

CIAAG civil society intervention: Lauren Deluca: Thank you for the floor, Chair, honored delegates, ladies and gentlemen. I would also like to thank the Vienna NGO Committee on Drugs and the International Association for Hospice and Palliative Care for their encouragement and support for my statement on behalf of patients who need internationally controlled essential medicines for the relief of pain. My name is Lauren Deluca and I am the Founding President of Chronic Illness Advocacy & Awareness Group, a national non-profit working in the United States to raise awareness of the crisis of untreated pain in our country. Our organization was formed as a result of my personal healthcare struggles in 2017 when I suffered from a pancreatic attack and was denied access to appropriate care. I have, quite literally, been fighting for my life since May of 2017 and I am only standing here today due to the extreme measures I took to get myself and fellow patients the help we need to manage our pain and severe symptoms. For nearly a year I was bounced doctor to doctor and turned away. One doctor told me he had taken all their patients off opioids rather than risk losing his license for anyone. Legitimate pain patients such as myself have been slandered by care teams when we attempt to advocate for pain control as our right. Several pain management clinics have told us they no longer take new patients as the US Drug Enforcement Agency has advised them they would be shut down and their licenses withdrawn if they prescribed to any new patients. I recently had a feeding tube put in as I can now, can no longer eat solid foods due to the damage I incurred; all stemming from a denial of care based on wholly on physicians' fear of law-enforcement and the legislative changes taking place to address the overdose crisis. Let me be clear. These measures are not addressing the current opioid overdose crisis. The tragedy of people using illicit opioids and dying from overdoses, should not impact pain or palliative care patients such as myself. Our lives matter as much as theirs, yet we are being punished by bureaucrats, regulators, and law enforcement agencies with no medical training. Sadly, what I went through, and many others are going through in the US is becoming the "new normal" for patients suffering with chronic illness, disease and incurable conditions. Law enforcement targeting of physicians and patients increased, and there is no relief in sight, either for families suffering from the opioid epidemic, or for patients and physicians. This is why I paid my own way to come from the US to speak to you today. If the current direction continues, all individuals will be cut off from rational access to essential opioids except for patients suffering from end-stage cancer. And even some cancer patients are coming under scrutiny, as regulators question whether their cancer is "painful enough" to warrant an opioid prescription, rather than Tylenol. Chronic Illness Advocacy & Awareness Group is working with Elected Officials and the patient community to help restore balance between protecting the public health from drug abuse and the safe, essential access to opioid analgesics for the chronically ill, older persons, and persons with disabilities. CIAAG is proposing a practical solution: we have recommended a Palliative Care Model to properly enable those with known painful conditions and illnesses to receive the appropriate care they need using a coordinated care team approach. Individuals would receive treatment for the various symptoms of their illness or condition, including appropriate pain relief, to promote quality of life for the patient and their family. In addition, we have devised a tracking method via the ICB-10 codes to categorize the data by the illnesses type rather than number of opioid doses. This tracking mechanism will permit law enforcement to ensure proper controls are in place

to alleviate diversion of controlled substances, while maintaining the ability to develop data on “best practices” for opioid prescribing. While we recognize the importance of having controls on scheduled medications, we must not lose sight of the fact that opioids are life-sustaining, essential medications. The United States approach to combatting the overdose crisis is fatally aggravating it, as reflected in the record breaking number of deaths in 2017 and 2018 despite prescribing being at a 25 year low. Failure to protect patients’ rights to access essential medications and healthcare, will result in the loss of innocent lives through suicide, and inflate an already deadly to a human rights crisis. And, we as a nation and a community, deserve better. The INCB and CND have been helping the world become aware of the crisis of access to controlled medicines in more than 75% of the world. The US opioid crisis must not be allowed to derail the progress made during the UNGASS, at the Human Rights Council, and at the World Health Organisation. I thank you.