



***Keeping up with CIAAG...
1st Anniversary!***

On November 8th, 2017: Chronic Illness Advocacy & Awareness, Group, Inc., was formally organized and hit the ground running. We are proud to be fighting back for the chronically ill, those suffering with chronic pain, and the disabled community's rights to pain management which include necessary opioid analgesics to manage the painful symptoms of their primary illness and/or condition.

November 17, 2017: Our team meet with Massachusetts Senator Ed Markey's Constituent Services Representatives to begin discussions regarding the opioid crisis and CIAAG's mission to ensure balanced legislation to protect both substance use disorder and chronic pain patients.

November 28, 2017: Chronic Illness Advocacy & Awareness, Group meet with US Congressman and US Senate Health Policy staff to discuss opioid crisis impact on the chronically ill and disabled community. We delivered over 130 personal "pain story" letters written by our members sharing the impact the current health policy environment is having on real individuals lives.

November 28, 2017: CIAAG Founder, Lauren Deluca, participated in interviews to discuss the meetings in Washington, D.C. and answered live questions from internet listeners regarding the meetings, advocacy work and more.

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December 4, 2017: We joined over 40 Organizations working collaboratively in Washington, D.C., on the grassroots efforts promoting Universal Healthcare and Single Payer system as well as, price caps on prescriptions drugs, palliative care and legal protections for chronic illness/pain and disabled patient access to pain management.

December 12, 2017: Our team meet with Andrew Kolodny; Co-Director, Opioid Policy Research Collaborative, Institute for Behavioral Health Heller School for Social Policy & Management, Brandeis University to discuss his views on health policies in America.

December 19, 2017: CIAAG Founder, Lauren Deluca, testified at Massachusetts Statehouse regarding House Bill 1181 & Senate Bill 1183 - An Act Relative to Pain Assessment & Management in a Healthcare Facility which passed favorably out of the Health Policy Committee on February 7, 2018.

January 3, 2018: We joined over 60 Organizations and Independent Groups urging the United States Senate to reject Alex Azar as Secretary of Health & Human Services.

January 15, 2018: CIAAG Founder, Lauren Deluca, was featured in Alcoholism & Drug Abuse Weekly story "Patients with Chronic Pain forced into opioid tapers by their prescribers"

January 16, 2018: CIAAG Founder, Lauren Deluca, testified at Massachusetts Statehouse regarding House Bill 4033 - An Act Relative to Combating Addiction, Accessing Treatment, Reducing Prescriptions and Enhancing Prevention, to request Section 41 of the bill to be repealed in its entirety. This portion of the bill establishes a panel consisting of individuals to determine prescription caps and disciplinary action for physicians who do not follow the guidelines established by the panel. Please visit our YouTube channel to view the testimony.

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February 1, 2018: CIAAG Founder, Lauren Deluca, was featured in Prevention Magazine story "[The Other Opioid Crisis](#)" by Peter Moore which highlights her personal story with chronic pain and the formation of Chronic Illness Advocacy & Awareness Group, Inc.

February 6, 2018: Our team meet with Massachusetts Representative District 12 Representative to further our testimony provided to the Mental Health Committee regarding CARE Act - House Bill 4033 and why CIAAG and our members support the removal of Section 41 from this piece of legislation.

February 15, 2018: Our team meet with Massachusetts Chief of Staff at the Health & Human Services to discuss House Bill 4033 - An Act Relative to Combating Addiction, Accessing Treatment, Reducing Prescriptions and Enhancing Prevention, to further on the testimony provided at the Boston Statehouse.

February 20, 2018: CIAAG meet with House Chair of Joint Committee on Mental Health, Substance Abuse and Recovery to discuss the CARE Act - House Bill 4033 to express our Organizations concerns for the bills potential impact on the chronic illness, chronic pain and disabled community.

February 23, 2018: CIAAG Volunteer Member, Heidi Caulkins, meet with Arizona Congressman Martha Mcsally's Constituent Services Representative to begin discussions in her home state regarding the opioid crisis and CIAAG's mission to ensure balanced legislation to protect both substance use disorder and chronic pain patients.

February 28, 2018: Our team meet with Senate Chair of the Joint Committee on Mental Health, Substance Abuse and Recovery to discuss CIAAG's concerns over developing a panel to determine non-established best practices in opioid prescribing and provided suggested expansions of coverage as well as requesting an immediate emergency measure to protect the chronically ill and disabled from DEA scrutiny over prescribing limits. This measure will allow the qualified physicians to start treating patients without fear of government reprimand. This emergency measure is the first step toward balanced legislation that promotes quality of life for those suffering from chronic illnesses and documented, diagnosed painful conditions for which opioid analgesics are warranted and evidence-based applied studies shows an overall improvement on the individuals life.

