



DEAR ADVOCATE ARMY

One of the most challenging obstacles facing advocacy today is the coordinated dissemination of misinformation, spoon fed to the public by the very entities meant to represent their interest.

In this day and age, many people rely on mainstream media, internet bloggers and podcasts as their primary source of information but herein lies the problem; the stories they are told, oftentimes lack context while excluding key material facts.

CIAAG's recent [correspondence](#) to President Biden highlighted our concerns regarding the coordinated disinformation campaigns emanating from the clinical research community, pain advocacy organizations/groups and media outlets (specifically those dedicated to covering the topic of pain management in healthcare).

One of our goals at CIAAG is to educate the citizenry about the public-health policies driving the current changes in our healthcare system. During the course of our work, we have witnessed certain organizations and individuals who publicly state they are dedicated to helping people in pain willfully use misinformation in an effort to exploit those they profess to serve.

This amounts to nothing more than an unethical, premeditated, public-relations campaign; used to sway public opinion in favor of those set to receive lucrative federal government grants for assisting the national strategic goal implementation. The issue, these organizations and individuals have crafted a public narrative that does not reflect the true nature of their work, their goals or legislative efforts. In fact, some have falsely portrayed themselves as advocating to restore opioid access when in reality, their work results in outcomes that ultimately restrict access.

There seems to be a concentrated effort undertaken in order to keep the patients who advocate for access to opioid analgesics at a disadvantage through gatekeeping of key information and facts surrounding public-health policy and those involved. This is a serious issue that must be addressed by our lawmakers.

Today, our team came across a blatant example of a media outlet using their platform to undermine public-education while spreading misinformation.

For context, you need to first understand that we at CIAAG (just like pain advocacy organizations, clinical researchers and media outlets) use social media to connect with our audience to promote our narrative. The primary aspect of our social media focus is teaching the public about the existence and implementation of the National Strategies.

Pain advocacy organizations/groups, clinical researchers and media outlets also use social media to connect with their audience to promote their narrative. However, their use of social media is used to exploit the patient community, spread misinformation, discredit opposing views and at times, have outright run smear campaigns against our organization and executive team as a means to interfere with our ability to educate the public. This is an underhanded tactic used by a small (but powerful) group of industry actors. This is not a victimless action. The patient community relies on thought leaders, pain advocates, clinical researchers and media outlets to provide current guidance and information. When the very entities charged with this task violate their duties by spreading misinformation and/or disinformation, they are harming the ability of the public to gather the information they need to make informed decisions.

Let's explore....

Before we get started, make sure to watch the video clip from The Daily Remedy, a newly established media outlet who's target market includes the online pain advocacy community forums.



"I had a meeting with the Association of American Physicians and Surgeons (AAPS) yesterday. I asked about legal tactics, advocacy strategies. AAPS is a prominent institution that has consistently gone to bat for physicians, surely they must have a strategy that can help with advocacy. Wrong! The reality is, there is no strategy, there is no grand plan, not with legislators, policymakers or anybody. There are only narratives. And, we have to ensure the right stories are told. So that the public has the right understanding, the right narratives. So whatever grassroots advocacy you're doing, keep doing it" - Jay, Daily Remedy

Let's break down & analyze this narrative:

He opens his video, advising of a meeting he conducted the day prior with AAPS.

This sets the stage for the listener so they understand where this sudden "Public-Service Announcement" is coming from.

Next, he explains to the audience that he asked AAPS about their "legal tactics and advocacy strategies". He then claims, "AAPS is a prominent institution that has consistently gone to bat for physicians, surely they must have a strategy that can help with advocacy".

This helps establish to the audience who AAPS is and gives the listener the impression that AAPS is a major organization that has been known to fight for physician rights, implying that if anyone were to have an advocacy strategy, it would be AAPS.

Once he established a basic understanding to his audience who AAPS is, he proceeded to explain that AAPS does not have any "advocacy strategies" in place.

This could not be any further from the truth. A quick view of the AAPS website reveals a detailed organizational strategy that includes a description of legal mechanisms to support their advocacy efforts.

The AAPS advocates for *The Preservation of Medical Freedom*. Our team reviewed their website and quickly identified a number of activities AAPS engages in as a part of their advocacy work. These activities include but are not limited to:

- The AAPS is currently in the appeals process of a lawsuit with Texas Medical Board in defense of physicians' due process rights
- Drafted legislation for reform of the Texas medical practice act and are advocating for its enactment
- Monthly Newsletter: Where they post information regarding "call to action" activities to their members

For an organization with "no advocacy strategies" in place, they sure are conducting a lot of advocacy work and associated activities. In reality, all organizations have strategies behind their efforts; to claim otherwise is either foolish or dishonest. What we are seeing here is a game of semantics.

While he may have confirmed with AAPS that they do not have a strategic plan related to pain management, they absolutely have a strategic plan to accomplish the organizational goals set by their Board of Directors. Given their involvement in litigation AAPS clearly has legal facts to support their chosen advocates goals. Just none dedicated to pain management.

After stating that AAPS has "no strategy to help with advocacy", he proceeds to proclaim:

"The reality is, there is no strategy, there is no grand plan, not with legislators, policymakers, or anybody. There are only narratives."

