



HypoPARathyroidism
Association, Inc.

www.hypopara.org

HPA Grassroots **Toolkit**



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Introduction

Right now, officials at the FDA are considering approval of multiple new medications to treat hypoparathyroidism. We need to do all we can to educate the FDA and Members of Congress with jurisdiction over FDA about the impacts of hypoparathyroidism on patients and the urgent need for approval of effective therapies.

The voices of those with a personal stake in each issue resonate the loudest on Capitol Hill and throughout government. That is why it's crucial Americans from the hypopara community--patients and providers alike--raise our voices to break through the noise.

This toolkit will help you elevate your voice where it matters the most: from how to contact legislators and the FDA, to how to tell your patient story in the most compelling, personal way possible.

Your patient journey is important and powerful and can help make real change -- to move one or many hypopara treatments forward, ushering in a new era where hypopara patients will have a choice of treatments that work best for them.

How to Tell Your Story

As you contact key decision makers in Washington, DC -- either in long-form writing, short-form writing, on the phone or on social media -- it is important to communicate your experience with hypopara, either as a patient or a provider, paired with brief informational context and a clear call to action for the decision maker you are engaging.

The following guide is meant to help you think through your patient journey and craft a message that will resonate throughout it. Keep in mind depending on the form, you may have very few words to devote to each section--and you should always strive to keep your story as concise as possible.

PATIENTS

- State your reason for reaching out, including a brief summary of what hypopara is:
 - “I am reaching out today as a patient with hypoparathyroidism, a rare disorder for which there is currently no FDA-approved treatment. I am asking you to stand with the hypopara community in urging the FDA to expedite its review process of two possible treatments.
- Describe your personal experience living with hypopara:
 - “I was diagnosed with hypopara in...”
 - “Hypopara has caused me to experience the following symptoms...”
 - “Because of my hypopara symptoms, I cannot...”
 - “For a brief time, we did have an FDA-approved treatment for hypopara. When I received that treatment, I was able to...”
 - “If the FDA were to finally approve one or both possible drugs, it would change my life by...”
- Reiterate what you are asking of them:
 - “I ask you to stand with our patient community and urge the FDA to prioritize its review and approval of one or both treatments as soon as possible.”

PROVIDERS

- State your reason for reaching out, including a brief summary of hypopara:
 - “I am reaching out today as a physician who cares for patients with hypoparathyroidism, a rare disorder that causes low calcium levels and high phosphate levels in the blood. There is currently no FDA-approved treatment, though the FDA is reviewing two possible treatments that could change the lives of my patients. I am asking you to stand with physicians and patients in the hypopara community in urging the FDA to expedite its review process and make treatments available as soon as possible.
- Describe the symptoms and impact of hypopara broadly:
 - “Hypoparathyroidism is a debilitating rare disease affecting 80,000 Americans. In the short term, symptoms include weakness, severe muscle cramps, tingling, burning and numbness, memory loss, impaired judgment, and headache. Over the long term, hypopara can cause calcium deposits in the kidney, brain, blood vessels, eye, and other soft tissues, increasing risk of kidney disease and other major complications.”
- Describe the treatments:
 - Until recently, hypopara patients did have access to more comprehensive treatment in the form of Natapara, a once-daily injection of the necessary hormone. Unfortunately, this drug was removed from the market due to safety concerns, leaving hypopara patients without an FDA approved therapy
 - The new treatments under review with the FDA are promising and have the potential to bring relief to hypopara patients. They are vastly preferable to the current available treatment of increased Vitamin D and calcium supplements, which can be burdensome and ineffective.
- Reiterate what you are asking of them:
 - “I ask you to stand with physicians and the 80,000-strong patient community to urge the FDA to prioritize its review and approval of these treatments.”

Letter-Writing Guide

EMAILING MEMBERS OF CONGRESS

Submitting a letter via hard copy or email to your representatives is an important piece of our advocacy, because it allows you to express thoughts and give necessary context in a longer form.

To know where to send a letter or email, you can find your Member of Congress by clicking [here](#), and your Senators by clicking [here](#). You will simply enter your zip code and receive information about the individual member and the best contact information for their office. It is important to only reach out to your representatives in Congress; Congressional staff and members alike do not enjoy hearing from people they don't represent and will not be inclined to read your letter.

You can also submit an email to your Member of Congress or Senators using a tool called Voter Voice that simplifies the process (more information below).

When you compose your letter, ensure you insert the name of the Member of Congress or Senator you are addressing at the top.

The following is a sample that you are encouraged to personalize as you see fit. You are encouraged to expand the bolded section with your personal experience:

Subject: Hypoparathyroidism patients need an FDA-approved therapy as quickly as possible

Dear [Congressmember or Senator],

I am writing to you as a constituent and an individual living with a rare and often debilitating disease called hypoparathyroidism. For most of the 80,000 Americans affected, hypoparathyroidism – or hypopara for short – occurs as a complication of neck surgery where the tiny parathyroid glands are damaged or removed. For others, it is inherited or is a complication of other diseases. Chronic hypoparathyroidism has no cure. And now, because of ongoing manufacturing issues, Natpara, a previously FDA-approved treatment, is unavailable to all but a relatively few patients under a special use program. With several other companies working on solutions, I am writing to ask you to contact the FDA to urge the agency to review and approve new treatment options for hypoparathyroidism as quickly as possible.

