Sick Cells SCDC Advocacy
Outreach Toolkit

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Background

Last week, the US Department of Health and Human Services (HHS) issued a series of reductions in force (RIFs), which are layoffs prompted by departmental restructuring. Among the most concerning changes was the elimination of the entire Division of Blood Disorders, including its personnel. This division houses the Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection (SCDC) program, a vital national resource for the sickle cell disease (SCD) community. In addition, the HRSA Advisory Committee on Heritable Disorders in Newborns and Children, a long-standing advisory body responsible for shaping newborn screening policies, was also terminated. These actions signal a troubling shift away from federal leadership and commitment to the sickle cell community. The future of the CDC's Sickle Cell Data Collection program is now at risk.

We are calling on the SCD community to use their voices and take action. We must advocate to reinstate the Division of Blood Disorders at the CDC, protect and preserve the SCDC program, and uphold the work and leadership of our trusted federal champions in this space.

The Ask: Contact your members of Congress

The Sickle Cell Data Collection program is more than just a data system. It is a catalyst for change in the lives of individuals and families affected by SCD. We are asking SCD community members, including patients, caregivers, clinicians, advocates, and allies, to take action by contacting their members of Congress.

Here is what you can ask them to do:

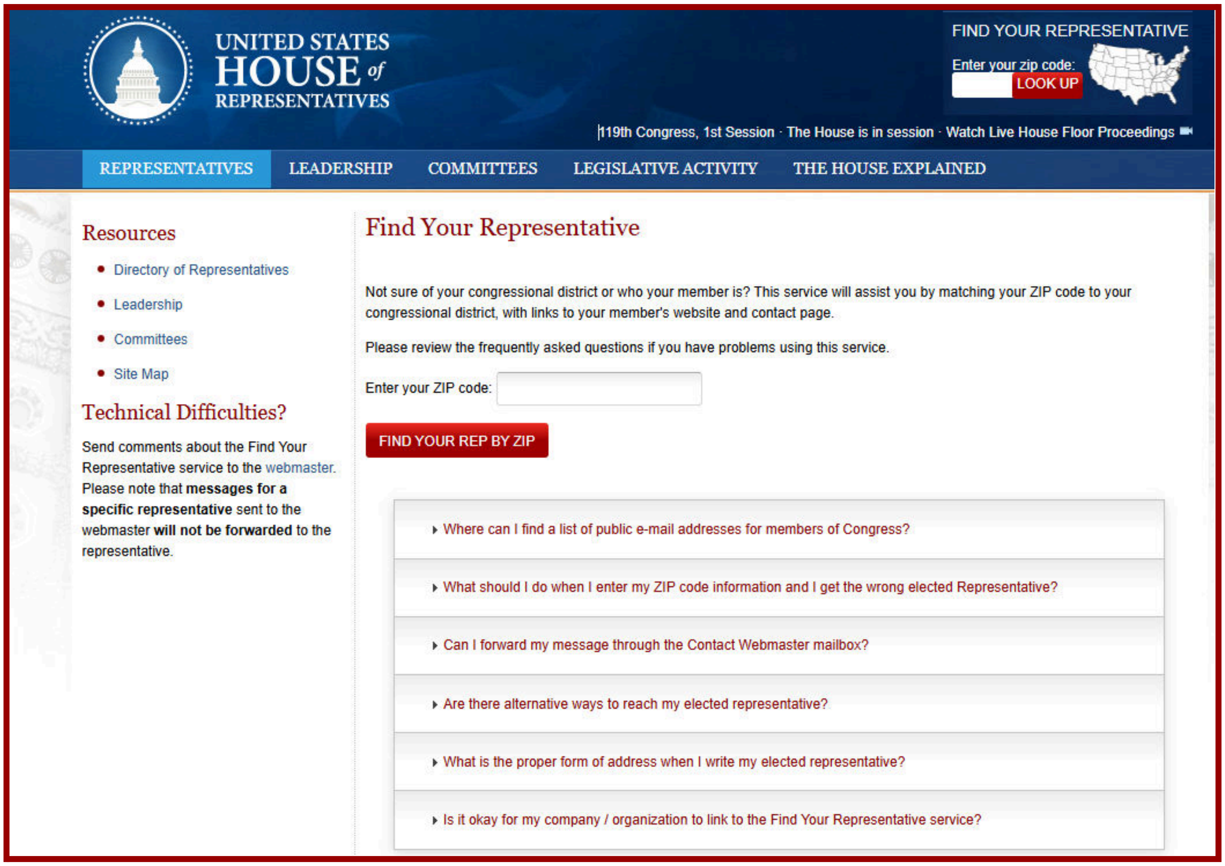
- Protect continued funding for the SCDC program
- Reinstate the Division of Blood Disorders and restore its staff

Use the resources in this toolkit to find your representative, send a message, or make a phone call. Every voice counts.

