSA), South African Journalists' Association (SASJA); Union for International Cancer Control (UICC) Global Lung Cancer Coalition (GLCC); SARCOMA PATIENTS EURONET (SPAEN); International; Waldenstrom's Macroglobulinemia Foundation (IWMF); Acute Leukemia Advocates Network (ALAN) World Bladder Cancer Patient Coalition(WBCPC) Pretorius is currently acting as a member representative to all such coalitions.





## **Dr Lydia Makaroff**

**President, WBCPC and Chief Executive  
Fight Bladder Cancer UK**

Dr Lydia Makaroff is the President of the World Bladder Cancer Patient Coalition and CEO of Fight Bladder Cancer UK. Prior to her current roles, she was the Director at Europe's largest cancer patient umbrella organisation – the European Cancer Patient Coalition (ECPC). Lydia holds a PhD in immunology and a Masters' degree in Public Health and has over ten years' international work experience in non-communicable disease research and policy.

She has worked across many different sectors in health: in academia, the pharmaceutical industry, and the non-profit sector. She previously conducted medical research at the Australian National University; worked as a senior post-doctoral fellow at the University of Washington; and for the International Diabetes Federation as their Epidemiology and Public Health Manager.



## **Dr Maria Rivas**

**Senior Vice President, Head of Global Medical Affairs,  
Merck/EMD Serono**

Dr Rivas is a senior biotechnology executive and experienced public corporate board director.

Dr Rivas is currently the Chief Medical Officer at EMD Serono, the healthcare business of Merck KGaA, Darmstadt, Germany, where she and her team are responsible for translating R&D innovation into commercially promising medicines to positively impact the lives of patients.

Dr Rivas is a board director at Cooper Companies, a public, large-cap medical device company. Previously, Dr Rivas served as a board director at Medidata, a public mid-cap health technology company until its successful M&A to Dassault Systemes.



## **Melanie Costin**

**Fight Bladder Cancer UK**

Melanie Costin is the Support Services Manager for Fight Bladder Cancer and a bladder cancer patient. Her role has many facets, including creating information and support resources; running support groups; raising awareness; running the Bladder Buddy service; advising on clinical trials; and being an administrator on a private forum.

When she gets invited to medical meetings, she ensures that the patients' voice is heard.



## Nathalie Bere

### Patient Engagement, European Medicines Agency (EMA)

Nathalie has been working with the EMA since 1998 and is currently responsible for its engagement with patients and consumers.

Over the years, Nathalie has been testing and implementing various methodologies to include the patient's voice in all aspects of the regulatory lifecycle of a medicine. As a steady increase in patient engagement at EMA has been observed, Nathalie continues to further strengthen and diversify these activities and ensure they are fit for purpose in an evolving health landscape.

Nathalie holds a master's in public health and a Bachelor of Science in Psychology.



## Susan Mullerworth

### Bladder Cancer Patient Advocate

Susan, diagnosed with Stage 3 High Grade Advanced Bladder Cancer, November 2017. A mental health Counsellor, and Patient Advocate. Susan enjoys family life and travel. Prior to diagnosis Susan had not heard of Bladder Cancer despite a lifetime of associations with other cancers. Susan describes herself as a natural carer and probably a challenging patient.

After opting for life changing surgery namely a Radical Cystectomy, Susan connected with the Fight Bladder Cancer Charity UK and is a voice for bladder cancer and a 'bladder buddy' to fellow patients. Susan's mission is to continue raising awareness of bladder cancer worldwide through advocacy and patient groups.



## Tony Cornacchia

### Bladder Cancer Canada

Tony is a metastatic bladder cancer survivor, first diagnosed in 2014. After 4 TURBT's and a number of different treatment regimes he has successfully participated in a Clinical Trial for Immunotherapy since late 2016. Along with volunteering at Bladder Cancer Canada, he is an active board member and previous Chair of his children's school Parent Council.

He is a buyer for an International Importer and Exporter of various grain products. Tony and his wife Nadia along with their 2 teenaged daughters enjoy entertaining family and friends by the family pool and during Covid times try to find creative ways to stay connected with the family's virtual game nights.



## Dr Wassim Kassouf

**Professor, Urologic Oncology,  
McGill University Health Center**

Dr Wassim Kassouf completed a fellowship in urologic oncology at M. D. Anderson Cancer Center in Houston, Texas following medical school and urology residency at McGill University. Dr Kassouf's clinical practice focuses on all aspects of urologic oncology whereas his research focuses on refining organ preservation approaches in bladder cancer. He is a Professor in

the Division of Urology and Vice-Chair, academic affairs, of the Department of Surgery at McGill University.

He has led several national guidelines for optimizing quality of care in urologic cancer management and has published over 360 peer-review manuscripts and book chapters. He served as an associate editor for BMC Urology, and currently the bladder cancer section editor for CUAJ, and is/has been on the editorial board of Urology, Clinical Cancer Investigation Journal, and International Brazilian Journal of Urology. He is the founder of the national Canadian Bladder Cancer Network, a cofounder of Bladder Cancer Canada, GU co-chair of the Canadian Clinical Trials Group, and an executive member of the NIH Genitourinary steering committee Bladder Cancer Task Force. Dr Kassouf is a graduate of the AUA Leadership Program and received several prestigious awards including the AUA Young Urologist of the Year, AUA Research Scholar Award, Quebec FRQS Distinguished Research Scholar Award, and Bladder Cancer Canada Medical Leadership Award.

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