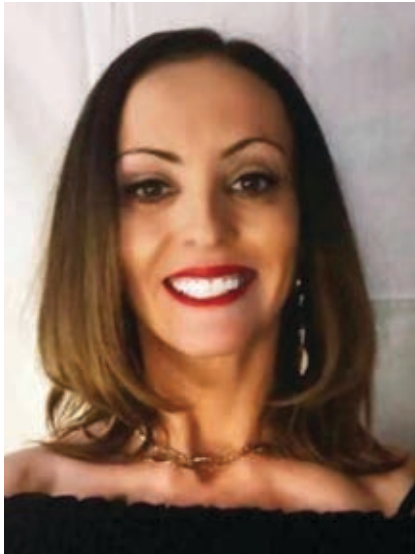

Advocating for the Chronic Pain Community

BY JENNY PICCIOTTO



Lauren Deluca is the founding member of the nonprofit Chronic Illness Advocacy and Awareness Group (CIAAG) which advocates and lobbies for the chronically ill. The organization is dedicated to patient education and empowerment. According to their website:

The Chronic Illness Advocacy & Awareness Group (CIAAG) envisions a world where those with disabilities and chronic illnesses are guaranteed palliative care and access to prescription life sustaining medications without stigma, fear or push-back, particularly from the medical community. We shape social narratives to promote inclusion of disabled rights and individualized patient-centered care. We lobby against political agendas and misinformation campaigns that interfere with patient's access to vital medications and palliative care.

In this time of healthcare policy change, a complex array of factors is contributing to a loss of adequate medical care for pain patients. The overreach of CDC Opioid prescribing guidelines has left many people with intractable pain suffering without adequate treatment, leading to an increase in suicides.

Healthcare policy is also subject to economic factors such as the influence of special interest groups, drug manufacturers, corporate profit, and the financial incentives for insurers to reduce the cost of pain care, estimated at \$650 billion/year. The business of healthcare has dehumanized real people, reducing them to statics.

Lauren's own experience at the hands of the healthcare system compelled her to create the organization. After her condition was mishandled, misdiagnosed, and left untreated, she faced a life threatening medical emergency. Yet she was perceived as a person seeking drugs, not a person in a medical emergency. "If I wasn't living it, I wouldn't believe it," she says.

She explained what happened to her at a session of the UN General Assembly Special Session (GASS) on Drugs in Vienna, Austria, in September of 2018. GASS is tasked with developing a plan to address the global drug problem and CIAAG, as a nongovernmental organization, was invited to speak on behalf of the chronic pain

community. Lauren presented the policy solutions CIAAG has developed to address the needs of the chronic pain community while balancing the issues of world drug abuse. Her compelling address is shared below.

"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, 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 statistic 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."

In the course of advocating for herself, Lauren realized two important things. First, that the State and Federal legislators she reached out to for help had no interest in meeting with her as an individual. By reframing her message and becoming a corporation, her voice gained legitimacy and she could get meetings with policy makers. Second, she realized how wide spread the problem of inadequate health care is.

Through the Facebook group she launched in fall of 2017, she met many people who shared similar stories. "Learning this

was happening to people all over the country was a wake-up call. It wasn't just my problem, it was society's problem. I felt compelled to fight for all these people who had no special interest group to speak for them."

CIAAG was formed to be a resource for patient advocacy education and a platform for lobbying on behalf of patient interests. Through their partnerships with other pain organizations, they can collaborate, monitor, and speak out, giving a voice to the chronic pain community. RSDSA was the first member of the coalition, which includes the National Pancreas Foundation, Chronic Disease Coalition, and the Endometriosis Research Center, among others.

"The biggest problem," Lauren explains, "is the lack of communication between independent disease groups. When we collaborate, we realize we have shared needs across different communities. Together we have a lot more strength to be heard in Washington, D.C."

Taking on topics like affordable drug prices, big pharmacy interests, and the effects of the CDC Opioid Guidelines, members of CIAAG meet with governors, legislators, and international organizations. Their efforts include sending a Joint-Letter to House health care representatives in support of Medicare negotiated prices, ending monopoly abuses, and requiring transparency from drug manufacturers and pharmacy benefit managers. They meet with leaders and present information at seminars educating both the public and policymakers about

how "the current approach to the Opioid Epidemic is in fact now creating a crisis of untreated pain leading to increases in patient abandonment, abuse and a drastic rise in suicides in America."

CIAAG invites you to join their efforts by becoming a member of the community through their website. Membership provides you access to their library of materials, advocacy training, tools for reaching out to your legislators, and email updates. You can also volunteer to take local action by becoming a member of the state leadership program. State leaders work together to monitor the progress of local healthcare legislation, make calls, write letters, and attend local meetings or hearings so patient's concerns can be weighed alongside the other factors driving the legislation of new laws.

"We want to develop a panel in each state to follow legislation," Lauren says. "We need to know what hearings are taking place, what bills are being written now. We need to be there or our rights will be taken away."

According to their website:

We all deserve compassionate, patient centered care that improves quality of life. CIAAG provides personal empowerment & education in our local communities. Learn about how you can get involved locally to help effect real time policy change to ensure access to medicine. This affects all of us: We are all one accident away from this becoming your life.

Reflecting on her journey, Lauren says that since getting her feeding

tube, she has gained weight and gotten stronger, both physically and mentally. "I was bed bound and hated being alive," she says. "I am still mostly homebound, with nerve damage and gastric episodes, but I'm learning how to deal with my limitations. I am relearning how to live my life, accepting what is, and adjusting my activities around my body. Having a focus – advocacy – keeps me sane. I was just an individual, but I learned how to engage legislative power. I want to teach others that their voices can be heard too, without even leaving the house."

ⁱ http://www.unodc.org/documents/commissions/CND/2019/Contributions/Thematic_Debate/26_Sept/Lauren_De_Luca_NGO.pdf

ⁱⁱ https://www.ciaag.net/uploads/1/1/6/5/116509489/membership_tier_flyer.png

ⁱⁱⁱ https://www.ciaag.net/uploads/1/1/6/5/116509489/why_become_a_member_of_ciaags_advocate_army__1_.pdf



ABOUT THE AUTHOR

Jenny Picciotto is a writer and CRPS patient who enjoys reading and playing the piano. She was a yoga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.