2021 House Bill No. 1139
Testimony before the House Industry, Business and Labor Committee
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Mr. Chairman and Members of the Committee: My name is Beth Larson-Steckler, I am a care-partner for my two adult children who have significant health issues inclusive of chronic pain as well as a patient advocate. I am a co-founder of Foundation of Childhood Pancreatitis; I am the North Dakota State Chair for The National Pancreas Foundation and belong to several other national and international health advocacy organizations. I am here today to provide testimony in opposition to House Bill No. 1139.

The CDC developed and published the *CDC Guidelines for Prescribing Opioids for Chronic Pain* (which I will refer to from here on out as *Guidelines*) in 2016. These guidelines provided prescribing recommendations for patients 18 and above in ***primary clinical care settings***. I want to emphasize that these guidelines were never intended for pain physicians, or those in palliative or hospice care. The *Guidelines* were in response to the opioid epidemic. Unfortunately, the data provided and public statements from the CDC failed to capture not only the complexity of the problem but also the distinction between licit and illicit opioids and their relationship to the increase in unintentional overdose.

Even prior to the implementation of the *Guidelines* there were concerns from various organizations and physicians that the guidelines would be rigidly applied and result in harm. Since the publication of the *Guidelines* these concerns have grown. These concerns are not just from caregivers and patients but from physicians, inclusive of pain physicians as well as addictionologists. While the nations prescribing of prescription opioids has dropped dramatically since the implementation of these *Guidelines*, the overdose deaths and addictions are on the rise, specifically those related to illicit fentanyl, methamphetamine, and cocaine, illicit substances not prescribed by physicians. In this alarming Health Advisory distributed by the CDC on December 17, 2020, the CDC warns of these facts. Notably absent is any mention of prescribed opioids.

The recommendations proposed in HB No. 1139 are reflective of the misapplications of the *CDC Guidelines.* The *Guidelines* were never intended to be utilized for legislation, in fact, the CDC explicitly warned about this. Unfortunately, multiple entities have misapplied these guidelines, these include insurance agencies, clinic administration, PBMs as well as other governmental entities. These misapplications have harmed patients who have legitimate medical needs for prescribed opioids, as well as causing grave concerns for health care professionals who have a medical and ethical duty to provide appropriate pain care. While substance use disorders and their often-serious consequences are currently receiving focused government action, those who suffer from intractable, persistent pain are often unable to receive appropriate pain care while enduring serious, life-threatening consequences due to the misapplication of these *Guidelines* by various entities.

Individuals with chronic pain, whether due to disease or injury have become stigmatized due to the misapplication of these *Guidelines*. A recent study, *Drug Misuse in America 2019: Physicians Perspectives and Diagnostics Insights on the Evolving Drug Crisis* found a large percentage (81%) of doctors are

hesitant to accept new patients who have been prescribed pain medications. Even more (83%) say the misapplication of the CDC *Guidelines* makes it harder to treat pain patients.

Another unintended consequence of the misapplications of these *Guidelines* includes suicides due to abandonment of treatment and under treatment of chronic pain. Since the publication of the *Guidelines* several advocacy groups comprised of both patients and physicians have been tracking suicide related to abandonment of pain patients. Recently, Dr. Stefan Ketesz has been given IRB approval from University of Alabama at Birmingham to investigate the links between the abandonment of pain patients, those who are unable to receive care for their chronic pain to deaths due to suicide. His study is entitled Clinical contexts of Suicide following Opioid TransitionS (CSI: OPIOIDS).

After several other organizations as well as individual practitioners raised concerns about the *Guidelines*, on April 24th of 2019 CDC finally released a statement raising the alarm of the misapplication of its guidelines and the harms resulting from these. Furthermore, and of great importance, the CDC is currently revising the guidelines due to patient harms and destabilizations that have occurred. In March of last year, CDC begun the process of interviewing individuals impacted by the CDC Guidelines. I was one of the individuals chosen to participate one-on-one with the CDC to discuss impacts of the *Guidelines* on my family. The 2016 *Guidelines* were developed by a core expert group which was largely comprised of those in addiction medicine. The CDC has reconvened a new core expert group. This group is comprised of not only those working in addiction but caregivers, patients, pain physicians, legal experts, and public health experts.

