



2019 Annual Report

Board of Directors

John Adams, Chair
Diana Ermel, Treasurer
Ganive Bhinder
Gerald Major

Chair Report (Highlights presented at the Annual General Meeting, September 25, 2019)

Overview

- The Best Medicines Coalition (BMC) remains a strong and credible voice for Canadian patients, focussed on its mission that all Canadians have safe, equitable, timely and comprehensive access to medications, which have been shown, based on best available evidence, to improve outcomes for patients.
- The BMC continues to address each of its stated goals:
 - Drug programs that deliver high standards of equitable and consistent access to medications for all Canadians.
 - Clinical trial, drug review and post-marketing surveillance systems that effectively address patient safety and ensure that patients have knowledge of risks and benefits throughout drug lifecycle.
 - Effective models for meaningful and equitable patient participation in clinical trials, drug reviews and policy development.
- BMC's membership includes diverse patient groups including both not-for-profits and health charities, each representing a specific patient community and actively involved in work related to the BMC's mission. At the time of this Annual General Meeting, the BMC has 28 member organizations, including Canadian Cancer Survivor Network, Cystic Fibrosis Canada, Huntington Society of Canada and Hypertension Canada, which were welcomed in the past year.

Organizational Structure and Governance

- The BMC Board of Directors provides governance and leadership to the coalition through discussions at Board meetings and ongoing communications. At the 2018 Annual General Meeting, Gail Attara, Ganive Bhinder and Gerald Major were elected for one-year terms, joining John Adams and Diana Ermel, who began the second year of their two-year terms as Chair and Treasurer, respectively. In June 2019, Gail Attara resigned from the Board.
- Paulette Eddy, Executive Director, provides management services to the BMC and Ron Kenny provides administration, both retained on an ongoing consulting basis. Jay Strauss also provides administrative and communication services on a project basis, and the BMC occasionally receives consulting assistance on projects in a range of areas, including facilitation, research and policy development.
- As highlighted in the 2018/2019 financial statements prepared by the public accountancy firm of Kreston GTA, and reviewed at this Annual General Meeting, the BMC remains in a stable position financially and has demonstrated financial practices in accordance with recognized standards.
- The BMC continues to adhere to the BMC *Code of Conduct Regarding Funding* which outlines guidelines on funding arrangements and relationships with the goal of safeguarding the BMC's independence and credibility, and is publicly available on our website. The BMC also fully supports the *Canadian Consensus Framework for Ethical Collaboration*, a guidance document developed in partnership with the Canadian Medical Association, Canadian Nurses Association, Canadian Pharmacists Association, Health Charities Coalition of Canada, and Innovative Medicines Canada. These documents are available at <https://bestmedicinescoalition.org/about/support/>.



- The BMC receives unrestricted funding from pharmaceutical industry sources, in accordance with the BMC *Code of Conduct Regarding Funding* to ensure activities undertaken serve the coalition's mission and goals and are not influenced by commercial interests. In 2018/2019 (fiscal year ending March 31, 2019), BMC received funding from: AstraZeneca Canada, GSK Canada, Gilead Sciences Canada, Innovative Medicines Canada, Merck Canada and Pfizer Canada.

Coalition and Capacity Building

- In the past year, the BMC hosted two major conferences for member organizations providing opportunities for issue education, networking and discussion among participants. Policy decision makers, stakeholders and other experts are included in conference proceedings to share developments and insights through presentations and discussions.
 - The November 2019 BMC conference, *National Pharmacare and Other Issues: Review and Discussion*, examined National Pharmacare funding issues. Members discussed funding options and shared perspectives which informed a subsequent position document. The conference also included a panel discussion on CADTH patient engagement issues, and an overview of pharmaceutical intellectual property protection.
 - The June 2019 BMC conference, *Pharmaceutical Policy, Access and Patient Voice: Issues and Opportunities*, included a panel presentation with representation from industry and public and private payers regarding current environmental challenges. A session on the national political environment included a presentation regarding 2019 federal election issues. Members also participated in a round table discussion on principles of patient involvement in health policy development.