Hormones affect many parts of the body, and those of us living with insufficient levels of parathyroid hormone can experience long-term health complications to the kidneys, bones, brain, heart, and gastrointestinal system. Many of us with hypopara experience challenges working, take care of our families, or just going about a normal day. Because this disease disrupts calcium levels, some patients end up in the emergency room with life threatening “calcium crashes.” And many of us fear the risks that come from the practice of treating some symptoms with high daily doses of calcium.

As a hypopara [patient/caregiver], I have experienced... [share your own story here].

Other endocrine disorders have effective hormone replacement therapies, and hypopara patients need help getting better treatment options. Once again, I ask that you contact the FDA to urge the agency to recognize this urgent need and to approve qualified new therapies for hypoparathyroidism as soon as possible.

Thank you,

[Your Name]

EMAILING THE FEDERAL DRUG ADMINISTRATION

In addition to submitting an email to your members of Congress, it is also possible to raise your voice in another way: by sending your thoughts directly to the FDA. Below is a template email, similar to the one above, that you may personalize however you wish.

Once you have finalized your email, you may send it directly to Bill Burke at bb@rubicondc.com, who will ensure it is delivered to the appropriate decision makers at the FDA.

Subject: Hypoparathyroidism patients need an FDA-approved therapy as quickly as possible

To Whom it May Concern,

I am writing to you as an individual living with hypoparathyroidism, a rare and debilitating disorder for which there are currently no reliably available FDA approved therapies. I am writing to ask the FDA to approve treatment for hypoparathyroidism as quickly as possible. There are two treatments going through the regulatory process that you have the ability to expedite: one from Ascendis Pharma, and one from BridgeBio. Either treatment would have life-altering impacts for the hypopara community.

Hypoparathyroidism (hypopara) is a rare endocrine disorder characterized by insufficient levels of parathyroid hormone (PTH), resulting in low calcium and elevated phosphate levels in the blood. Hypopara affects approximately 80,000 people in the United States. With hypopara, patients often experience decreased quality of life and long-term health complications. In the short term, symptoms include weakness, severe muscle cramps (tetany), abnormal sensations such as tingling, burning and numbness (paresthesia), memory loss, impaired judgment, and headache. Over the long term, this complex disorder can cause calcium deposits in the kidney, brain, blood vessels, eye, and other soft tissues, increasing risk of kidney disease and other major complications.

As a hypopara patient, I have experienced severe symptoms, limiting my daily activities and overall quality of life in notable ways.

Hypopara patients currently have few options available to them for treatment of the disease. The current standard of care often consists of supplements of calcium and active vitamin D, which can be both burdensome and ineffective. As you may know, until recently, hypopara patients did have access to more comprehensive treatment in the form of Natapara, a once-daily injection of recombinant human parathyroid hormone. Unfortunately, this drug was recently removed the market due to safety concerns and is now only accessible in an extremely limited fashion through a special use program. Natapara's removal from the market has had a significant impact on hypopara patients, and we are anxiously awaiting approval of new treatments so that hypopara patients may once again have a choice of therapies that work best for them.

Once again, I urge the FDA to approve new treatments for hypoparathyroidism as quickly as possible.

Thank you,

[Your Name]

Using Voter Voice

You can submit an email to your Members of Congress or Senators using a tool called [Voter Voice](#) that simplifies the process of finding their information and manually entering it into your email.

With Voter Voice, you can quickly and directly contact your representatives in Congress and share your story to encourage the FDA to streamline the approval of a new, safe treatment for hypopara. With this tool, you can ensure you are reaching your representatives, which is important as they only want to hear from their direct constituents on prominent issues.

Here is how the tool works:

- Edit and personalize the template email (especially in the bolded section). The more you share your personal experience with hypopara, and how your life would be improved with an FDA-approved treatment, the more impactful your letter will be.
- Enter your zip code
- Click to submit the letter directly to your representative.

[Click here to be directed to the Voter Voice tool now.](#)

Guide to Sharing Your Story via Social Media

FINDING YOUR REPRESENTATIVES' ACCOUNTS

To find your representatives' social media pages, simply go to the platform you are using—in this case, either Twitter or Facebook—and search their name in the search field.

On both sites, you will be looking for a page with a checkmark next to the name, indicating they are verified. There will likely be two verified accounts for the same individual (more on that below).

ON TWITTER:



ON FACEBOOK:



Members of Congress also have their social handles displayed on their official House of Representatives and U.S. Senate websites, along with additional contact information.

