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Fighting for patients and their prescribers

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ADVOCACY TIPS FOR CHRONIC PAIN ADVOCATES - OUTREACH TO MEMBERS OF CONGRESS

Important note: Postal mail is the slowest method to send a message to a Member's DC office. All mail must be scanned offsite for security reasons, and it could take additional weeks to arrive. Most offices encourage constituents to send emails. Every member has a link on their website that allows you to submit email through their website. Those messages will be routed to a staffer who handles specific issues. Most offices track the number of emails they get about specific issues, so this outreach does matter!

*Below is sample text that is intended to serve as guidance only. Sending a unique, personal note is **the most effective way to advocate for yourself and other chronic pain patients**. Form emails and emails that use almost identical text are not as effective and are more likely to be overlooked.*

Sample Email - Writing to Members of Congress -

Dear Representative (Last Name) or Senator (Last Name):

In most circumstances, it is MOST effective to focus on outreach to your US Representative or Senator. Writing a miscellaneous Chairman/Chairwoman or bill sponsor is unlikely to make an impact if you are not a constituent.

Always begin by stating your relationship to the legislator. If you have met with the Member or a staff member about this issue, mention those interactions. State why you are writing.

It is helpful to summarize your journey as a chronic pain patient. Mention the circumstances of your ailment and the restrictions you face.

I am writing to you as a constituent, a small business owner and a chronic pain patient. For the last 20 years I have served as the President of Pengab Co, a supplier of widgets to the aerospace industry. I employ over 215 employees across my four facilities in Ohio. I have been recognized by the SBA as a

notable small business and in 2013 you sent me a congratulatory letter when I was named “Businesswoman of the Year” by the Regional SBA office.

Today I write to request that you consider the plight of chronic pain patients as you contemplate sponsoring, co-sponsoring or voting for any health care legislation in the 119th Congress. I have balanced my business accomplishments with a personal health struggle that has endured for decades. In 2018, after 10 years of misdiagnosis and disruption to my quality of life, I was informed that I had Crohn’s Disease. I felt lucky to have a medical team that empathized with my condition. Because of the excruciating pain associated with the disease, I was prescribed a maintenance dose of pain medication. To be clear, without the medication I am unable to function at a high level due to the toll on my body. Due to my primary care doctor’s retirement, I had to find a new health care provider. My new provider has access to all my medical records but has expressed concern with prescribing pain medication because “of the current climate” and has suggested that I try alternative pain treatments such as acupuncture. I had already tried every alternative and they didn’t work. I lost access to my pain medication and I wasn’t even compassionately tapered. I am now bedridden. Unfortunately, many providers have similar responses and hundreds of thousands or even millions of chronic pain patients are now medically abandoned.

I am sympathetic to people and families that have been impacted by the overdose crisis. In our state, it is clear the epidemic has impacted our urban and rural communities, across all incomes and demographics. **However, one forgotten casualty of the overdose epidemic response are the millions of chronic pain patients in our country who use their daily FDA -medications as prescribed and do not have addictions.** We have been unfairly labeled as having Opioid Use Disorder (OUD) and we are made to feel like criminals when we seek medication for our confirmed medical ailments. The federal government, while well-intentioned, has rushed to make recommendations that make the situation worse. The irony is that there are legitimate chronic pain patients who are now forced to seek illegal options out of desperation. In theory, government policies are creating a new class of addicted Americans. These policies are causing people to become suicidal or obtain their medication illicitly when they never would have considered either option before these policies were put into effect. The Doctor Patient Forum, a network of chronic pain advocates across 50 states, has served as a resource to thousands of patients who have lost access to prescriptions. They have compiled thousands of stories similar to mine.

If you have a specific ask such as a request to introduce specific legislation, sponsor an existing bill or a request to vote in favor or against a bill, state the request and explain why this is important to you and other constituents. If you belong to any groups or coalitions, mention them and their level of support for similar actions.

