



### Why Patients Are in the #FightforOurLives

- Breaking News! Innovative medicines will change how we treat life-threatening diseases – forever. New medicines will cure cancer, restore eyesight, grow new bones, prevent heart attacks and kidney failure, replace blood cells, and repair and replace faulty genes.
- Good News! Those new medicines are transforming patient lives across the globe – today!
- Frightening News! Canadian patients might not access these new medicines – not today and maybe never. Changes proposed by Canada’s Patented Medicine Prices Review Board (PMPRB) are the biggest barriers to new drugs coming to Canada, including breakthrough, lifesaving, life-altering, first-ever treatments for rare and common conditions.

### Rising Drug Budgets – Good or Bad News?

- Good News! Thanks to new medicines, people are living longer with chronic conditions (cancer, heart disease, diabetes, hepatitis, HIV) that were once fatal; people with rare diseases have first-ever therapies; cell and gene therapies cure diseases but have one-time high upfront costs.
- Bad News! Drug budgets designed for older 20<sup>th</sup> century medicines have not been updated to 21<sup>st</sup> century innovative therapies; siloed drug funding does not offset reductions in other healthcare costs (emergency care, disability, organ failure); collaborative, innovative drug financing solutions have not been implemented.

### New PMPRB Regulations Will Harm Patients

- In response to concerns about rising drug budgets, the PMPRB has stepped away from its legally mandated role to *review* drug prices to ensure they are not excessive—to a self-designated role to *set* drug prices with a two-pronged process.
- First, list price of drugs cannot be higher than the median price of 11 comparative countries. Not unreasonable and not likely to stop drugs from being brought to Canada.
- Second, the PMPRB proposes to restrict the actual selling price of all new medicines to a *single arbitrary standard*, without regard for severity of condition, unmet need or the added benefits over existing therapy. For about 80% of new medicines, this single arbitrary price, which was set with no evidence as to appropriateness, with no consultation as to impact on patients, and with no consensus among stakeholders as to feasibility, will be far below manufacturers’ cost of research, development and ongoing support. Not surprisingly, manufacturers have indicated they will not bring new medicines to Canada – perhaps after pricing has stabilized in other countries and perhaps never.

- The big losers are the Canadian patients who will be deprived of critically needed medicines. Indeed, fearing the impact of the new drug price controls, manufacturers have already reduced clinical trials in Canada by about 40% for 2019 and at the beginning of 2020, announced withholding the launch of a half-dozen important new drugs, with more to come. Canadian patients are already being harmed.

### Patients Are Speaking Out About the PMPRB Impact

- *“The recent tragic passing of Chantelle Lindsay should be a wake-up call for politicians. This is just the first of many life-saving medicines that will not come to Canada because of PMPRB price restrictions.”* – Chris MacLeod, cystic fibrosis patient
- *“After decades of no effective treatments for sickle cell disease, we now have a revolutionary new drug that can prevent red blood cell deformation, but, thanks to the PMPRB, it doesn’t look like it will be available in Canada any time soon.”* – Biba Tinga, Sickle Cell Disease Association of Canada
- *“If companies feel they can’t afford to launch new drugs in Canada, they will not conduct clinical trials here. This will be a serious blow to rare disease patients with severe, progressive and life-threatening conditions who have no other effective treatments.”* – Durhane Wong-Rieger, Canadian Organization for Rare Disorders
- *“Given that Canada is only 2% of the global drug market, companies will simply bypass Canada. The new targeted therapies that can vastly improve quality of life will not be available to our patients.”* – Gail Attara, Gastrointestinal Society

### Patients Call Upon Political Leaders and Policy Makers to STOP the PMPRB!

- **Patients support the role of the PMPRB to ensure that Canadian drug prices are not excessive relative to comparable countries.**
- **Patients agree that drug prices must balance affordability and sufficient return-on-investment to support research and development.**
- **No other developed country is proposing a similar non-evidence based draconian slashing of prescription drug prices.**

### About the Canadian Organization for Rare Disorders (CORD)

CORD is Canada’s national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada. For more information on CORD, visit:

[www.raredisorders.ca](http://www.raredisorders.ca)