



## 2024 Chair Report

### **Board of Directors**

John Adams, Chair  
Kim Steele, Vice-Chair  
Diana Ermel, Treasurer  
Wendy Gerhart  
Michel Long

Presented at the **Best Medicines Coalition Annual General Meeting**, September 25, 2024.

### **Introduction:**

- Guided by its mission statement, the Best Medicines Coalition (BMC) is a strong and credible patient voice, focussed on member issue education, consensus-based position development and policy advocacy, striving to ensure that patient-driven positions are heard by decision makers and those who inform and influence policy development.

***Mission Statement:*** The BMC seeks timely access to a comprehensive range of medically necessary, safe, and effective drugs and related treatments, informed by patient-driven evidence and values, and delivered equitably and affordably to all patients in Canada.

- Serving this mission, the BMC pursues the following standing goals, most recently revised in 2022:
  - Effective models for meaningful, proactive, and impactful patient engagement in health and pharmaceutical policy development 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.

### **Structure and Governance:**

- The BMC is comprised of 30 patient organization members, including the recent addition of the cancer collaborative in March 2024. As a condition of membership, all organizations must operate with a recognized governance structure, such as not-for-profit incorporation or registered charity status, and be actively involved in work related to the BMC's mission and goals.

- BMC is a registered not-for-profit corporation which operates under the direction of a Board of Directors comprised of representatives of member organizations and elected annually. At the 2023 Annual General meeting, Diana Ermel, Wendy Gerhart, Michel Long and Kim Steele were elected to the Board of Directors, continuing previous terms, with John Adams entering the second year of a two-year term. At a subsequent Board meeting, Kim Steele was appointed Vice-Chair and Diana Ermel appointed again as Treasurer.
- Diana Ermel has decided to step down from her Board Director role. We wish to thank Diana for her many years of service to the BMC on the Board, always providing thoughtful and common sense advice on all topics of discussion, and taking on the role of Treasurer and its responsibilities. Thank you, Diana.
- Sarah Rogers, Brain Tumour Foundation of Canada, has come forward as a candidate for the Board, and so we put forward her name, along with John Adams, Wendy Gerhart, Michel Long and Kim Steele, to be Directors. We look forward to working with you, Sarah.
- Paulette Eddy provides management services to the BMC as Executive Director, Jay Strauss provides communication and coordination services, and Ron Kenny provides accounting services, each retained on a consulting basis. In addition, BMC receives assistance from other consultants as needed, including on policy and government relations.
- As stated in the report and financial documents for fiscal year ending March 31, 2024, prepared by public accountancy firm Kreston GTA, and presented at this Annual General Meeting, the BMC is financially stable and demonstrates financial practices in accordance with recognized standards for not-for-profits.
- The BMC and its member organizations adhere to a *Code of Conduct Regarding Funding* (available [here](#)) which offers guidance on funding arrangements to ensure that activities undertaken serve the coalition's mission and are not influenced by commercial interests. BMC also 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, Food, Health & Consumer Products of Canada, Health Charities Coalition of Canada, Innovative Medicines Canada, and Medtech Canada.
- The BMC receives funding from pharmaceutical industry sources, including in 2023/2024 from: Abbvie Canada, Amgen Canada, AstraZeneca Canada, GSK Canada, Innovative Medicines Canada, Janssen Canada, Merck Canada, Novartis Canada, NovoNordisk Canada, Pfizer Canada and Takeda Canada.

**Core function overview:**

The BMC's ongoing core activities encompass capacity and consensus building, direct advocacy, and outreach and awareness, as outlined below:

**Capacity and Consensus Building.** BMC educates members on relevant policy issues and facilitates the development of consensus positions through expert presentations, information sharing and discussions at meetings, webinar-style sessions and working group discussions. Efforts focus on ensuring an inclusive and comprehensive approach to building consensus and presenting patient-driven positions in effective submissions and other formal documents.

