New legislation to improve access to essential pediatric and rare disease medications introduced in Parliament

March 11, 2026

New legislation to improve access to essential medications not available in Canada was introduced in Parliament on March 11, 2026. The Private Member's Bill, *An Act to Amend the Food and Drugs Act* was tabled by former emergency room physician, now Member of Parliament for Thunder Bay – Rainy River, Dr. Marcus Powlowski. The legislation is the culmination of months of collaborative work led by the RareKids-CAN network and the Child Health Policy Accelerator at The Hospital for Sick Children, with contributions from RareKids-CAN representatives and patient advocates from across the country. Together, these groups worked to elevate the urgent challenges faced by children with rare diseases and to advance practical policy solutions to improve timely access to life-saving treatments.

The legislation aims to reform Health Canada's Special Access Program (SAP) which provides access to therapies that are not authorized or available for sale in Canada. While the SAP plays an important role in providing access to necessary medications, often for rare disease patients, too often the program creates delays that are difficult to justify, particularly when a medication is well-established, approved in trusted foreign jurisdictions, and considered the standard of care.

Every year, clinicians and pharmacists draft more than 12,000 individual SAP applications. For care providers and families alike, navigating this process is time-consuming and frustrating – especially when applying for a medication they have successfully used before. MP Powlowski's Private Member's Bill will streamline the SAP by establishing a 'Pre-Approved Special Access List' comprised of routinely used therapies that physicians will be able to prescribe and import without seeking prior approval from Health Canada, eliminating thousands of unnecessary applications each year.

The Bill also removes the current requirement that physicians and patients must try and fail all potentially effective on-market treatment options prior to accessing the preferred medication through the SAP. This 'fail-first' requirement causes significant distress for physicians, patients and families who are forced to manage potential side effects, knowing that a more suitable treatment may be available elsewhere.

Thirdly, as medical science advances and precision therapies become increasingly available, the SAP must evolve to reflect modern medical practice. MP Powlowski's Private Member's Bill will expand access to newer treatment options by requiring Health Canada to establish transparent, publicly accessible program standards that consider the full

range of medical evidence when approving access to treatments. This is particularly impactful for rare disease patients, as it is expected to provide more opportunities for emerging therapies to be delivered under expert clinical oversight, avoiding the costly process of establishing a clinical trial for a single patient in circumstances where the primary purpose of administering the therapy is treating the patient.

Australia and other peer nations have developed similar, risk-proportionate frameworks that expand access to non-marketed therapies while maintaining appropriate safety oversight. Canada should follow their example.

RareKids-CAN and the Child Health Policy Accelerator at The Hospital for Sick Children are proud to have worked alongside Dr. Powlowski in developing this legislation. The bill is grounded in the expertise and lived experience of clinicians, researchers, patients, and families from across Canada who understand the consequences when patients cannot access the medicines that they need. For families facing rare and serious illnesses, delays are not abstract policy problems — they are measured in lost time, worsening health, and missed opportunities for treatment. We are grateful for Dr. Powlowski's leadership and call on Parliamentarians from all parties to come together to pass this practical, patient-centered legislation.

About RareKids-CAN and the Child Health Policy Accelerator at SickKids

RareKids-CAN is a diverse coalition of researchers, patient and family partners, research networks and patient organizations across 16 pediatric research institutions in Canada. It aims to develop and accelerate high quality pediatric rare disease clinical trials and enable access to innovative treatments in Canada for children and their families.

The SickKids Child Health Policy Accelerator is Canada's first hospital-based applied child and youth health and social policy initiative. It aims to close the gap between what we know is effective in optimizing the well-being of children and youth, and what we do to attend to the needs of young people in the provincial and federal public policy space.

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