Priority Issues

- The BMC's priority issues are directly connected to its mission and goals as follows: regulatory oversight, pharmaceutical assessment, drug supply and patient access and reimbursement. National Pharmacare reform and the related issue of drug pricing has been a significant focus, including in the last year. Improving the patient voice in policy development and decision making is an ongoing priority and in the past year a major project was initiated in this area. Following are highlights of BMC work on these issues:

Priority Issues/ National Pharmacare Reform/Drug Pricing

- Throughout the past year, long term reform including national pharmacare was a major focus for the BMC, building on the important work in the first half of 2018 regarding the Advisory Council on Implementation of National Pharmacare. Ongoing interaction with the Advisory Council members and staff continued throughout late 2018 and through 2019, through meetings and correspondence. A series of meetings with leading officials and political staffers were organized for Chair John Adams where he was given an opportunity to share and reinforce BMC positions on key issues including National Pharmacare, drug pricing and government restructuring including the proposed Canadian Drug Agency.
- As an adjunct to the core submission to the Advisory Council, BMC prepared and provided a position document on funding of National Pharmacare, presenting member-driven perspectives on options including taxation and patient cost sharing. The document was shared with the Council and relevant stakeholders.



- As the Advisory Council released its interim and final reports, the BMC provided brief position points, informed by its core consensus-based submission to the council, stressing the need for reform which achieves equitable and comprehensive care at the highest level for all Canadians. The BMC outreached to media and other stakeholders to communicate these positions. Formal correspondence outlining BMC's response was sent to federal, provincial and territorial political leaders.
- Reform of Canada's framework for regulating pharmaceutical prices continued as a major focus through 2018/2019 as consultations regarding the mandate of the Patented Medicines Prices Regulation Board were underway. The BMC was fully involved through this process providing opportunities for member organizations to learn about these issues and liaising with other health stakeholders and policy decision makers. BMC was represented on the PMPRB's Steering Committee and provided support, including preparation of formal input. As the regulatory reform process has unfolded, BMC continued to voice concerns about future timely access to emerging medicines for unmet needs stressing that regulations must facilitate the ability of Canadian patients to get the drugs they need when they need them.

Priority Issues/Pharmaceutical Regulatory Oversight/Drug Supply

- The BMC continues to advocate on behalf of patients to ensure that regulations protect the needs and interests of patients and contribute to optimal patient care. The BMC is frequently called upon by Health Canada and others to participate in consultations and provide patient group representation. The BMC has been involved in other federal policy issues, including medical cannabis where BMC joined other health organizations to call for reduced taxation as medical cannabis is the only medicine subject to taxation.
- In addition, BMC has been involved in international regulatory consultations. For example, BMC has recently been invited to speak for Canadian patients at a global public consultation on harmonizing rules for clinical trials across many health regulators.
- Drug shortages are an ongoing issue, sometimes with critical shortages impacting patient care. The BMC continues to provide input, along with other stakeholders, through representation on Health Canada's multi-stakeholder committee on shortages.
- Recent developments in the U.S.A. have potential to exacerbate these already critical shortages, with laws and plans to enable mass importation of drugs meant for Canadian patients to the U.S.A. The BMC joined forces with other Canadian health organizations including the Canadian Medical Association, the Canadian Pharmacists Association and the Alliance for Safe Online Pharmacies to express concerns and call for action by the Federal Government. This resulted in first a meeting with the Health Minister and then a technical briefing for the group, and work will continue. In addition, BMC Chair John Adams was sought out by the Partnership for Safe Medicines, a U.S.A.-based advocacy non-profit, to provide a Canadian patient perspective to Washington policy makers.

Priority Issues/Patient Access and Engagement

- Pursuing opportunities to ensure programs deliver optimal, equitable, and consistent care to patients within a challenging access and reimbursement environment continues to be an important part of the BMC's advocacy activities. The pan-Canadian Pharmaceutical Alliance (pCPA) is an important body and the BMC continues to be involved in liaison with the pCPA regarding patient positions and establishing opportunities for coalition members to be briefed on pCPA developments.
-



- The BMC continues to advocate for improved patient engagement and incorporation of patient perspectives in policy development and decision-making regarding pharmaceuticals. Regarding the Canadian Agency for Drugs and Technology Assessment (CADTH), for example, BMC used its involvement with the *CADTH Patient Community Liaison Forum*, as a network for raising issues regarding the role of patients in health technology assessments and laying the groundwork for CADTH's new patient and community advisory body.
- In mid-2019, the BMC initiated a significant project in conjunction with the Health Charities Coalition of Canada aimed at improving the role of patients in health policy development and decision making. The project involves gathering input from BMC and HCCC member organizations through discussions and surveys on concerns and best practices and using that to inform content for a discussion paper with recommendations for policy makers.

As members of the BMC, we will continue to work together to ensure strong and credible representation of patient groups in all aspects of policy development regarding pharmaceutical care, particularly critical in this period of important discussion and reform.

Thank you, members of the BMC, for your work on behalf of Canadian patients.

John Adams
Board Chair, Best Medicines Coalition
President and Chief Executive Officer, Canadian PKU & Allied Disorders