**Direct Advocacy.** Where policies related to how patients access necessary medicines are under review, BMC ensures that patient perspectives are heard by policymakers through discussions, meetings and conferences, and by participating in consultations, including with Health Canada, Canada's Drug Agency (CDA-AMC), Patented Medicine Price Review Board (PMPRB), pan-Canadian Pharmaceutical Alliance (pCPA) and private and public drug programs.

**Outreach and Awareness.** BMC shares patient-driven positions with stakeholders and influencers, amplifying the patient voice and informing discussions, communicating directly and through media/social media, conferences and other platforms. Where appropriate, the BMC pursues collaborative projects to further educate and build awareness.

#### **Coalition activities, priority issues: 2023/2024**

##### **Coalition education, information sharing and priority setting:**

- The BMC hosted an in-person member conference on June 13, 2023, the first since prior to the COVID-19 pandemic. Representatives from most BMC member organizations participated, learning from expert presenters and sharing insights and experiences on current challenges and barriers to patient care and access to drugs and related treatments. With a workshop format, the meeting culminated in identifying priorities for future advocacy.
- In January 2024, the BMC initiated a bi-weekly member information bulletin, *BMC Roundup*, providing updates on advocacy efforts, opportunities to input on policy consultations, relevant events and reports, as well as recognizing noteworthy member highlights. In addition, member organizations use this platform to share developments, events and issue-specific reports.
- Through the period, the BMC supported active working groups, as well as several ad-hoc member meetings on specific topics, providing opportunities for representatives of member organizations to gather virtually to learn about issues, share perspectives and plan action points on specific files. In 2023/2024 the following working groups were active, each meeting several times throughout the year:
  - National Pharmacare Working Group
  - Drug Pricing (PMPRB/pCPA) Working Group
  - Drug Supply Working Group
  - Rare Disease Strategy Working Group
- The BMC has continued to facilitate virtual education and discussion opportunities for member organizations, with updates on policy developments and discussions. Notably, the BMC provided opportunities for members to learn about the public policy environment, offering several national issues updates throughout the period, with Santis Health consultants sharing information and insights on priority policy files.

##### **Advocacy Priorities: 2023/2024**

- As part of its priority setting exercise at the June 2023 meeting, BMC member organizations together explored common barriers to access drugs and related treatments, and identified advocacy targets for the period, as follows:

**Extended delays:** Lengthy drug approval and reimbursement decision processes prolong delays for necessary drugs to get to patients. Long wait times are exacerbated by complex and convoluted processes, and this applies to all drugs and related treatment but are particularly critical regarding treatment of complex diseases.

**Inequities:** Variability of treatment and care across jurisdictions, settings and drug programs creates significant inequities. Systems are marked by inconsistent and uncertain reimbursement by geography and critical private and public drug plan gaps for a wide range of drugs and related treatments, vaccines and specialty medicines.

- In addition to the above, the following related challenges were identified: uninsured and underinsured patients, including prohibitive co-pays; drug supply disruptions including drug shortages; and medicines and vaccines not introduced/available in Canada.
- Based on the above priorities, BMC members identified the following advocacy goals for 2023/2024, and beyond:

***Simplify and Expedite Processes:*** Streamline, simplify and rethink drug approval and reimbursement processes to get necessary drugs to patients in a timely manner while recognizing the value and contribution of innovation.

***Improve equity:*** Address provincial and territorial drug program and employment status access disparities, often called the postal code lottery, with consistent, predictable and equitable access to necessary medicines and other treatments while tackling cost barriers.

***Effective national oversight:*** Improve drug access oversight through an effective Canada's Drug Agency, health technology assessment and initiatives related to the concept of national pharmacare, drugs for rare diseases, drug pricing regulation and other national initiatives, promoting a unified and standardized approach and a focus on improved patient care and outcomes.

***Secure supply.*** Institute mechanisms to ensure secure supply of all medicines and measures to avoid discontinuation of drugs patients need.

