

2023 Chair Report

Board of Directors

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

Highlights presented at the **Best Medicines Coalition Annual General Meeting**, September 26, 2023:

• The Best Medicines Coalition (BMC) remains a strong and credible voice for patients in Canada, guided by a focussed mission statement:

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.

- The BMC's core activities include issue education, consensus-based position development, and advocacy, making certain that patient-driven positions are communicated to decision makers and other stakeholders. Importantly, the BMC works to ensure that patients in Canada are meaningful participants in health policy development, specifically regarding pharmaceutical care.
- The BMC has 30 patient organization members, including the recent addition of the Eczema Society of Canada. Member organizations, including both not-for-profits and registered charities, represent a specific patient community or regional umbrella group, and are actively involved in work related to the BMC's mission.

Structure and Governance:

- 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
 2022 Annual General meeting, John Adams, Diana Ermel, Wendy Gerhart, Michel Long and
 Kim Steel were elected to the Board of Directors, continuing previous terms. At a subsequent
 Board meeting, John Adams was again appointed as Chair for a two-year term and Diana
 Ermel again as Treasurer for a one-year term.
- 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, 2023, 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 2022/2023 from: Amgen Canada, AstraZeneca Canada, GSK Canada, Innovative Medicines Canada, Janssen Canada, Merck Canada, Novartis Canada, NovoNordisk Canada, Pfizer Canada, Takeda Canada.

Core Activities:

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 and meetings and by participating in formal consultations, including with Health Canada, Canadian Agency for Drugs and Technologies in Health (CADTH), Patented Medicine Prices 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 networking and education:

- Given the pandemic, the BMC did not host an in-person member conference in the fiscal year ending March 31, 2023, but commenced planning for a member conference held in June 2023.
- The BMC has continued to facilitate virtual education and discussion opportunities for member
 organizations, including overview and issue-specific presentations, with updates on policy
 developments and discussion. Notably, the BMC provided opportunities for members to learn
 about the public policy environment, offering several national issues updates throughout the
 period, where Santis Health shared information and insights on priority policy files.
- Through the period, the BMC supported active working groups, including on drug pricing and rare disease strategy, and ad hoc issue-specific meetings, providing opportunities for representatives of member organizations to gather virtually to learn and share perspectives.

Standing advocacy goals:

Through the fiscal year ended March 31, 2023, the BMC pursued the following standing goals, adopted 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 patientinformed 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.

Priority issues:

Driven by its mission and the above standing goals, the BMC focussed advocacy efforts on key priority issues during this period.

Rare Disease Strategy:

- The year ending March 31, 2023 was pivotal regarding the development of a National Strategy for Drugs for Rare Diseases, and the BMC played a role in moving this forward. Representatives of member organizations formed a productive BMC Rare Disease Strategy Working Group to review and discuss issues, recommend positions, and develop advocacy strategies.
- Driven by this working group, BMC provided Health Canada with a follow up submission on strategy considerations, submitted in December 2022, and then executed a targeted advocacy program to amplify its positions. This included round table discussions between officials and a group of BMC representatives where positions were reiterated. An opinion piece placed in the Ottawa Citizen, again reinforcing positions, was well-received.
- 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. These positions have been communicated in formal consultations, meetings, and correspondence.
- BMC welcomed the federal government's decision to move forward on the rare strategy and
 was honoured to be directly involved in the announcement event. Additional work is
 necessary to further develop the strategy and the BMC is well placed to have a strong role
 in this process and to bring patient positions forward in this next phase.

Drug Pricing:

- Through an active PMPRB Working Group, BMC continued its work to ensure that pricing regulations are not a barrier to timely access to new medications, continuing to support a balanced approach, including adoption of a new basket of comparator countries, while not proceeding with controversial and potentially problematic economic factors.
- BMC continued to relay its core advocacy positions to decision makers through a series of meetings and communications, including submitting to consultations related to draft Guidelines to implement regulations. BMC welcomed the decision to pause on implementation of the Guidelines.
- In addition, in this period BMC engaged on the issue of generic drug pricing, specifically as
 it related to drug supply and discontinuation of long-standing drugs that patient rely on.
 BMC facilitated member education on how generic drug prices are managed and engaged
 with the pCPA urging a balanced and flexible framework to encourage a healthy generic
 drug environment.

Drug Supply and Shortages:

- Drug shortage and supply issues continue to challenge positive patient care and the BMC remains active on this file, continuing its work as the sole patient voice on the Multistakeholder Steering Committee – Drug Shortages (MSSC-DS), 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, including in this period inputting on MSSC-DS strategy, encouraging a broadened mandate to address discontinuations and improved reporting and communication.

Additional priority activities:

- The BMC engaged with policymakers on ongoing national pharmaceutical policy reform considerations, such as the proposed Canadian Drug Agency including participating in briefing sessions and sharing perspectives on issues and frameworks. In addition, the BMC shared positions on national pharmacare concepts in advance of future legislation.
- The BMC also liaised with the pCPA regarding its transition and strategic plan, participating in briefing sessions and sharing perspectives.
- The BMC provided input to CADTH on its Draft Real-World Evidence Reporting Guidance consultation, encouraging the adoption of improved patient care as a primary goal, improved patient engagement and ongoing impact analysis and adjustments.
- The BMC prepared input as part of Health Canada's proposed agile regulations and guidance consultation, putting forward a range of position points including more comprehensive patient engagement, clarity and transparency, rigorous evaluation, and measures to address the needs of underrepresented populations.
- The BMC provided input to policymakers in the context of the Federal Budget considerations, sharing positions in pre-budget consultation submissions.

BMC and its members will continue to work together to ensure that all Canadians 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 Association of Psoriasis Patients
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 Psoriasis Network
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