Chronic
Disease
Coalition

2025
Impact Report

Patients First, Progress Together

In October 2025, we celebrated the 10th Anniversary of the Chronic Disease Coalition (CDC). What started out as a relatively small focus project has grown to encompass all 50 states. Working together, we continue to build a stronger, more unified patient movement—one that is heard in state capitols across the country and recognized as a trusted, nonpartisan voice for change.

This year's legislative sessions showed what happens when advocacy is strategic and personal. From Texas to California, our ambassadors helped advance bills improving access to Medigap coverage and protecting the 340B program. Through special projects and targeted campaigns, we reached millions online and brought lawmakers into meaningful conversations about affordability, access, and representation.

The numbers tell part of the story—more letters to legislators, more social engagement, more partners—but the heart of our work remains the same: people helping people navigate a complex healthcare system and finding purpose in advocacy. Every patient who shares their experience moves us closer to policies that reflect compassion and common sense.

10th
CHRONIC DISEASE
COALITION
ANNIVERSARY

As we look ahead, the Coalition will continue to expand the reach of patient-centered policymaking, working with state leaders, healthcare partners, and—most importantly—the patients themselves. Thank you for your partnership, your belief in our mission, and your shared commitment to ensuring every voice counts.

With appreciation and determination,

Mary Kay

Mary Kay Clunies-Ross
Executive Director

Wendy

Wendy Schrag
CDC Board Chair
Fresenius Medical Care

POLICY In Action

2025 was a significant year for healthcare and health policy. With the beginning of a new presidential administration which put "fighting chronic disease" at the top of the healthcare agenda, and with many states following their policy lead, the Coalition was off to a fast start.

At the national level...

While new federal agency leaders raised the issue of chronic disease, 2025 is marked by significant steps backwards in terms of access to care: Congress and the administration significantly cut Medicaid funding, medical research, access to vaccines and other essential health programs. These planned cuts threaten to roll back decades of progress we have made in both the access and affordability of care and treatments.

> *Medicaid means my kids can go to the doctor; I'd struggle badly without it. For me because of Medicaid and Medicare, I'm able to better manage my conditions. It's not the perfect system, but my conditions are better managed. If my kids lost Medicaid too, I'd have to be prepared for medical emergencies."* **—CDC AMBASSADOR**

CDC Ambassador **Heather Guidone** sees the impact of medical research cuts beyond progress in developing treatments, saying:

> *Cutting or stalling [medical research] funding doesn't just slow progress, it actively deepens inequities. It leaves patients in limbo, stifles the pipeline of new scientists, and forces promising leads into obscurity."*

At the state level...

The CDC worked with MultiState to help track more than 1,500 bills introduced to legislatures across the country. We also tracked legislative trends in our key areas of access, affordability and representation. While many legislators were navigating new political uncertainties, there was also important bipartisan progress on behalf of patients.

The CDC is proud to have been a part of coalition efforts to enact Medigap bills in Georgia, Nevada, Texas, Utah and Virginia. Hundreds of people answered our calls to action and engaged with their legislators to make these bills happen.

Lesley Perkins, a 62-year-old Texan in need of a kidney transplant, is exactly who Medigap plans are intended to help. She said:

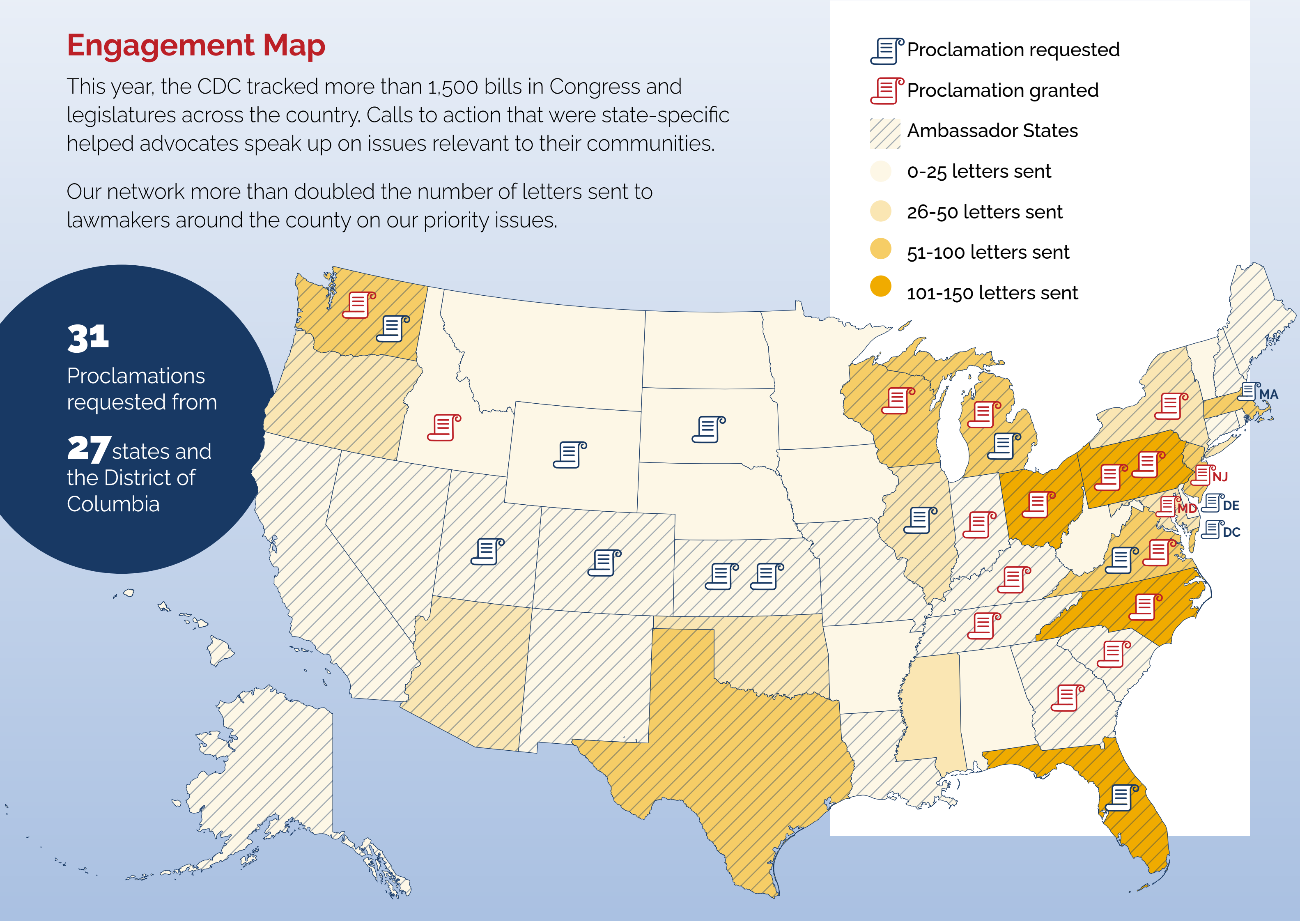
> *"I don't wait to take cruises and fancy vacations, I just want to live independently, somewhere safe and comfortable. I want to be able to pay my health insurance premiums and my utilities, and those are expensive. So much of my income has to go to healthcare."*

Engagement Map

This year, the CDC tracked more than 1,500 bills in Congress and legislatures across the country. Calls to action that were state-specific helped advocates speak up on issues relevant to their communities.

Our network more than doubled the number of letters sent to lawmakers around the county on our priority issues.

31 Proclamations requested from **27** states and the District of Columbia



2025 LEGISLATIVE ENGAGEMENT:

Guided by our shared values of Access, Affordability, and Representation

ACCESS

- Step therapy
- Nonmedical switching
- Prior authorization
- Living donor protections
- Medigap
- Telehealth access

AFFORDABILITY

- Copay accumulator bans
- Third-party assistance
- PBM reform
- 340B programs

REPRESENTATION

- Rare disease advisory councils
- Chronic Kidney Disease task forces

3,082 Total Letters

1,284 Letters from CDC Staff

1,798 Letters from the General Public

71 Ambassadors

23 Calls to Action

34 States + District of Columbia

10,000+ Coalition Advocates

6,400 Email Subscribers

COALITION Engagement

152,918
Video Views

2,004,779
Impressions

36,329
Link Clicks

57,677
Engagements

@chronicrights

SPECIAL PROJECT FOCUS

In 2025, social media ads highlighting the impact of 340B reform in Tennessee, Oklahoma and California reached more than 100,000 unique users, driving thousands of engagements. In Texas, a campaign supporting Medigap expansion reached more than 125,000 people in support of expanded coverage for vulnerable patients.

Digital Engagement

In 2025, the CDC strengthened our digital advocacy network and continued to turn online engagement into meaningful, on-the-ground action. Through our growing social media community, we connected hundreds of individuals living with chronic conditions with key lawmakers—keeping policymaking focused on patients.