Research the Member to see how they voted on recent bills on the topic.

Be careful how you discuss the overdose epidemic. A Member who may have lost a loved one or led a prevention/treatment bill may not respond well to certain arguments. If you have questions about this, please reach out to bev@thedoctorpatientforum.com or claudia@thedoctorpatientforum.com

It is very important to rely on facts and not use too many anecdotes. It helps to reference the federal angle – do not write a Member of Congress about state legislation. Instead, focus on the federal agency or Congressional committee that has jurisdiction.

National media outlets have picked up on this important issue. CDC has acknowledged this issue in recent guidance revision issued the beginning of November. However, I am concerned this will not be enough to address the challenges chronic pain patients face on a day-to-day basis. The CDC and FDA both released clarification statements in 2019 attempting to address the issue of abandoned patients, forced tapers, and misapplications of the 2016 CDC guideline, but nothing changed. The recent revisions will not address the issue as long as state laws and insurance policies that were created based on the 2016 arbitrary thresholds are still in effect. The following states bills have been passed and have been supported by the Doctor Patient Forum. A similar bill in my state will help me and other constituents by protecting the sanctity of the doctor-patient relationship, and will exempt people with chronic intractable pain from the 2016/2022 CDC Guidelines:

- Oklahoma’s Intractable Pain Bill – [SB57](#)
- New Hampshire’s Bill – HB1639
- Rhode Island – [Senate Bill 384](#)
- Arizona – [SB1162](#)
- Minnesota – [Stat. 152.125](#)

I am requesting an opportunity to speak to your Legislative Director or a health care staffer in your office about this important topic. I can be reached via email at ([insert your email](#)) or by phone (insert your [phone number](#)). Chronic pain is a legitimate health condition and it is important for the federal government to work with states to ensure that patients are not denied access to treatments due to external factors. The occurrence of medically abandoned chronic pain patients and lack of access to adequate treatment is increasing and isn’t currently being addressed. I look forward to discussing this with your staff in more detail.

Sincerely,

[Your name and address](#)

Join us for a Congressional Advocacy Webinar

Want to receive more advocacy tips? On January 27, 2022 Doctor Patient Forum Founder/CEO, Claudia Merandi, will host a webinar with a consultant (and former Congressional staffer) who can provide an overview of how a Congressional office is structured and share tips for effective advocacy. To register, [click here](#)

Final Recommendations

General suggestions about tone:

- Staffers on Capitol Hill are confronted with angry constituents on a regular basis. While some of this anger is justified across a wide range of issues, the tone of a constituent message may change what type of response is received.
- Your letter should include requests (not demands). The Member you are writing may not be aware of the issues you are raising. Allow them an opportunity to respond and meet with you to learn more.
- Do not include political generalizations – “All Democrats are wrong”, “All Republicans are wrong” or “President X is to blame”. Approach this as a non-partisan issue that affects all Americans, regardless of how they vote.
- Know your audience. If the Member you are writing to has introduced prevention/recovery bill, recognize that you understand why they did so but ask they consider this additional angle in future opportunities. Disregarding their past efforts will not convince them to take on this cause.
- Speak from your perspective. If you are a patient, or family member, speak from your perspective and avoid speaking on behalf of doctors or other stakeholders. If you are a doctor, speak generally about some of the challenges you have witnessed your patients endure through, but emphasize how the stigma of pain medication affects your role as a health care provider to chronic pain patients.
- Understand this communication will not be private. If you are not comfortable sharing high level of detail (specific diagnosis, etc), that is fine.

If you choose to send a letter via postal mail -

- Use your residential or business address. If you are writing a Representative, we recommend [you verify you are in the Member's district](#). As mentioned above, staff prioritize constituent inquiries.
- Be patient. It may take some time to receive the letter and they need time to respond. If your letter is addressing a time sensitive issue – like a bill heading to the floor for a vote, we strongly suggest you send an email or call the district or state office.