**Priority issues:**

Driven by its mission, standing goals, and advocacy targets, the BMC focused efforts on key priority issues during 2023/2024, outlined below:

***National Pharmacare:***

- In late 2023/early 2024, the BMC reviewed its policy positions on National Pharmacare in preparation for enabling legislation which emerged as Bill C-64, the Pharmacare Act, introduced in Parliament in late February 2024.
- The BMC National Pharmacare Working Group spearheaded a review of 2018/2019 positions, developing renewed points and proposed legislative amendments. Recommendations included strengthening the patient voice through an empowered Chief Patient Officer with lived experience inside Health Canada, a Patient Ombudsman reporting independently to Parliament and accountability measures such as required annual reporting, and the introduction of an exceptional patient pathway.
- BMC was invited as a witness to the House of Commons Health Committee hearings on Bill C-64, the Pharmacare Act, in May 2024.
- Related to National Pharmacare, the BMC continued to engage with policymakers on ongoing national pharmaceutical policy reform considerations, such as the newly formed Canada's Drug Agency, including participating in briefing sessions and sharing perspectives on issues and frameworks.

### ***Drug Pricing:***

- Through the BMC Drug Pricing Working Group, the BMC continued its work regarding the Patented Medicines Price Review Board (PMPRB) regulations and pan-Canadian Pharmaceutical Alliance (pCPA) negotiations, with the goal of improving timely access to new medications.
- The BMC continued to relay its core advocacy positions as the PMPRB conducted consultations, focussing on incorporating the patient voice through meaningful engagement and encouraging the PMPRB to conduct impact assessments on all proposals.
- The BMC presented to the PMPRB in person in December 2023 as part of its consultation on the development of new Guidelines, and reiterated points in a written submission. The BMC also presented to the House of Commons Standing Committee on Health (HESA) as part of its consideration of PMPRB issues in April 2023.
- Regarding the pCPA, the BMC initiated several points of contact given pCPA's restructure and new leadership. The pCPA presented to BMC in April 2024, outlining processes and progress, and providing an opportunity for BMC members to voice issues of concern and areas of improvement.
- As the pCPA consulted on the pan-Canadian Temporary Access Process (pTAP), the BMC stressed that improved transparency and accountability, and faster patient access must be enshrined as fundamental goals, and that the framework must be designed to encourage drug developer participation.

### ***Rare Disease Strategy:***

- The BMC continued its leadership role bringing the patient voice to the development of a National Strategy for Drugs for Rare Diseases, along with other patient organizations. Within BMC, representatives of member organizations continued involvement in the BMC Rare Disease Strategy Working Group to review and discuss issues, recommend positions and develop advocacy strategies.
- The BMC has called on the government to establish a clear path forward, and work to streamline processes to deliver efficient and timely care to ensure that the framework is built on collaboration and transparency with improved engagement with patients. The BMC supports a fully resourced framework, with more robust data and evidence, and policies which will deliver comprehensive care which addresses patient exceptionality.
- The National Strategy for Drugs for Rare Diseases' Implementation Advisory Group has provided an avenue to directly inform decision makers, with BMC represented by Board Chair John Adams, and Board Vice-Chair Kim Steele as alternate. While progress on implementation has been slow and extensive work is yet to be done to bring the strategy to fruition, the BMC is well placed to have a strong role in this process and to bring patient positions forward in this next phase.

### ***Drug Supply and Shortages:***

- Drug shortage and supply issues continue to disrupt patient care, and the BMC remains active on this file, spearhead by the Drug Supply Working Group.
- The BMC continues as the sole patient voice on the Multi-Stakeholder Steering Committee on Drug Shortages (MSSC), convened by Health Canada and a rotating provincial co-chair. Through this forum, the BMC reports on shortages experienced by patients and various related issues.