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March 1, 2018: CIAAG Volunteer Member, Betty Miserando reached out to a local New York paper where her editorial was published in the "Voicers" regarding her concerns about the opioid crisis' impact on patients ability to access proper pain medications.

March 10, 2018: CIAAG Founder, Lauren Deluca, was a returning guest on "[The Foundations of Change](#)" on BATV with host Janine Zagel where they discussed CIAAG's trip to Georgia for the 2018 RX & Heroine Summit.

They discussed common misconceptions and misinformation about opioid analgesics and the law. Intentional misinformation and profiteering by individuals involved in writing the "2016 CDC Guidelines".

March 22, 2018: Our team meet with the Arizona Chief of Staff at the Health & Human Services to discuss the Arizona Opioid Act of 2018 and express our concerns for safe implementation of the law to ensure chronic illness and those with intractable pain are protected in this new piece of legislation.

March 28, 2018: CIAAG Member, Betty Miserando, successfully had her editorial regarding the Illegal Acetyl Fentanyl and voiced her opinion regarding the DEA's attacks on Pain Management and the need to focus on illegal drug smuggling verses our qualified physicians inciting fear and disrupting individuals medical care.

March 30, 2018: CIAAG Founder, Lauren Deluca, was a featured guest on "[The Jordan Levy Show](#)" where she discussed the "Other Opioid Crisis" and its impact on the local Massachusetts constituents as well as address the National direction of health care policy and CIAAG's work to protect the chronically ill, disabled and those with intractable pain.

April 2, 2018: Our team flew to Atlanta Georgia where we attended the 2018 National RX Drug Abuse & Heroin Summit and meet with other leaders, elected officials, government agencies, clinical researchers, lawmakers and policymakers. Our team attended seminars and meet with various stakeholders to discuss our organizations work with legislature and the community.

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April 9, 2018: CIAAG Founder, Lauren Deluca and New York Volunteer Member, Betty Miserando meet with New York Senate Finance and Counsel to discuss the urgent public health emergency facing the chronically ill. We also discussed various concerns we had in light of our attendance at the 2018 National RX Drug Abuse & Heroin Summit which further heightened our concerns for safe, quality health care to be uninterrupted for individuals whom medically necessitate the use of this medicine.

April 10, 2018: CIAAG Co-Founder Jayne Flanders was interviewed by Circa News "[The Stigma on Opioids made it hard for this chronic pain patient to find relief](#)" where she shared her personal story as a chronic pain patient and how it motivated her to Co-Found Chronic Illness Advocacy and Awareness Group.

April 11, 2018: CIAAG Founder, was featured as a Guest Expert where she was interviewed by Trisha at *AlphaAdvocates*. During the 40 minute discussion Trisha and Lauren reviewed a variety of health policy changes surrounding opiate pain management and regulatory changes taking place that effect various patient groups. They discussed current political and regulatory climate as well as what organizations and patient advocates can individually and as a community. She provided tools and resources for other patient advocacy groups to help empower their organizations in preparing for the patients in need of guidance during these uncertain times in health care.

April 23, 2018 - April 25- 2018: Our team flew to Washington D.C. to attend several days of meetings with United States Congressman, United States Senators and health policy staff to discuss our organizations work. Our team discussed the urgent need for federal legislation to be presented to protect those suffering under the weight of new regulatory changes that are forcing individuals previous in safe care off their medication regimes and barring new patients from safe effective treatments.

April 30, 2018: We meet with the Department of Justice; *Civil Rights division*, to discuss the American with Disabilities Act and our concerns regarding the discriminatory practices being imposed upon those with painful incurable conditions. We discussed ways to foster reporting of violations of the ADA with the Department.

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May 7, 2018: Chronic Illness Advocacy & Awareness Group launched our sister Organization "[World of Pain](#)" - a video broadcast where Host, Lauren Deluca, discusses the current state of all things chronic pain and the law in America.

On World of Pain we deliver the legal aspects of health policy changes, as well as the false narrative set by special interest groups. World of Pain is designed to help our members and the community differentiate between the truth & the lies surrounding the opioid crisis and how to effectively advocate for change.