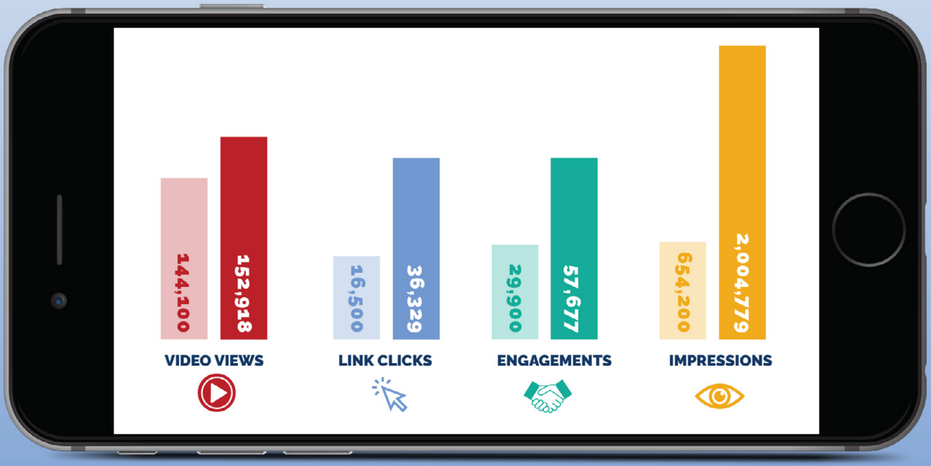
Our strategy centered on **authentic patient storytelling**, using real experiences to inspire action and shape policy conversations. We expanded our ambassador network, introduced new voices, and refreshed our story collection to reflect the full diversity of the chronic disease community. These narratives helped humanize the policy debate while driving measurable engagement from supporters across the country.

For the first time, we mobilized our most active digital advocates to participate in **targeted campaigns across several key states—including Texas, California, Oklahoma, and Illinois**. This approach allowed us to connect advocacy directly to active legislative priorities, and the response exceeded expectations.

Supporters contacted lawmakers, shared personal stories, and amplified calls for improved access to care and stronger patient protections. The success of this state-based targeting demonstrates how a coordinated, digital-first approach leads to tangible advocacy results.

By combining **data, storytelling, and direct advocacy**, we kept the focus where it belongs—on improving lives, protecting access, and ensuring that patient voices guide the future of healthcare policy.

2024 vs. 2025 SOCIAL ENGAGEMENT TRENDS



Partners & Allies

Partnerships and collaborations remained a cornerstone of our work, and we were proud to support other patient groups in their advocacy and awareness efforts.

We met individually, collaborated on legislative strategy, jointly signed on to letters, featured them in our social media feeds, highlighted their educational work in our newsletter, and promoted them on our website.

We are especially proud to celebrate the awareness work being done by the organizations who focus on specific disease groups. They are uniquely important to helping the public understand patient challenges and in supporting the cures that are most desperately needed.

ELEVATING THE LEADERSHIP ROLE OF PATIENTS

This year, we convened our first Patient Advisory Council (PAC). While we often reach out to all our ambassadors for feedback and insights, the Patient Advisory Council is a formal body within the Coalition, providing strategic advice, advocacy insights and patient-centered perspectives. 2025 Council members are:

- **Anna Ball – DE**
- **Darcy Bonjour – KS**
- **Tiffany Coles – PA**
- **Casey Doherty – DC**
- **Dustin Miller – WI**
- **James Myers – IN**
- **Claire Sachs – MD**
- **Christina Thielst – NV**
- **CJ Walker – VA**
- **Curtis Warfield – IN**
- **Anna Williams – IN**

We are so grateful to this inaugural group of all-star advocates, and we look forward to another year of working together!

CLAIRE SACHS, AMBASSADOR AND PATIENT ADVISORY COUNCIL MEMBER SPEAKS ON THE STEPS OF THE U.S. CAPITOL.

