



## 2021 Annual Report

### Board of Directors

John Adams, Chair  
Diana Ermel, Treasurer  
Michel Long  
Gerald Major  
Kim Steele

Highlights presented at the Best Medicines Coalition Annual General Meeting, October 19, 2021:

### Overview

- The Best Medicines Coalition (BMC) remains a strong and credible voice for patients in Canada. The BMC is focussed on ensuring that all patients are able to access a comprehensive range of drugs and related treatments in a equitable, affordable and timely manner, and that policies and decisions are informed by patient-driven evidence and values.
- The BMC's work is guided by the following standing goals, developed through the 2020/2021 strategic priorities initiative:
  - Effective models for meaningful, proactive, and impactful patient engagement in health and pharmaceutical policy development, recommendations and decision making, where patients and patient organizations are recognized as legitimate and integral contributors and patient-informed evidence is valued and incorporated.
  - Drug programs deliver higher standards of equitable and consistent access to a comprehensive range of safe, effective, and affordable medicines for all patients in a timely manner.
  - Streamlined, transparent and accountable health policy and regulatory frameworks uphold patient-driven principles, invest in both incremental and breakthrough advancements, provide improved pathways to timely access to all medically necessary medications, protect patient safety and ensure ongoing secure drug supply.
- BMC's membership includes diverse patient organizations, 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 29 member organizations, including the most recent addition of Migraine Canada.

## Organizational Structure and Governance

- BMC is organized as a not-for-profit corporation under federal law and its Board of Directors provides governance and leadership through discussions at Board meetings and ongoing communications. At the 2020 Annual General Meeting, Kim Steele was elected to the Board along with continuing Directors John Adams, Diana Ermel, Michel Long and Gerald Major. At a subsequent Directors meeting, John Adams was again appointed as Chair commencing a two-year term, and Diana Ermel was again appointed as Treasurer for a one-year term. In August 2021, Gerald Major announced he would not seek another term as a Director, following several years of providing valuable input to the BMC informed by his advocacy work, representing Medical Cannabis Canada and, previously, the Canadian Spondylitis Association.
- Paulette Eddy, Executive Director, provides management services to the BMC, and Ron Kenny provides accounting services, both retained on an ongoing consulting basis. Jay Strauss provides communications and government outreach services on a project basis, and the BMC receives advice and assistance from various consultants on projects in a range of areas, including facilitation and public policy.
- As highlighted in the 2020/2021 financial statement and review prepared by public accountancy firm Kreston GTA, and reviewed at this Annual General Meeting, the BMC remains stable financially and has demonstrated financial practices in accordance with recognized standards for non-profits.
- 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 BMC members are required to adhere to this Code. BMC also fully supports the *Canadian Consensus Framework for Ethical Collaboration*, a guidance document developed in partnership with Canadian Medical Association, Canadian Nurses Association, Canadian Pharmacists Association, Health Charities Coalition of Canada, and Innovative Medicines Canada, available at <https://bestmedicinescoalition.org/about/support/>.
- The BMC receives funding from pharmaceutical industry sources, received in accordance with the *BMC Code of Conduct Regarding Funding*, ensuring that activities undertaken serve the coalition's mission and goals and are not influenced by commercial interests. In 2020/2021 (fiscal year ending March 31, 2021), BMC received funding from: AstraZeneca Canada, GSK Canada, Gilead Sciences Canada, Innovative Medicines Canada, Janssen Canada, Merck Canada, Novartis Canada, NovoNordisk Canada and Pfizer Canada.
- Given limitations necessitated by the COVID-19 pandemic, the BMC did not hold in-person conferences in the 2020/2021 fiscal year (beginning April 1, 2020 and ending March 31, 2021). Instead, BMC hosted webinar-style presentations where external experts delivered educational overview and issue-specific presentations, updating on the policy and policy developments and implications, followed by facilitated discussions.
- In this period, BMC shifted its focus to support active working groups, providing opportunities for representatives of member organizations to gather virtually to learn and update, discuss policy implications, and together develop action plans and draft BMC positions.

- In late 2020, the BMC proceeded with a strategic priorities initiative to identify current pharmaceutical access challenges and identify priorities to guide the work of the coalition moving forward. The initiative began with Board Directors and other representatives identifying and discussing issues, which in turn informed an extensive survey which was completed by members in early 2021. Survey results were then presented to members and discussed. Finally, a draft strategic priorities outline was circulated to member organizations and revised to reflect further input. As a result, BMC has a refreshed mission statement and standing goals, pending final Board approvals, as outlined earlier in this document.

## **Priority Issues**

- In 2020/2021, in addition to COVID-19 related-issues, pharmaceutical pricing regulatory reform continued as a dominant issue and work proceeded regarding rare disease strategy, broad pharmaceutical reform, drug supply, and patient engagement. Following are highlights on priority issues in 2020/2021:

### **Priority Issues: Pharmaceutical Pricing**

- The movement to reform Canada's framework for regulating pharmaceutical prices began in 2016 and in 2020/2021 advocacy on behalf of patients to ensure pricing regulations do not hinder patient access to therapies continued as a BMC focus. Throughout this period, BMC has provided opportunities for member organizations to learn about complex pricing issues, liaised with other patient coalitions regarding positions and strategies, and consistently voiced patient-driven consensus positions to decision makers. There has been success to date in terms of prompting a pause in implementation of the regulations.
- Formal communications through 2020/2021 were numerous, including submission and testimony to the House of Commons Standing Committee on Health as part of its consideration, submissions to the Patented Medicines Prices Review Board (PMPRB) regarding versions of draft Guidelines to implement the proposed regulations, pre-budget submissions, as well as formal correspondence to the Federal Minister of Health and other Parliamentarians. Throughout this period, BMC executed a comprehensive advocacy program to communicate positions directly to federal officials and Parliamentarians, through one-on-one discussions and meetings. In addition, BMC liaised with a variety of stakeholders on pricing issues and positions, including the pharmaceutical industry, academic community, and others.
- A dedicated group of representatives of BMC member organizations took an active role as part of the BMC PMPRB Working Group to facilitate collaboration among member organizations to drive position development and continuing advocacy moving forward.

### **Priority Issues: Rare Disease Strategy**

- In 2021, consultations commenced on the development of a National Strategy for High-Cost Drugs for Rare Diseases. BMC took an active role in initial Health Canada stakeholder consultations, including facilitating involvement of member organizations in briefings. BMC developed a consultation document outlining consensus positions informed by interviews with member organizations, drafting and review of core positions and discussion points. BMC has called for a broad approach to rare disease strategy focussed on improving patient care and outcomes and urging the federal government to move beyond a narrow focus on drug costs.

- BMC's continued advocacy work on rare diseases has strong support from a range of BMC members. Several representatives of organizations with a specific interest in this area formed a BMC Rare Disease Working Group to update, review issues, recommend positions and develop advocacy strategies.

### **Priority Issues: Pharmaceutical Policy Reform, Assessment and Reimbursement**

- Regarding ongoing pharmaceutical policy reform, BMC continued to be active in putting forward patient-driven positions on National Pharmacare and related topics, building on its extensive advocacy related to the *Advisory Council on the Implementation of National Pharmacare*. Where possible, BMC has stressed the need for all patients to have access to a comprehensive range of medicines and to reduce the burden of out-of-pocket drug costs, including, for example, in discussions related to the proposed Canadian Drug Agency and potential National Formulary.
- BMC pursues opportunities to provide patient-driven positions to those agencies involved in pharmaceutical policy and management, including Health Canada, Canadian Agency for Drugs and Technology in Health (CADTH), the panCanadian Pharmaceutical Alliance (pCPA) and provincial/territorial drug programs. For example, the BMC is frequently called upon by Health Canada and others to participate in consultations and provide patient representation including regarding Health Canada's self care review and reform initiative, facilitating input from member organizations. In addition, as in previous years, BMC participated in Health Canada's general stakeholder briefing session.
- Regarding private, employer-based drug programs, concerns about diminished coverage resulting from COVID-19 job loss were expressed by member organizations. BMC surveyed members on trends and patient impact, communicated results and continued monitoring.
- The BMC took an active role in communicating positions to CADTH regarding its review of deliberative processes for drug reviews, participating in stakeholder sessions and liaising with member organizations to provide informed input.
- BMC is sometimes called upon to provide input on international policy deliberations regarding pharmaceuticals. For example, BMC provided input to a consultation of the International Council for Harmonization of Technical Requirements for Pharmaceuticals for Human Use (*ICH*) regarding patient-focused drug development, liaising with other patient organizations under the leadership of Clinical Trials Ontario.

### **Priority Issues/Drug Supply**

- Drug shortage and supply challenges are ongoing with strong potential to negatively impact patient care. The BMC continues its work as the sole patient voice on the Multi-stakeholder Steering Committee – Drug Shortages (MSSC – DS), co-chaired by Health Canada and a province/territory with Ontario serving in this role through to end of 2020. BMC's Denis Morrice represents the BMC on the MSSC – DS, reporting on shortages experienced by patients and raising patient perspectives on policy issues.

- Due to COVID-19, specific drug shortages escalated because of treatment protocols and supply chain disruptions. BMC participated in MSSC-DS meetings sharing shortage information and perspectives on mitigation measures, along with other stakeholders. For example, the BMC advocated for policies which support patient care and outcomes such as in consideration of 30-day prescription restrictions. In addition, the BMC continued to communicate with federal officials and Parliamentarians that measures to address drug shortages must be prioritized, moving beyond short-term measures.
- BMC continued to liaise with other stakeholders, including the Association for Safe Online Pharmacies, in monitoring ongoing and emerging developments in the United States that have potential to exacerbate already critical shortages by enabling mass importation of drugs meant for Canadian patients.

### **Priority Issue: Patient Engagement**

- The BMC continues to advocate for improved patient engagement and incorporation of patient perspectives in health policy development and decision-making, including regarding pharmaceuticals. Throughout 2020/2021, in all communications and advocacy efforts, BMC continued to stress the value of meaningful patient engagement and the need to establish appropriate channels and processes to enable fulsome dialogue and incorporation of perspectives.
- A joint initiative with the Health Charities Coalition of Canada to develop a patient engagement position paper was postponed due to COVID-19 and competing priorities within the health charity sector, The BMC plans to continue work on developing formal positions on this topic.
- BMC is frequently asked to provide patient perspectives and positions as various health stakeholders review issues and develop positions. For example, together BMC member organizations reviewed and inputted to the National Association of Pharmacy Regulatory Authorities (NAPRA) on medication incident reporting processes.