How to Contact Your Members of Congress

Not sure how to reach your representative? Don’t worry — it’s easy, and it only takes a few minutes. Here’s how you can do it:

Step 1: Find your representative
Go to this website: www.house.gov/representatives/find-your-representative



Technical Difficulties?

Send comments about the Find Your Representative service to the webmaster. Please note that **messages for a specific representative** sent to the webmaster **will not be forwarded** to the representative.

Find Your Representative

Not sure of your congressional district or who your member is? This service will assist you by matching your ZIP code to your congressional district, with links to your member's website and contact page.

Please review the frequently asked questions if you have problems using this service.

Enter your ZIP code:

- Where can I find a list of public e-mail addresses for members of Congress?
- What should I do when I enter my ZIP code information and I get the wrong elected Representative?
- Can I forward my message through the Contact Webmaster mailbox?
- Are there alternative ways to reach my elected representative?
- What is the proper form of address when I write my elected representative?
- Is it okay for my company / organization to link to the Find Your Representative service?

Step 2: Enter your ZIP code
Type in your ZIP code to find your member of Congress.

UNITED STATES HOUSE of REPRESENTATIVES

FIND YOUR REPRESENTATIVE

Enter your zip code: LOOK UP

119th Congress, 1st Session · The House is in session · Watch Live House Floor Proceedings

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Resources

- Directory of Representatives
- Leadership
- Committees
- Site Map

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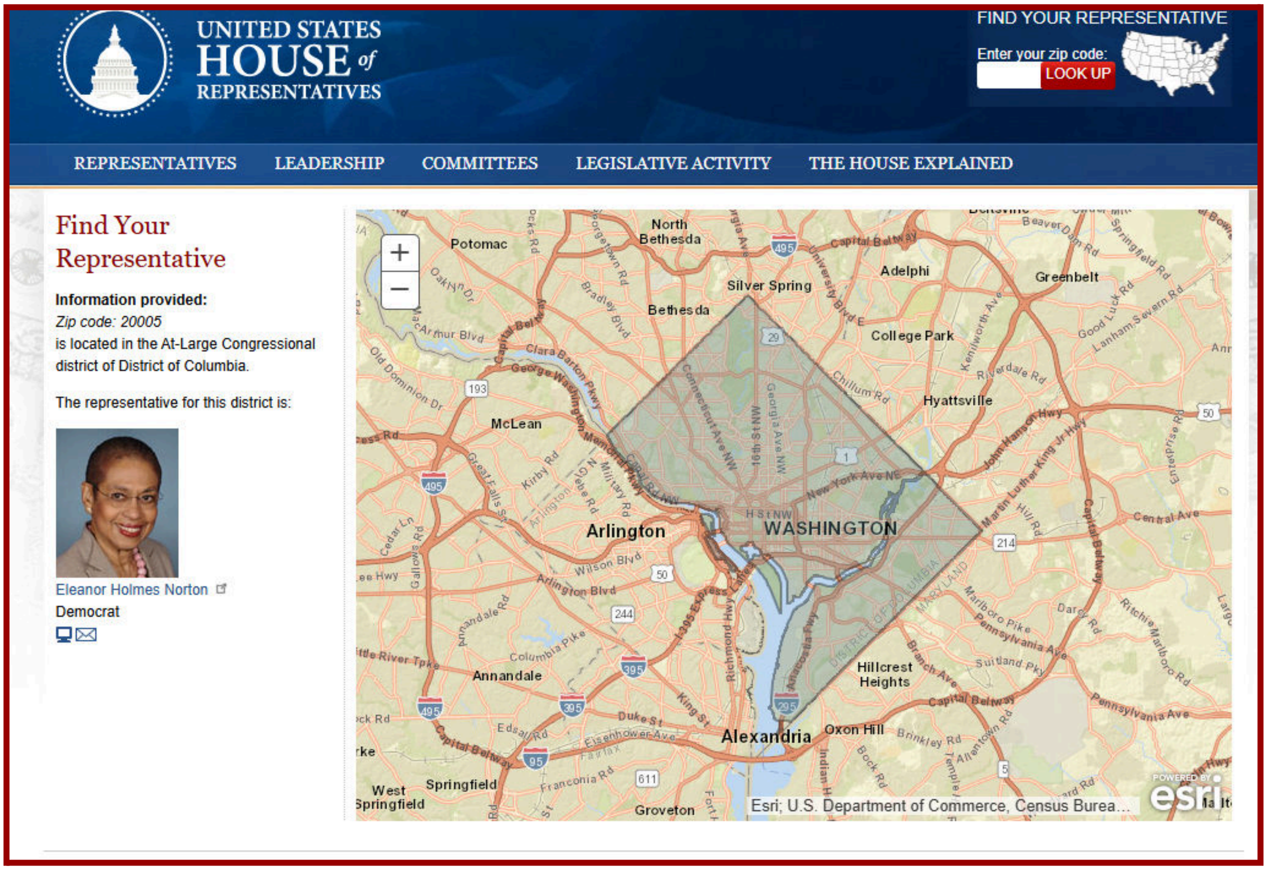
Enter your ZIP code: 20005

FIND YOUR REP BY ZIP

Step 3: Click on their name

You'll be taken to their official website where you can find contact information, including phone numbers, mailing addresses, and an online contact form.



