

Testimony in Support of HB18-1260**Presented by Drs Peter Bergmann, Erica Boettcher, and Amy Duckro****March 2018**

Good afternoon, Madam Chair and members of the Committee

My name is Dr. Peter Bergmann and I am a Neurologist practicing in Denver and a co-director of the Colorado Society of Clinical Neurologists. Along with the support of the Society, my colleagues and I are here in support of House Bill 18-1260. We appreciate the opportunity to share with you how we see pharmaceutical pricing interfering with our ability to provide the best quality care to patients here in Colorado.

Cost is a common factor in how I am able to care for my patients and often prohibits patients from getting the best possible care. My specialty works with expensive medications with the costliest topping out at \$750,000/year! Two of the disorders that carry the highest medication cost are multiple sclerosis and epilepsy.

Medications for multiple sclerosis can cost over \$80K per year. Multiple sclerosis is a common disease affecting about 1 in every 1000 Coloradoans and is a leading cause of disability in working-age individuals. I have had many patients that do not take medications that can prevent disability because they are too expensive. One of my patients is a 38-year-old woman who formerly worked as an elementary special education teacher. She was on a very effective medication for her MS, but she had trouble making the payments to stay on it despite the copay assistance program she was in. Copay assistance programs do not consistently make medications affordable. At certain points during the year she wouldn't be able to pay for her medication and would stretch it out by taking it every other day or every third day until she could afford a refill. During one of these times

she had a flare of her MS that left her unable to walk without a walker. I think it's likely that were she able to afford her medication she would still be able to work and be able to do the things she loves in life, like hiking and skiing with her kids.

Another disease where medication cost negatively affects patient care is in epilepsy. Epilepsy is very common - over 60K Coloradoans have epilepsy. The costs of both brand and generic anti-seizure medications are skyrocketing. One man I treat for epilepsy is in his 20s and was on a generic medication that cost \$4 per month a few years ago and now is over \$100/month. When the cost of the medication increased, he was unable to pay for a monthly prescription, so instead would pick up a prescription only when he could afford it. He would sometimes be off the medication for weeks before he was able to afford more. He had seizures without his medications leading to emergency room visits and hospitalizations. In one year, he accrued about \$100K in medical bills all because he couldn't afford a medication that used to be \$4 per month or less than \$50/year. About 1/3 of individuals with epilepsy don't take their anti-seizure medications consistently, and medication costs are one of the leading drivers of medication non-adherence.

These are just two examples out of many where the high cost of medications directly affected my patients' quality of life. Thank you for your consideration of this bill.

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March 1, 2018

My name is Dr. Erica Boettcher, and I am a physician specializing in gastroenterology and hepatology, which means I treat patients with diseases of the GI tract and liver.

Every single day I see patients in my practice that are concerned with the cost of their medications. They often make major clinical decisions based on how much a particular therapy will cost them. Recently one shared, "I just can't spend our life savings on this. I have to think of my family."

Many of my patients choose 2nd or 3rd line treatments because the best options are unaffordable and inaccessible to them. Even worse, some forgo a medication altogether due to lack of financial assistance. I remember a 68-year-old female with ulcerative colitis who was not able to afford the first-line agent to treat her condition. She also did not qualify for state or federal assistance. She was quoted a \$2000 out of pocket cost for the first 2 weeks supply of the medication, then an additional \$5850 per year out-of-pocket.

Eventually she was hospitalized for severe symptoms and failed to improve with 2nd line treatment. She subsequently developed a bowel perforation that ultimately required the removal of her entire colon. Following this operation, she suffered complications, including respiratory failure and infection. After a month-long hospital stay, she was discharged to a skilled nursing facility. She is still recovering from this hospitalization and continues to struggle with medication costs.

There are countless other patients who are not able to afford the preferred medications for their inflammatory bowel disease and instead are being treated with older agents. Older medications often come with a high pill burden which can reduce compliance with

treatment, or worse yet, be associated with significant side effects. For instance, there is compelling evidence that patients with inflammatory bowel disease treated with long-term steroids have worse outcomes, yet many patients remain on prednisone as an inexpensive way to control their disease, with potential side effects such as high blood pressure, osteoporosis, diabetes, and glaucoma.

Every day that I make rounds in the hospital, there is at least one patient with end stage liver disease admitted with hepatic encephalopathy. This is a condition where the liver cannot filter out toxins which then build up in the blood and cause mental status disturbances. It can manifest as mood or personality changes or in its most severe form, stupor and coma. There is a highly effective medication for treating hepatic encephalopathy. Unfortunately, many patients cannot afford it, and there is no generic alternative. One of these patients underwent 4 hospitalizations within one year and had his driver's license revoked. This resulted in loss of employment among other negative impacts to his life. With his income, he did not qualify for patient assistance for the needed treatment, and it was too expensive for him to afford independently.

Thank you for your consideration.

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My name is Dr. Amy Duckro, I'm a physician specializing in infectious diseases.

'Work arounds' in medical care are not what any of us would want for ourselves or for our families. We know from clinical research that interrupted therapy for HIV worsens outcomes. Yet, the cost of these medications becomes such a barrier that some patients stop their treatment altogether. In the case of HIV and hepatitis C, cost barriers not only worsen the outcomes for individuals, the lack of access to affordable treatment and prevention makes ongoing transmission inevitable.

Financial considerations are a constant concern for the patients I serve. I have had patients left with no other choice but to delay treatment because their medications costs are insurmountable. An HIV infected, otherwise healthy man in his mid 30s delayed therapy repeatedly due to cost – his income was too high to qualify for state and federal assistance, and paying for his medications independently was not feasible. He would have had to lose his home in order to afford anti-retroviral therapy. About a year after his HIV diagnosis, he developed lymphoma. Soon after that, he died. Had he been able to access anti-retroviral therapy, his death may have been prevented.

Another patient, a 19-year-old man seeking to be proactive in risk reduction, declined an HIV prevention medication because he could not afford it. About 6 months later, he tested positive for HIV. He will surely not be facing more affordable options now that he has a chronic disease for which the recommended treatments are some of the highest priced medications available. Yet, had he been able to afford

medications for prevention, it is unlikely that he would have contracted the infection.

A single mother in her 40s who works full time and is trying to manage her health wrote to me that she was waiting anxiously to see if she would qualify for drug assistance programs: "...I have been off my medications for 2 weeks. I have asked if they could give me some until my application [for financial support] is approved as I cannot afford to buy the meds. Please let me know if this will throw off my status or not. I am very concerned." Having to interrupt treatment or delay a start of treatment causes patients great anxiety, knowing the detrimental impact to their health, well-being and life expectancy.

The system in its current form is simply unsustainable. These stories we have shared today are just a few of many. Patients being treated by our colleagues in other specialties, such as rheumatology and oncology, encounter similar challenges. In the case of transmissible diseases, unmanageable medication costs result in ongoing transmission with new people being infected every day.

On behalf of Drs. Boettcher and Bergmann, we ask for your support of HB 1260. Thank you very much for your time.