SHARING YOUR STORY AND MAKING AN IMPACT, BRIEFLY

Even if you are not a regular social media user, it is important that you take advantage of this valuable tool to raise your voice using these tips and best practices:

As opposed to submitting a letter or an email, using social media to contact your representatives requires you to be brief—especially via Twitter, where posts are limited to 280 characters. That said, social media is a powerful tool to reach lawmakers, because these accounts (especially Twitter) are monitored by the lawmaker and/or their staff, and it is easier to see visually the traction a particular issue or conversation is having using hashtags and other tools. Social media is also a crucial tool because you can contact key decision makers without being a constituent.

TWITTER

Members of Congress and their staff use Twitter more than any other social media outlet. Its bite-size form ensures messages can be received by all parties quickly.

Here are important best practices to ensure your story breaks through:

KEEP IT TO 280 CHARACTERS

While it's possible to extend a message into multiple tweets, called a "thread," it is much less impactful in terms of reaching a member of Congress and delivering a complete message. It is undoubtedly challenging to pack a full message on hypopara into 280 characters, but it's crucial you push yourself to share your story and make your direct ask of them in short order.

- **Example:** .@RepDebbieDingell I am a patient living with hypoparathyroidism, a debilitating disease for which two safe & effective treatments are under review by the FDA. Please help us by urging the FDA to approve treatments as soon as possible. #hypopara

ADD A PERIOD BEFORE THE @HANDLE

Twitter uses handle names to ensure individual people notice your comment to them. Putting a period before the handle ensures your tweet will appear in all your followers' feeds, guaranteeing a wider distribution. Without the period, the tweet will be visible only to you, the person you mentioned, and anyone who happens to follow both of you.

- **Example:** @GKButterfield Please ask the FDA to speed up its review process of treatments for hypoparathyroidism, a debilitating disease impacting 80,000 people. Please stand with us patients and help move this treatment forward!

TWEET AT BOTH OFFICIAL AND CAMPAIGN ACCOUNTS

Most members of Congress have separate Twitter accounts—one for their "official" government work, and one for their "campaign" activities. These are split up for legal reasons and are generally monitored by different staff. This distinction is always made clear in the account description.

As we are reaching out to representatives on official government business, you should ensure you are reaching their official account, but there's no reason to not include their campaign account as well, or in a separate tweet, if you wish. This will increase the likelihood the individual or their staff sees it.

- **Example:** California Congresswoman Doris Matsui's official account is @DorisMatsui. Her campaign account is @Matsui4Congress.

USE ONE HASHTAG, CONSISTENTLY

Hashtags are used on Twitter to categorize and organize conversations, so that if a user searches or clicks on a hashtag, every post including that hashtag is listed in one stream. By attaching the same hashtag to all posts calling on Members of Congress and Senators to take action, we can ensure the sheer volume of posts is viewable in one place—a key part of gathering momentum online. The hashtag should be an uncommon one, so that there are no unrelated posts attached to it. A good option for our efforts would be #hypopara, as noted above.

FACEBOOK

While members of Congress and their staffs do not check their Facebook accounts as often, the site is a helpful tool because it allows you to share a message without a hard character limit—though it is, as always, important to be as brief as possible.

KEEP IT TO 100 WORDS OR FEWER

This will ensure a staffer or representative will read the entire post; a multi-paragraph essay will be too long for anyone to read and digest in detail.

- **Example:** I am one of 80,000 patients living with hypoparathyroidism, a rare but debilitating disease for which two treatments are under review by the FDA. Without treatment, we are unable to live full or easy lives; the disease decreases calcium in the blood, resulting in weakness, muscle cramps, and memory loss in the short term, as well as kidney disease and decreased life expectancy in the long term. Please help us by urging the FDA to approve therapies as soon as possible.

POST ON YOUR CONGRESSMEMBER AND SENATORS' FACEBOOK PAGES, AND DIRECT MESSAGE THEM

There are two ways to reach your members of Congress on Facebook: by posting directly to their page, and by direct messaging them; both are worthwhile methods, for varied reasons. By issuing a public post, other users can engage in the post through comments; by direct messaging, you increase the odds the message will be seen by a staffer.

You should not, however, send your message via these two methods at the same time, as this will dilute their impact and increase the likelihood the staffer monitoring the page treats your message as spam.

PRIORITIZE REACHING THE OFFICIAL PAGE, NOT THE CAMPAIGN PAGE

Similar to Twitter, most members of Congress have two Facebook pages—one where they discuss their activities in an official capacity, and one where they discuss their campaign events and milestones. Since there is less attention paid to Facebook overall, your message to the campaign page will likely not be processed or dealt with. While it can't hurt to reach out to both, ensure you are prioritizing reaching the official page.

- **Example:** Congresswoman Doris Matsui's official Facebook page is [facebook.com/doris.matsui](https://www.facebook.com/doris.matsui). Her campaign page is [facebook.com/Matsui4Congress](https://www.facebook.com/Matsui4Congress).

MISSION: To improve the lives of people impacted by HypoPARAthyroidism through education, support, research and advocacy

HypoPARAthyroidism Association

695 Montecito Ct., Lemoore, CA 93245 | www.hypopara.org