UNITED STATES HOUSE of REPRESENTATIVES

FIND YOUR REPRESENTATIVE

Enter your zip code: LOOK UP

REPRESENTATIVES · LEADERSHIP · COMMITTEES · LEGISLATIVE ACTIVITY · THE HOUSE EXPLAINED

Find Your Representative

Information provided:

Zip code: 20005

is located in the At-Large Congressional district of District of Columbia.

The representative for this district is:

Eleanor Holmes Norton

Democrat

Step 4: Call or send a message
Call their office or fill out the contact form with a message. If you're calling, ask to speak with the staff person who handles health issues.

Here's a simple message you can send or say:

> *"Hi, my name is [Your Name], and I live in [City, State]. Last week, Secretary Kennedy dismantled the CDC's division of blood services. This division is important for the sickle cell disease community.*
>
> *I'm calling to ask Representative [Last Name] to protect funding for the CDC's Sickle Cell Data Collection program and reinstate the Division of Blood Disorders. These programs are vital to the sickle cell disease community. Thank you."*

That's it! A quick message or phone call can make a big difference.

Want to Say More?

If you'd like to go beyond a simple message, here are a few key points you can include when speaking or writing to your representative. These talking points highlight why the CDC's Sickle Cell Data Collection program is essential:

1. **The program helps us understand how many people live with sickle cell disease.**
   The SCDC program collects data from hospitals, Medicaid, and clinics to provide accurate numbers on how many people are living with SCD in each state. This data helps guide funding and services.
2. **The data is used to improve care and close gaps.**
   Information from the program has already helped states like Michigan expand services to adults with SCD, and helped North Carolina identify a 25 percent undercount in people living with the disease.
3. **It ensures people with SCD are not left behind.**
   The SCDC program is the only national effort to track care patterns and health outcomes for this population. Without it, federal and state programs risk making decisions based on incomplete or outdated information.
4. **Data drives policy.**
   This program is the foundation for many federal efforts to improve sickle cell care, including Medicaid planning and gene therapy access. We need this data to keep moving forward.

How Does the SCDC Program Impact the SCD Community?

At the 2025 SCD Policy Forum, community advocates from across the country gathered to elevate critical federal priorities, including **Federal Request #3: Funding for the CDC's Sickle Cell Data Collection (SCDC) program**. The SCDC program is the only national public health surveillance initiative solely focused on individuals living with sickle cell disease (SCD). It collects and analyzes data on prevalence, care patterns, health outcomes, and mortality. These insights are vital for driving policy, improving care, and closing health equity gaps.

In 2019, thanks to community advocacy, the SCDC program received its first congressional appropriation, which allowed the program to expand from two states to 16. This expansion has led to measurable local impact. Here are three examples:

California

SCDC data revealed that 22 percent of children and 50 percent of adults with SCD had no hematology visits over a three-year period. These findings highlighted major care gaps and helped inform the state's decision to allocate $10 million in community funding to address these barriers.

North Carolina

In April 2025, the North Carolina General Assembly introduced **House Bill 633**, titled *Expand Sickle Cell Disease Programs and Services*, in response to SCDC data showing a 25 percent increase in the number of individuals living with SCD in the state — rising to at least 7,000 people.

The bill includes a request for over $3 million in funding across two years to:

- Expand services at six comprehensive SCD medical centers
- Fund full-time Transition Coordinators to support youth transitioning from pediatric to adult care
- Provide grants to community-based organizations (CBOs) in underserved counties
- Support the North Carolina Sickle Cell Syndrome Program through new staff and an emergency department toolkit to improve urgent care for people with SCD

Michigan

Data from the SCDC program directly supported the expansion of **Title V benefits to include adults with SCD**. This enabled the state to identify and reach eligible individuals who had previously been overlooked. Hundreds are now enrolled in a program that provides essential health services, thanks to strategic data use and collaboration between agencies.

The loss or even temporary disruption of the SCDC program would undermine more than a decade of hard-fought progress in building a national infrastructure for SCD surveillance. As advocates, we must take action to prevent this. Contacting members of Congress is a key way to show support for protecting this vital resource and ensuring continued momentum toward equitable care and treatment for the SCD community.

We encourage you to use your voice to protect this vital program. Every message makes a difference.