

## **CDC Reductions Mobilization Playbook**

The *CDC Reductions Mobilization Playbook* is designed to help advocates take swift, effective action in response to the severe staffing cuts affecting the CDC's Division of Blood Disorders and Public Health Genomics.

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#### **About the Playbook**

## Mobilizing for Action - Protecting Blood Disorder Programs and Patient Access

The *CDC Reductions Mobilization Playbook* is your guide to taking swift, coordinated action in response to recent threats to critical public health programs. Following staff reductions at the CDC's Division of Blood Disorders and Public Health Genomics, our community must respond decisively to protect the services and support systems we rely on.

This playbook empowers Advocacy Network members with the tools and messaging needed to engage directly with lawmakers, educate their offices on the value of these programs, and call for immediate restoration of the functionality of the division.

Now is the time to act. With Congress in recess from April 14-25, constituents have a unique opportunity to connect with their elected officials and their staff in their local district offices. This recess presents the perfect moment to deliver a clear message:

Take immediate action to ensure continued service functionality provided by these essential offices so they can continue to effectively serve the public.



Together, we can defend vital programs, promote equitable healthcare access, and ensure our community's needs remain front and center.

Let's get started.

#### **How to Connect with Your Lawmaker**

There are three primary ways to connect with your members of Congress outside of traveling to Washington DC:

- **1.** Calling their office A quick and effective way to voice your concerns.
- **2.** Scheduling an in-district meeting A structured opportunity to discuss key issues.
- **3.** Conducting an in-district drop-by A simple way to deliver materials and make an impression.

## 1. Calling Your Member of Congress

It's easy to contact your members of Congress by phone. You can find their office numbers on their websites or call the Capitol Switchboard at (202) 224-3121 to be connected. If you are unsure who your Members of Congress are, visit GovTrack to find their contact information.

## **Best Practices for Calling**

- Ask to Speak with the Health Legislative Assistant This staffer handles healthcarerelated issues and can relay your message effectively.
- Introduce Yourself Clearly state your name, where you live, and that you are a
  constituent.
- Identify the Issue Mention the topic you are calling about and briefly state your position.
- Make a Clear Ask Ask if your legislator supports the issue and request specific action (e.g., co-sponsoring a bill).
- Leave Your Contact Information Request a return call or written response to ensure your voice is heard.

## 2. Scheduling an In-District Meeting

Meeting your lawmaker in person allows for more in-depth discussions. To do this, follow these steps:

## Best Practices for Scheduling a Meeting

Find Your Lawmaker's Local Office - Visit GovTrack to locate their district office.



- Contact the Local Office Call and ask about the preferred process for scheduling in-district meetings.
- Email the Scheduler Most offices require an email request, which should include:
  - Your name and organization (if applicable)
  - The purpose of your visit
  - The names of participants
  - Your availability for the meeting
- Confirm Your Appointment Since schedules change frequently, confirm your appointment a week before the scheduled meeting.

## Best Practices for the Meeting

- Introduce Yourself Start by stating your name, where you live, and why you are visiting.
- Share Your Story Personal experiences help make the issue more impactful and relevant to the district.
- **Present Your Asks** Clearly state what action you want the legislator to take, such as co-sponsoring a bill.
- Answer Questions Honestly If you do not know the answer to a question, offer to follow up with more information later.
- Offer to Be a Resource Let the legislator or staff know that you are available for future discussions on the issue.

## After Your Visit

- **Send a Thank-You Email** Reiterate key points from your conversation and express appreciation for their time.
- **Provide Follow-Up Information** If any questions were left unanswered, send the requested details.
- **Keep in Touch** Stay engaged with the legislator's office to build a lasting relationship.
- Capture the Moment & Take Action on Social Media Snap a photo or selfie with the office sign in view and post it on social media tagging your lawmaker.



## 3. Conducting an In-District Drop-By

If you cannot schedule a meeting, you can still participate by dropping off materials at the office during business hours. This method is particularly useful during congressional recess periods when lawmakers are in their districts.

## Best Practices for a Drop-By

- Find Your Lawmaker's Local Office Use GovTrack to locate the office.
- **Bring Informational Materials** Have a one-page document summarizing the key issue and your request.
- Ask Staff to Pass Along Your Materials Politely introduce yourself, explain why you are there, and ask the staff to deliver your document to the legislator.
- Follow Up If possible, send an email to confirm that the materials were received and reiterate your ask.
- Capture the Moment & Take Action on Social Media Snap a photo or selfie with the office sign in view and post it on social media tagging your lawmaker.

#### 4. Follow-Up & Report Back

- Collect business cards from congressional staff.
- Report your advocacy action using our Advocacy Report Back Form.

# Talking Points: IMPACT OF CDC REDUCTION IN FORCE ON THE BLEEDING DISORDERS COMMUNITY

#### **KEY MESSAGE**

The April 1st Reduction in Force at the CDC has, through major staff reductions, effectively eliminated the CDC's Division of Blood Disorders and Public Health Genomics and its branches – Blood Disorders Surveillance and Epidemiology, Hemostasis Laboratory, and Public Health Genomics. This devastating cut threatens the safety of people with bleeding disorders and compromises blood supply safety monitoring that has protected Americans since the "bad blood era" of the 1980s.

