

Dear Minister Duclos,

Sent Dec. 13. 2021 e-mail. With attach.

Thank-you for inviting us to meet with you on December 2, 2021 and for engaging with us on important issues that are top of mind for many Canadians.

Your portfolio is challenging and complex, and although we touched on some key points, we provided only a general overview of the issues that we see are crucial to a strong health care system and accessing drugs that are safe, effective and appropriately priced.

You requested further reading material and we will forward/have forwarded/will continue to forward material relevant to the points raised during the meeting, including:

1. **Importance of implementing PMPRB regulations** – Controls on drug prices and health care spending is crucial to a sustainable and effective health care system. Canadians are overwhelmingly supportive of government measures to support access to affordable and high-quality medicines. For the five years the PMPRB has been consulting with Canadians to update drug cost and quality measures, pharmaceutical companies and their patient group representatives have lobbied actively against these changes. This has led to multiple delays and the steady watering down of PMPRB's proposals. Minister Duclos, we strongly urge Health Canada to adopt PMPRB's most recent (and modest) proposals rather further delaying this decision. Adopting these proposals will demonstrate to Canadians that drug prices and quality are clearly the priorities of the Government of Canada.

- o Salon article, "[*This one drug threatens to tank Medicare's entire prescription drug model*](#)". December 4, 2021

2. **Drug innovation, or lack thereof** – The pharmaceutical industry's self-portrayal as an "innovative" industry is highly problematic. This industry markets many drugs at exorbitant prices on the pretext that "innovation" is necessarily expensive. However, the problem is not only that the prices applied by the industry do not reflect the cost of research and development (which are frequently inflated), but more importantly, that most drugs do not represent a true therapeutic advance for patients. In short, the evidence shows that many very expensive drugs generally offer no proven therapeutic advantages compared with existing treatments. Hence, succinctly, Big Pharma is not 'innovative': Approximately 1.2 percent of the drugs the industry produces are innovative; the others can be described (at best) as possessing "some value but does not change practice" to (at worse) "without evident benefit, but with potential or real disadvantages." (Table).

- o See attached article ("*New products and new indications in 2016: a system that favours imitation over the pursuit of real progress*" *Prescrire International*, May 2017) and corresponding Value of New Drugs table
- o U.S. Congresswoman Katie Porter video confronting a CEO on the pharma industry's research and development track record https://youtu.be/qYvW4pm0_fI

3. **Drug safety and effectiveness** – Drug safety and effectiveness are inherently linked to health care costs. Too many approved drugs fail to meet standards of safety and effectiveness, resulting in wasting of scarce health care dollars and resulting in poorer health care. Health Canada has recently agreed to

review Biogen's application for Aduhelm (aducanumab), for the treatment of Alzheimer's disease. The FDA's approval of this drug has been shrouded in controversy due, in part, to a lack of evidence on its effectiveness and its serious adverse effects. An exposé of backroom consultations between the company and the FDA has resulted in two Congressional investigations (the *Committee on Oversight and Reform* and the *Committee on Energy and Commerce*). The publicly funded US Centre for Medicare and Medicaid Services (CMS) announced that, were they to provide coverage for this \$56,000 drug, along with the additional costs for MRI's, CT scans and increased funding for staffed infusion clinics. Individual monthly premiums that seniors and low-income Americans pay for health benefits would increase by 10% due to this drug alone.

Expensive and ineffective drugs, such as Aduhelm, were Health Canada to approve its use, would not only lead to unsustainable pressures on our health care budget, but lost opportunity costs. Important and effective interventions that result in less harm are urgently needed, such as, physical therapy, home care, better nursing home care, psychological support, hearing aids, etc. These interventions make a big and lasting difference in people's lives.

- o See attached copy of letter sent to Health Canada in regards to Aduhelm

4. On patient groups and industry funding - IVSED recognizes that people who join patient groups are often desperate for help and eager to see improvements in the health system. Joining a group can have tremendous value, providing social support and opportunities to learn from others with the same condition. Many group leaders and boards have, unfortunately, turned to the pharmaceutical industry as one source of funding, particularly to support advocacy. As a result, "patient advocacy" has become equated with gaining access to expensive new drugs. Pharmaceutical companies also engage in activities with groups that they describe as "education" (webinars, conferences, etc.), but these become opportunities to promote the company's new drugs and to teach patient leaders, known as "influencers," how to pressure the government to approve new drugs quickly and have them placed on provincial funding formularies. These leaders may honestly believe they are doing what is best for patients; however, they rarely talk about the harm drugs can do, the high cost of new drugs, the many needs patients have that are not drug related, or the unethical strategies drug companies use.

Drug company representatives are trained to form personal relationships with vulnerable patients, a process that Erin Little, a mother with a child with a rare disease, described in our call as a form of grooming, manipulating patients with compliments, gifts, money and status. Meanwhile, the leaders of the groups are often highly paid professional advocates who move up the disease charity ladder on the strength of communication skills and industry connections (some prominent advocates come to their jobs from pharmaceutical companies or from Innovative Medicines Canada). They may have no personal experience with the disease their group members are living with.

For all these reasons, IVSED opposes industry funding of patient groups and we refuse to take industry money.

- o CBC article on how the industry and patient groups stalled the implementation of the PMPRB regulations, "[Canada has found the key to lowering drug prices but it won't be anytime soon.](#)" (November 24, 2018)
- o Letter in the BMJ: "[Who will support independent patient groups?](#)"

5. And lastly, **Pharmacare** - Canadians have been advocating for a national drug plan for decades and it is a program that will not only help patients, but will help put cost controls on drug prices.

- Op-ed from Steven Morgan and Linda Silas: [*No More Excuses-National Pharmacare Now*](#) [\(The Winnipeg Free Press, September 2, 2021\)](#)

We wish you all the best in this challenging portfolio and look forward to working with you on these and other issues in the future.

Sincerely,

Dr. Sharon Batt, Ph.D., Halifax

Colleen Fuller, Vancouver

Dr. Linda Furlini, Ph.D., Montreal

Dr. Janet Currie, MSW, PhD. Edmonton and Vancouver

Erin Little, Ontario

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