Again, this is factually inaccurate. He already admitted conducting a meeting with AAPS about their advocacy work. Simply because AAPS does not have a strategic advocacy campaign dedicated to the issue of opioid access and pain management, does not mean that one does not exist with other associated entities. It means that one organization they spoke to does not have a campaign dedicated to that particular issue. Further, an organization does not need to have a "strategic advocacy plan" in order to participate in one. In fact, many organizations do not have "their own strategic plan" or "advocacy program" for restoring rational access to opioids but they still partake in the National Strategic plans assisting in associated work to support the strategic goals.

He attempts to proclaim that even legislators and policymakers have "no strategies" and that there is "no grand plan" which implies the idea of a "National Strategic Plan" driving policy changes is no more than a conspiracy. However, once again, what he proclaims is outright false.

The United States has launched dozens of federal and state level strategies over the past decade directly related to the management of pain, disease and opioid utilization and accessibility. Some of these strategies include but are not limited to:

- [The National Prevention Strategy](#)
- [The National Pain Strategy](#)
- [The Federal Research Strategy](#)
- [Health in all Policies Strategy](#)
- [National Health Initiatives, Strategies & Action Plans](#)
- Even the CDC Opioid Prescribing Guidelines themselves are a strategy!

These are just a few examples of the hundreds of federal guidance documents outlining the national strategic work being undertaken by federal agencies via the public, private-partnership mechanism (speaking of, there is even a Public-Private-Partnership Strategy)!

To make a broad statement that "no one" has any strategies is blatantly dishonest. When it comes down to it, nothing in this nation happens randomly. All policy changes are well thought out and developed by committees, task forces and other think-tanks; it is their job to implement processes that will support and guide the implementation of the larger national strategic plans. This is how our nation's systems are managed. Proclaiming there is "no strategy" behind the public health policy changes taking place is either foolish (at best) or willfully deceitful (at worst).

Moving on to the next section of our analysis.

After proclaiming there are "no strategies by anyone," he proceeds to state:

"There are only narratives and we have to ensure the right stories are told so that the public has the right understanding - the right narratives."

Here he is claiming that there are no strategies, only narratives. Again, this is false. Facts exist, even in the presence of promoted narratives; they are not mutually exclusive. For example, the existence of the National Strategies that are driving public health policy and access to care. The existence of (or any discussion about) these strategies is not a narrative, it is a fact. The only narrative seen here is the coordinated attempt to discredit valid information from being discussed and understood by the general public.

Further, what are these "right stories" that need to be told? Who decides what is "the right story" and what is not? In reality, a story is just a story. A so-called "right story" is code for the stories that support their chosen narrative. In essence, he is proclaiming that his content portrays the "right narrative" but in reality, his statement is invalidating the narratives and discussions taking place regarding the National Strategic plans.

In conclusion, he states:

"So whatever grassroots advocacy you're doing, keep doing it."

After proclaiming there are "no strategies," he goes on to encourage people to keep doing what they have historically done without deviation. But what were the patients doing? Unfortunately, not much. Due to gatekeeping of information and intentional disinformation campaigns coming from the public-private-partners patients have been put at an incredible disadvantage. They are told that they must share their stories to get help but sharing their stories alone does nothing for the patient. It does however benefit the individuals and entities that use the patient stories to advocate for their desires.

Additionally, this is a very timely message, given that CIAAG's public messaging has been based on encouraging patients to learn about the national strategies and to break away from individuals and entities whose interests do not align with the patient's goal to restore rational access to opioid medications. In recent weeks, the public has been discussing the national strategies on social media forums. This message directly undermines the facts of what is taking place in the healthcare system and discourages individuals from learning otherwise or doing any active advocacy on their own behalf.

Just My Opinion:

So why was this video message sent? What was the point?

Well, in my opinion, this is an attempt at discrediting the messaging coming from CIAAG (which focuses on teaching about the existence of the National Strategies, what they are, who was involved and direct activities people can engage in to help advocate for their rights. The message appears to be carefully crafted to undermine the facts and to redirect the patient community back to sharing their "pain story."

P.S. After the original posting of the video, Jay from the Daily Remedy added the following commentary proclaiming:

"What I have been told is that we have to continue telling our stories. Once enough stories are out there, the legal strategy will form. This is what organizations like AAPS and legislators tell me."

"Advocacy is the way. However, I was told by legislators that we need to continue telling our stories so we can gain voting power through awareness."

Well, isn't that interesting; he did a full 180 here! In the video, he advised the public that "there were no strategies, no grand plans" specifically citing AAPS and legislators. Suddenly, when faced with public push back on the original message, he walks back his statement and proclaims that "AAPS and legislators have a strategy that supposedly relies on patients continuing to share their stories."

Now we see the reason for this message; to deter the public from learning about the national strategies and advocating against them. Directing patients back to simply sharing their pain stories and nothing more which permits professional stakeholders to control the narrative and use the patients' stories to their advantage.

Unfortunately, this type of activity is not new and is one of the primary reasons patients are unable to effectively advocate for their rights. The patient community has been exploited by the very individuals and entities that claim to represent their interests for many years now. This is the problem, the dissemination of coordinated misinformation and disinformation to the patient community.

The patients deserved to be included in this work from the beginning to end; not locked out, patronized and exploited by the entities they trusted to protect their interests.

Remember, Together We Are #CIAAGStrong!!!

Thank you,

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