## **CRITICAL CONCERNS**

#### Threat to Public Health Surveillance

• The Division maintained essential national surveillance of bleeding disorders through the Community Counts program, documenting critical information about disease prevalence, comorbidities and joint disease, treatment outcomes, and more.



- Without this surveillance, we lose our ability to track disease progression, treatment effectiveness, and emerging complications in real-time.
- This data helps clinicians provide evidence-based care and allows researchers to develop improved treatments.

## **Loss of Laboratory Services**

- The CDC provided specialized inhibitor testing services that are crucial for patients
  receiving factor replacement therapy. The loss of this will result in challenges in
  obtaining this testing for smaller HTCs and rural patients, as well as increased out-ofpocket costs for patients and families.
- Rural and underserved communities rely disproportionately on these CDC laboratory services, making them especially vulnerable to service reductions or disruptions.
- Inhibitor development can render treatments ineffective and significantly increase treatment costs, which could result in major delays in treatment without this service.

## **Compromised Blood Supply Safety**

- The CDC's monitoring for blood-borne pathogens (HIV, Hepatitis, Zika, Ebola) in the national blood supply is now severely compromised due to the loss of cross-collaboration with other vital work within the CDC.
- This surveillance system was established following the devastating "bad blood era" when thousands with bleeding disorders were infected with HIV and Hepatitis through contaminated blood products.
- Without proper monitoring, we risk repeating history's tragic mistakes.

#### No Transition Plan

- The abrupt RIF came without advanced public input, and there are no publicly known plans for how these critical public health functions will continue.
- As of the most recent information, only two staff members remain, making functional operations impossible.
- Decades of institutional knowledge and expertise have been lost overnight.



## **Request to Congress**

Take immediate action to ensure continued service functionality provided by these essential offices so they can continue to effectively serve the public.

This is not a political issue but a matter of public health and safety. The bleeding disorders community has already experienced devastating consequences from government inaction during the "bad blood era." We cannot allow history to repeat itself. Lives depend on these critical CDC functions.

## Call Script: Urgent Advocacy for Division of Blood Disorders at CDC

For those opting to call their Congressional Members here is a call script you can use.

Hello, my name is [YOUR NAME], and I'm a constituent from [YOUR CITY/TOWN]. I'm calling today as a [BLEEDING DISORDER PATIENT/FAMILY MEMBER/ADVOCATE] to highlight an urgent issue affecting the bleeding disorders community.

Last week, the bleeding disorders community suffered a major setback. The Division of Blood Disorders and Public Health Genomics was cut down to just two staff members, leaving them virtually inoperable.

These offices are crucial. They track bleeding disorder prevalence, identify community needs, and help protect the safety of the U.S. blood supply and treatment products.

This directly impacts [ME/MY FAMILY MEMBER/OUR COMMUNITY] because [SHARE BRIEF PERSONAL CONNECTION TO BLEEDING DISORDERS].

I'm calling to urge Representative/Senator [NAME] to:

Take immediate action to ensure continued service functionality provided by these essential offices so they can continue to effectively serve the public.

Can I count on Representative/Senator [NAME] to act on this critical issue? This is literally a matter of life and death for members of the bleeding disorders community.

Thank you for your time. Can I leave my contact information for a response on what steps the Representative/Senator will be taking? I can be reached at [YOUR PHONE/EMAIL].

#### **Social Media Posts**

Sample social media posts [Snap a photo or selfie with the office sign in view]

**SAMPLE POST 1 (After a Meeting)** Just met with @[LawmakerHandle] to urge action on the devastating April 1st CDC cuts that eliminated the Division of Blood Disorders. We cannot afford to lose blood safety monitoring or critical surveillance like Community Counts. #SaveCDCBloodDisorders



**SAMPLE POST 2 (After a Call)** I called @[LawmakerHandle] today to express deep concern about the elimination of the CDC's Division of Blood Disorders. These cuts threaten lives and roll back decades of public health progress. Please act now! #SaveCDCBloodDisorders

**SAMPLE POST 3 (After Dropping Off Materials)** Just dropped off materials at @[LawmakerHandle]'s office highlighting the urgent need to restore the CDC's blood disorder programs. We cannot go back to the "bad blood" era. #SaveCDCBloodDisorders

**SAMPLE POST 4 (Data/Surveillance Focus)** Without CDC's Community Counts surveillance, we're flying blind. Clinicians, researchers, and patients depend on this data to manage care. @[LawmakerHandle], please fight to restore this lifeline. #SaveCDCBloodDisorders

**SAMPLE POST 5 (Blood Safety Focus)** The CDC cut its blood safety monitoring team. No HIV, Hepatitis, or Zika tracking? We *cannot* afford another "bad blood" crisis. @[LawmakerHandle], stand up for patient safety. #SaveCDCBloodDisorders

## **Connect with Your State Member Organization**

We highly encourage you to connect with your state bleeding disorders organization to learn more about local resources, programs, and state advocacy opportunities. They are an important partner in supporting and amplifying our community's voice!

Visit www.hemophiliafed.org/member-organizations-2/ to find your nearest Member Organization.