Since the implementation of the *Guidelines,* I have personally witnessed the devastating impacts to those that have chronic pain including my own children. In response to the *Guidelines*, Insurance companies, PBMs, clinic administrators and legislators have implemented numerous 'hoops' that physicians as well as patients need to jump through to be prescribed necessary opioid pain medication. Due to all these layers, it is exceedingly difficult for pain physicians to treat patients individually based on their needs. Currently in North Dakota, many pain physicians are hesitant to prescribe opioid pain medications. Some have totally forgone the utilization of opioid pain medications in their practices.

Approximately two years ago a large pain clinic in North Dakota notified all patients on opioid pain medications that it would be titrating all individuals off these medications. One of those patients, was my son. Only three weeks earlier at his pain management appointment it had been discussed that opioid therapy was the best option for him. When I contacted clinic administration, I was informed that this action was being taken due to the national standards on opioid prescribing. There is no, national standard, there are recommendations for primary care physicians not for pain physicians. I was fortunate enough to receive a referral to one of the only pain physicians left who prescribes opioid pain medications, most other patients did not receive a referral. I have been in contact with a number of those patients. Some had been able to work due to opioid pain treatment. Others lead a more functional life. When they were titrated, many lost the ability to work, some were forced to move home with their parents because they were unable to support or care for themselves, some are bedridden. Everyone I have talked to experience a substantial decrease in the quality of their life. I know of one individual that did attempt suicide fortunately it was not completed.

As a mother, I have searched high and low for other options besides opioids. I have literally drained my bank account attempting other strategies, ketamine treatments, acupuncture, essential oils, mindfulness, tapping, distraction, biofeedback, reiki, massage therapy, psychotherapy, physical therapy,

occupational therapy, water therapy, injections, various medicatins, ablations. For many of the treatments I had to travel out of state. A few of these treatments were very detrimental to my kids. The ablation treatment destroyed harvested islet cells that had been placed in my daughter's liver from her pancreas. It also caused issues with her back. Now instead of just chronic stomach pain, she has both chronic stomach and back pain. Opioids have been the best option for both my kids. Most individuals on Long Term Opioid Therapy (LTOT) have tried other options. Opioids are rarely, if ever, the first option.

It is critically imperative to balance the needs of properly treating pain while still caring for those with substance use disorders. Balancing these dual vital health issues, without sacrificing one for the other, is one of the highest health care priorities that many states are facing.

The passage of HB No. 1139, I believe, will further perpetuate the harms done by the misapplications of the CDC *Guidelines* impacting both North Dakota residents who have chronic pain resulting from injury as well as physicians. Again, these guidelines were for primary care physicians, not pain physicians, not for those on palliative or hospice care. The CDC is revisiting these guidelines. One of the major focuses is on the opioid limits, the opioid limits indicated in HB No. 1139. 90 MME was an arbitrary level. It was not based on any relevant research and has caused substantial harm.

As a patient advocate, I am concerned for those, who due to injury, develop chronic pain, but are unable to access necessary treatment due to this legislation. Instead of receiving individualized care, care will be dictated by legislation, not what is ultimately the best for the patient. Unfortunately, in healthcare we are seeing this more and more. Instead of physicians determining best care regimen based on individuals needs, care is being based on other entities. This is not only in the area of pain but occurs overall in healthcare. Due to this, nationally we are losing physicians. Many are leaving medicine; others are choosing not to pursue medicine. Suicide rates for physicians are at an all time high. Many physicians have expressed concerns that they no longer are the ones driving care, instead it is multiple other entities that do not possess the knowledge, skill or training of physicians nor do they know the patient. I truly believe the best person to determine care, is the physician that is in the exam room with the patient, who knows the history, goals of the patients and other nuances of medicine.

One of my greatest concern if HB No 1139 passes is for those individuals that are currently on Long Term Opioid Therapy (LTOT) that will need to be titrated down to 90 MME. One aspect that researchers and physicians all agree on is that forced titration is harmful and often has deadly consequences. As I previously indicated, many chronic pain patients have committed suicide due to titration of pain medications. I cannot impress upon you how difficult it is for individuals that are in pain 24/7. I, myself, have not experienced it but I have spent twenty years watching my husband, son and daughter deal with severe chronic pain. It is truly devastating and there is not a plethora of options. For many opioid pain medications improves outcomes for those with chronic pain. I look forward to the day when other options with less risk are available but until they are, I am grateful for the therapeutic aspect of opioids.

This concludes my testimony, and I will be happy to answer any questions you may have.