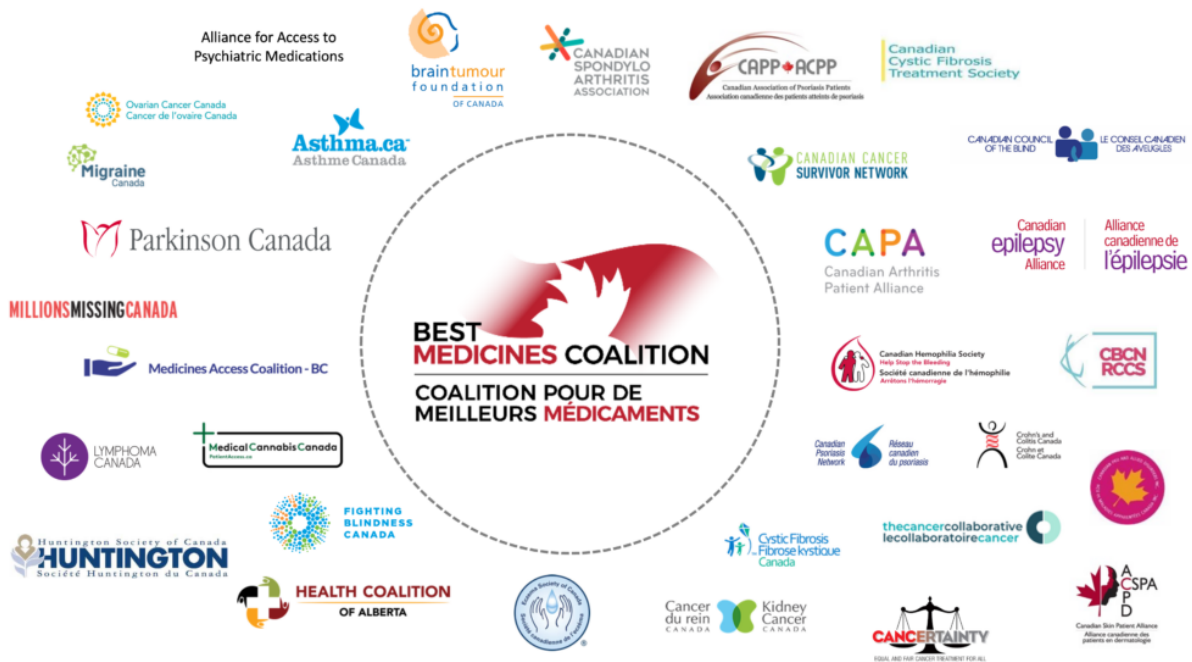
- As Health Canada consulted on improving drug access and specifically on drug shortages in August 2023, the BMC supported development of a long-term strategy to improve prevention and management of shortages, along with prioritizing communications to patients, professionals, and other supply chain players.
- In addition, the BMC prepared input as part of Health Canada's proposed agile regulations and guidance consultation in April 2023, with recommendations focused on authorization processes, improved transparency, monitoring and evaluation.

**Conclusion:**

BMC and its members will continue to work together to ensure that all patients in Canada have timely access to the medications they need and that patients and the organizations that represent them have a strong and powerful voice in all aspects of policy development regarding pharmaceutical care, particularly critical in this period of significant health challenges and reform.

John Adams  
Chair, Board of Directors  
Best Medicines Coalition

## Best Medicines Coalition Member Organizations



Alliance for Access to Psychiatric Medications  
 Asthma Canada  
 Brain Tumour Foundation of Canada  
 Canadian Arthritis Patient Alliance  
 Canadian Breast Cancer Network  
 Canadian Cancer Survivor Network  
 Canadian Council of the Blind  
 Canadian Cystic Fibrosis Treatment Society  
 Canadian Epilepsy Alliance  
 Canadian Hemophilia Society  
 Canadian PKU & Allied Disorders  
 Canadian Skin Patient Alliance  
 Canadian Spondyloarthritis Association  
 CanCertainty  
 Crohn's and Colitis Canada

Cystic Fibrosis Canada  
 Eczema Society of Canada  
 Fighting Blindness Canada  
 Health Coalition of Alberta  
 Huntington Society of Canada  
 Kidney Cancer Canada  
 Lymphoma Canada  
 Medical Cannabis Canada  
 Medicines Access Coalition – BC  
 Migraine Canada  
 Millions Missing Canada  
 Ovarian Cancer Canada  
 Parkinson Canada  
 Psoriasis Canada  
 the cancer collaborative