May 8, 2018: CIAAG Founder, Lauren Deluca, was a featured guest on "[Barbara & You](#)", the longest running public access talk show in America, of 41 years

March 10, 2018: CIAAG Founder, Lauren Deluca, was a returning guest on "[The Foundations of Change](#)" on BATV with host Janine Zagel where they discussed CIAAG's trip to Georgia for the 2018 RX & Heroine Summit. They discussed common misconceptions and misinformation about opioid analgesics and the law. Intentional misinformation and profiteering by individuals involved in writing the "2016 CDC Guidelines".

May 15, 2018: Our team meet with Hawaii Governor Ige's, Chief, Alcohol and Drug Abuse Division to discuss the untreated pain crisis in America. Hawaii has not been impacted as widely by drug abuse as the inland United States. This puts Hawaii in a unique position to ensure as they move forward to combat drug abuse without imposing arbitrary health policy changes for their citizens. We are pleased to be working with the state of Hawaii to ensure the mistakes made in other states are not repeated in the state of Hawaii.

May 17, 2018: Our team meet with Massachusetts Congressman Joseph Kennedy's health staff to discuss the untreated pain crisis in American and build a relationship to ensure all citizens are protected; including those suffering from Substance Use Disorder and Chronic Illness/Disease.

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May 18, 2018: We joined 27 Organizations in an open letter to Secretary Alex Azar, specifically requesting the U.S. support efforts to increase transparency in the biomedical innovation system.

May 22, 2018: CIAAG Founder, Lauren Deluca, joined Host, Matt Taylor on the popular radio show "[Worcester Speaks Out](#)" on Central Massachusetts Radio Station - WSRS 96.1 F.M. They discussed a variety of issues facing the chronically ill and chronic pain patients - including off label writing of dangerous prescriptions, the medical abuse taking place in America and the intentional misinformation campaign surround the opioid crisis implemented by federal agencies and special interest groups.

May 30, 2018 & May 31st: Our team attended the first meeting of the Federal "Pain Management Best Practices Inter-Agency Task Force" The Executive Team & Founders of CIAAG, Lauren Deluca and Jayne Flanders, made public commentary regarding the Task Force duties and our concerns regarding the medical abuse taking place in American. CIAAG Founder, Lauren Deluca, shared her personal story with denial of care which has lead her to facing surgery for a feeding tube.Co-Founder Jayne Flanders brought to light what living with chronic illnesses is like as well as the dangers if enforcing un-established "Best Practices" for opioid prescribing would have on the chronically ill and disabled community.

May 31, 2018: We joined patient lead meeting with Jeff Rhodes, Senior Policy Advisory to Governor Kate Brown. CIAAG was invited to join this meeting by patient leaders in the state of Oregon to discuss the untreated pain crisis in America and the Oregon Opioid Task Force role. We emphasized the importance of Oregon's Opioid Task force role in combating opioid abuse while continuing to ensure the safe and necessary opioid analgesics to manage their painful illnesses/conditions.

June 7, 2018: Chronic Illness Advocacy & Awareness Group joined 45 Organizations in a Joint Letter to the Honorable Charles E. Grassley and the Honorable Dianne Feinstein in their role as Chairman and Ranking Member of the "Committee on Judiciary" in support of the "CREATES Act"

The Creates Act is a bipartisan, market-based reform that will speed the introduction of generic medications to help restore the balance between innovation and affordability of medications.

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June 15, 2018: We introduced "[Words of Pain](#)" - a blog run by the chronic pain community, in hopes of enlightening the public of the realities of chronic illness pain.

June 26, 2018 to June 28, 2018: Our team joined organizational partners at the "Affordable Medicine Now" Conference hosted by the powerful consumer action group Public Citizen.

While in Washington our team engaged in a number of activities to help raise awareness of the untreated pain crisis in America, including:

June 26, 2018: CIAAG, Founder, Lauren Deluca, met with Senator Claire McCaskill's healthcare staff to discuss the untreated pain crisis in America and Senator McCaskill's introduction of Senate Bill 3000 - "Pain Advocacy Transparency Act"

CIAAG expressed our concerns over this bill's intentions as while CIAAG fully supports transparency under the Sunshine Act to ensure there are not undue conflicts of interest there are deep concerns this bill is setting forth further obstacles to Freedom of Private Non-Profits to fundraiser to support their activities.

Pain Advocacy Groups are required to file taxes and are private organizations - therefore those whom donate may do so without having to have their name listed for any public entity or individual to see. Their ability to do so anonymously increases Pain Advocacy resources and therefore we oppose this bill unless amended to specifically apply the same standard of practice toward Addiction Advocacy Groups, Medication Assisted Therapies and Manufacturers.

