

A Call to Arms: moving forward from "Fostering the Partnership" Canadian GU Cancers Survivorship Conference 2011

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Fostering the Partnership was a unique and innovative forum for genitourinary (GU) cancer survivors, advocacy groups and health care professionals (HCPs) to explore ways to collaboratively enhance GU cancer survivorship. The idea evolved from the growing recognition that new models of care are required to: (a) meet the diverse needs of an increasingly active and informed patient population; (b) respond to the desire of cancer survivors to give back; and (c) leverage their growing skill set as expert patients and potential research collaborators. The event, endorsed by the Canadian Urological Association, the Canadian Uro-Oncology Group and the Urology Nurses of Canada, and supported by industry partners, was held on January 19-20, 2011 in King City, Ontario. Forty-three individuals attended: 18 cancer survivors/caregivers, 22 HCPs and 3 researchers representing bladder, kidney, prostate and testicular cancers, clinical subspecialties and GU patient advocacy groups, including Bladder Cancer Canada, Kidney Cancer Canada, Prostate Cancer Canada and the Canadian Testicular Cancer Association. The event was an overwhelming success. Evaluations showed that 99% of attendees were extremely pleased with the event and would like to hold another. The following were identified as priorities. Meeting participants would like the Canadian GU community to recognize them as important future initiatives.

1. Review current strategies and best practices that foster partnerships between cancer survivors and HCPs.
2. Assess the knowledge of HCPs regarding the needs of GU cancer survivors, existing advocacy groups/community support organizations and their services, as well as barriers and facilitators for promoting active partnerships with cancer survivors.
3. Establish priorities for GU cancer survivorship research with collaborative input from and participation by GU cancer survivors and HCPs.
4. Facilitate direct communication, knowledge exchange and collaboration between GU cancer

- survivor advocacy groups and the HCPs.
5. Facilitate networking, collaborative programming and fundraising among GU cancer survivor advocacy groups.
6. Define the ideal patient journey for each GU cancer type, identify gaps in current services, and disseminate tools (e.g., Survivorship Care Plan/ Passport to Health) to facilitate improvement in these areas.
7. Synthesize up-to-date information about GU cancer survivor advocacy groups/community support organizations and their services in an easy-to-access, web-based format for HCPs and cancer survivors.
8. Facilitate ongoing opportunities for peer-to-peer support, community building and networking among GU cancer survivors throughout the cancer journey.
9. Hold a follow-up conference led collaboratively by GU cancer survivors and HCPs based on the recommendations of this report.

This is our "Call to Arms" to you, our colleagues. It is time to embrace survivorship in our practices and address these priorities. A complete description of the event, its recommendations and strategies to accomplish them is forthcoming.

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Conference attendees: Stephen Andrew, Armen Arikian, Peter Armstrong, Andrew Attwell, Naveen Basappa, Joan Basiuk, Christina Canil, Joseph Chin, Deborah Erwin, Michael Evans, Doug Gosling, David Guttman, Mary Gospodarowicz, John Hastie, Doris Howell, Alejandro R. Jadad, Glenn Jones, Ada Jeffery, Laura Legere, Curtis Legrow, Kevin Leonard, Andrew Loblaw, Barry Marvel, Deborah Maskens, Andrew Matthew, Valerie McLeod, Dale Miron, Jack Moon, Ronald Moore, Howard Pai, Gerry Pielsticker, Heather Pugh, Roanne Segal, Michael Sharpe, Bob Shiell, Heather Sinardo, Alan So, William M. Tatham, Scott Tyldesley, Padraig Warde, Diane Zipursky Quale

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