I Am Canadian. Don’t Follow Our Lead on Drug Pricing.

By Sandy Stevens

Policymakers in the United States have increasingly been turning to international reference pricing as a mechanism to lower drug prices. It has been messaged as a silver bullet by both the Administration and Congress. In the latest development, an Administration executive order has been introduced that would import drug pricing policies from countries like Canada. While this may be a good “America First” talking point, international reference pricing should not be treated lightly. It is far from benign and has the potential to harm patients and people with disabilities by limiting their access to needed medical treatments.

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As lawmakers in the U.S. continue to use international reference pricing, it is important to understand the realities of the Canadian patient experience. My daughter, Laura, was diagnosed with cystic fibrosis (CF) at one month of age. She had a swollen abdomen, so we took her to get checked by her pediatrician in our hometown of Edmonton in Canada. We left with a diagnosis we could never have prepared ourselves for.

CF shook my family to the core. We knew enough about the disease to understand that it was going to shorten her life and that she would require extensive medical care and treatments. As we researched and learned about the disease, we were heartened by recent advances in the understanding and treatment of CF by the medical research community, found cause for hope, and approached head on what we knew would be the biggest challenge of our lives.

Laura’s journey has been difficult. Not only does she have CF, she is allergic to many antibiotics, so the lung infections so common in CF present even more of a medical challenge for her. When Laura turned eight, she got a very bad lung infection, and everything changed. She was not able to rebound as quickly and began spending more time in the hospital and was able to spend less time doing things like going to school and playing soccer — being a normal kid. I am a nurse by training, and I quit my job to be Laura’s fulltime caregiver.

Laura is fourteen now, and her entire life has been filled with hospitals, doctors, and medications. It has been trying for her and our family, both physically and emotionally. If Laura continues on the path that she’s on, she won’t be able to finish school or start a career — achieve all the milestones a mother wants for her daughter. And the most frustrating part of this is that there are medications that exist to treat Laura, but we have struggled to access them because our policymakers have put arduous regulations in place that make it nearly impossible for Canadians to access cutting edge treatments.

At this point, there are four drugs available for CF that target the underlying cause of the disease and slow the progression of CF. It’s difficult to overstate the value of their development for patients who

once had only maintenance therapy and knew once lung function began to decline, it was unlikely to come back. Three of these drugs, including Orkambi, were approved by the FDA in the United States by 2016. The fourth, Trikafta, which is effective for 90% of CF patients was approved by the FDA in 2019.

Meanwhile in Canada, eight years after the first of these new drugs’ approval, even with substantial advocacy from the patient community, three of these four medications are not widely available, and Trikafta is totally inaccessible.

Laura’s doctors recommended she be put on Orkambi. For her to access to this drug under our system she had to experience a reduction in lung function of 20% and maintain that drop for at least six weeks. Anyone familiar with CF knows this to be scary and harmful. When CF patients lose lung function, they rarely regain it. Laura’s physicians were concerned that forcing her to get this sick before receiving Orkambi would mean the medication was less effective once she got it, and that, in this period of waiting, and getting sicker, she would progress to the point where the only option was a lung transplant.

As a parent, this was terrifying. I wanted my daughter to get better, but part of me didn’t, because I knew she needed this medication. That is a horrible feeling to have about your own child. Laura eventually qualified for Orkambi, but even after meeting these cruel benchmarks, it took six additional weeks for administrative boxes to be checked and for her to receive the treatment. Orkambi made a difference, but given how drastically Laura’s health had declined in the year of trying to qualify for the drug, not enough. As the next course of action, her doctors recommended Trikafta.

So we are, again, fighting a battle for a medication my daughter needs to live a full, productive life. I see CF patients in the United States, like Gunnar Esiason, talk about how Trikafta has changed their lives and brought them to place where they can see a future. I want that for Laura.

The very hard reality is while patients in the United States are experiencing the life changing effects of cutting-edge therapies, Laura is getting sicker by the day. Unfortunately, this is not a uniquely

Canadian problem. Thousands of CF patients worldwide are unable to access these revolutionary new treatments due to similar coverage restrictions. I don’t wish our system on the United States. Learn from our mistakes and avoid importing our payment policies that restrict and delay patients’
access to needed treatments.

Sandy Stevens is a Canadian nurse, mother, and advocate who serves as the fulltime caregiver for her fourteen-year-old daughter with cystic fibrosis.

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