The one sided bill would impede private donors to support "controversial" causes such as those who seek protections for opioid medications. CIAAG opposes this under the pre-text of its discriminatory basis and one-sided focus on Pain Advocacy Groups which seek to protect the most vulnerable citizens in this country from corporate abuses and abuse of power.

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June 26, 2018: CIAAG, Founder, Lauren Deluca, met with Senate HELP Committee to present CIAAG's request for a Federal Bill, "[Equal & Fair Access to Palliative Care](#)" to address the untreated pain crisis.

In addition, she discussed CIAAG's concerns regarding the speed with which our Federal Government and State Governments are proceeding with opioid related legislation when news reports have confirmed:

1. *CDC Admitted to Grossly Inflating the Overdoses in 2016.*
2. *Opioid Prescribing is at a 25 year low We submitted our proposed amendment to be added to the 58 Opioid Related Bills which were passed the House of Representatives on June 11th.*

August 28, 2018: CIAAG Founder, Lauren Deluca, was featured in Politico: "[How the Opioid Crackdown is Backfiring](#)"

September 21, 2018: CIAAG Founder, Lauren Deluca, hosted a booth at the "**Abilities Expo**" in Boston, Massachusetts.

September 22, 2018: CIAAG Founder, Lauren Deluca, Op-Ed was featured in Times Union: "[Chronic Pain Requires Access to Medication](#)"

September 26, 2018: CIAAG Founder, Lauren Deluca, addressed the United Nations at the: [61st session of the Commission on Narcotic Drugs.](#)

Where she delivered a speech on behalf of the millions of American citizens whom are losing access to life-sustaining opioid analgesics as a result of draconian regulatory change and corrupt political agendas.

This speech was broadcast LIVE in 7 Countries including:

- Austria
- China
- France
- Germany
- United Arab Kingdom
- United States of America
- Russia

Miss the speech? Check it out on CIAAG's [YouTube Page](#)

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September 27, 2018: The "[Pain Advocacy Coalition](#)" featured CIAAG Founding President, Lauren Deluca, and her speech at the United Nations in Vienna, Austria in their Blog: [Meet Lauren and the CIAAG Team](#).

September 30, 2018: CIAAG signed a jointed letter in an an effort for: [Health Professionals Call on the CDC to Address Misapplication of its Guideline on Opioids for Chronic Pain through Public Clarification and Impact Evaluation](#).

October 18, 2018: CIAAG & Time Thread Studio's Presents the Trailer to our new Documentary: [Untreated: The Healthcare Crisis](#).

Fundraising Goal \$20,000 by 12/17/2018.

October 31, 2018: We joined over 45 Organizations to call upon *United States Senate* to reject any measures that would increase drug costs for consumers, including rolling back the provisions in the **Bipartisan Budget Act of 2018 (BBA)** that make brand-name prescription drugs more affordable for people with Medicare.

November 2, 2018: CIAAG Founder, Lauren Deluca, discussed CIAAG's work and attendance at the United Nations Commissions on Narcotic Drugs on [Narcotica](#) with Hosts & Investigative Reporters, from the front lines of the American Drug War; Chris Moraff, Zach Siegel and Troy Farah. [Episode 8: Collateral Damage - Patients Fight Back](#)

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In the past year we have welcomed 13 Organizations and 13 Independent Groups to our Coalition partnerships. We stand together, for compassionate, patient centered healthcare that improves quality of life for those living with disabilities and chronic pain.

13 Organizations

- Adrenal Alternatives
- Center Pain Nerve Center
- Chronic Disease Coalition
- Chiari Fund
- EmPower the Patients
- Endometriosis Research Center
- Gastroparesis: Fighting for a Change
- Medical Bill Gurus
- Migraine Mantras
- RSDSA
- The National Pancreatitis Foundation
- Unchargeables
- World of Pain

13 NGO & Independent Groups

- American Sign Language (ASL) Express
- Association for Ethical Treatment of Pain Patients
- Chronically Badass
- Confessions of a Professional Patient
- Count My Spoons
- Fibromyalgia in Albania
- Fight like a Warrior
- Living with Abdominal Disease & Illnesses
- People in Pain Unite
- Tears of Truth
- R.A.S.E for Invisible Illnesses
- Spoonspirations

As we approach our 2nd year we are excited to expand our network of Coalition partners, continue our work proactively with Elected Officials and our Members in order to enact common-sense policy & legislative changes that protects those living with painful conditions.

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