2025 AMBASSADOR SPOTLIGHT

Oliva Ayiku
Illinois

Tara Dulohery
Kansas

Sophia Feng
Maryland

Milli Garala
Texas

Donovan Guerrero
New Hampshire

Mariana King
Pennsylvania

Kevin Lee
Virginia

Brittany Leech
Oregon

Victoria Lopez
Florida

Sydney Lucky
California

Saida Mahoney
California

Giusiana Prosser
Washington

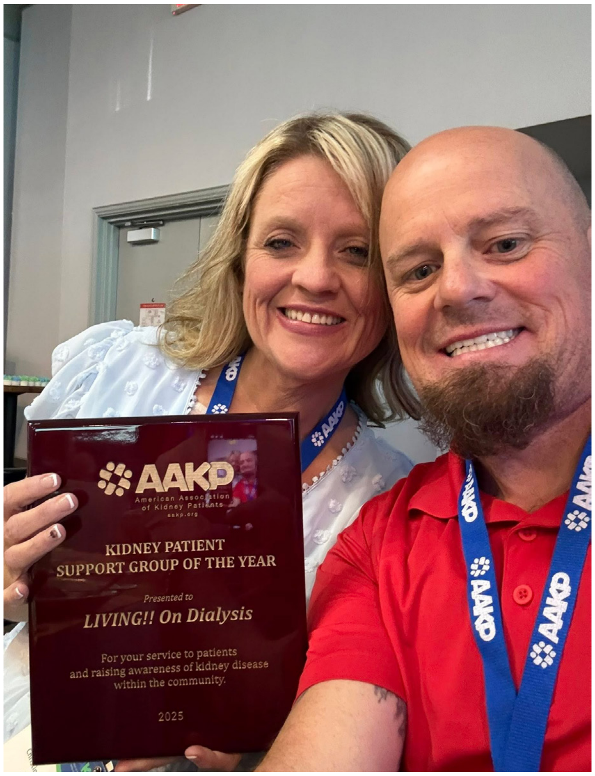
Samantha Smith
Massachusetts

Sarah Vinci
Maryland

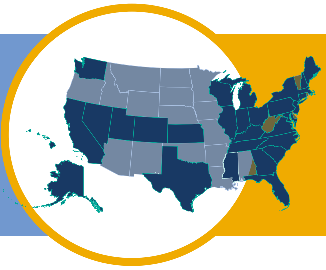
Ambassador Program

The word "ambassador" has a connotation of stately old gentlemen who wear tuxedos and attend state dinners. Our ambassadors are quite the opposite. A significant wave of ambassadors are under 25, and some of them are even in high school. With their whole lives ahead of them, these young people need—and are willing to ask for— better care, better diagnostics, better treatment, and more affordability.

2025 AMBASSADORS IN ACTION



75 Ambassadors



in 34 States and the District of Columbia

33 New Ambassadors

CHRONIC DISEASE Month

PATIENTS FIRST, PROGRESS TOGETHER

This year's Chronic Disease Month theme was Patients First, Progress Together. Our goal was to highlight how far we've come improving diagnostics and treatment for chronic disease patients and the access to and affordability of those treatments– and how we 're going to continue making progress, together.

New Insights

We also hosted a **State of the Patient Summit** on Chronic Disease Day (July 10) that included an expert-led deep dive on state legislation, implications of the One Big Beautiful Bill Act and approaches to healthcare reform that both lower costs and improve patient outcomes.

Ambassadors and patient advocates requested a record 31 state proclamations for Chronic Disease Month (or Day). Governors in 17 of those states awarded them.

CHRONIC DISEASE MONTH BY THE NUMBERS

16 Legislative Champions

250 Letters Sent

31 State Proclamations Requested

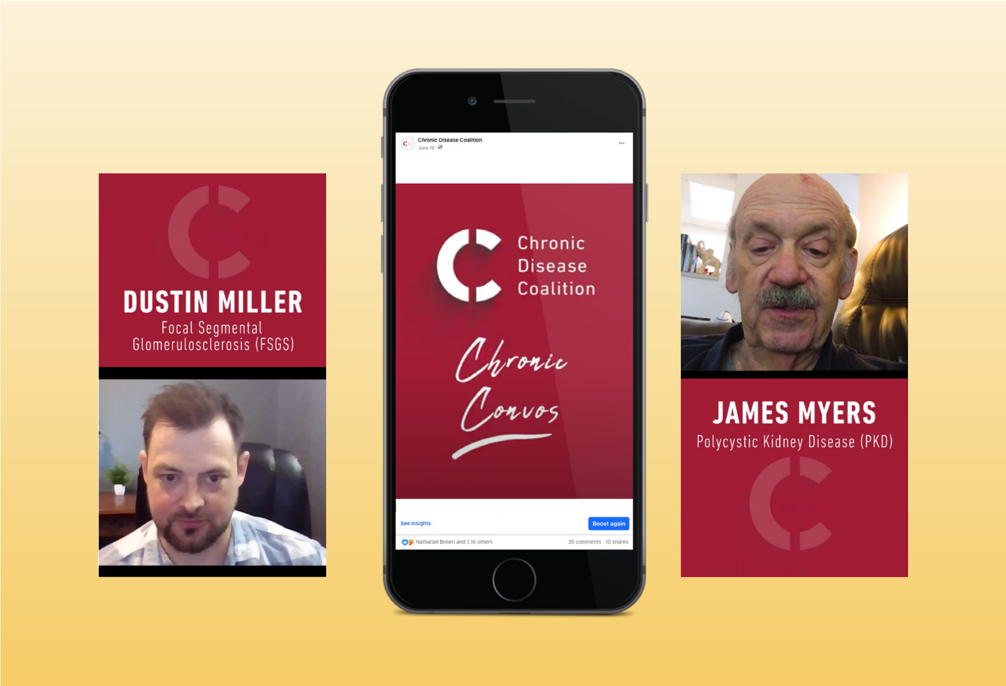
ON JULY 15, CDC AMBASSADOR CJ WALKER JOINED OTHER ADVOCATES AND THE COMMONWEALTH OF VIRGINIA TO OFFICIALLY RECOGNIZE JULY AS CHRONIC DISEASE MONTH.

PATIENT ADVOCATES WITH THEIR STATE PROCLAMATIONS

CHRONIC DISEASE MONTH

New Stories

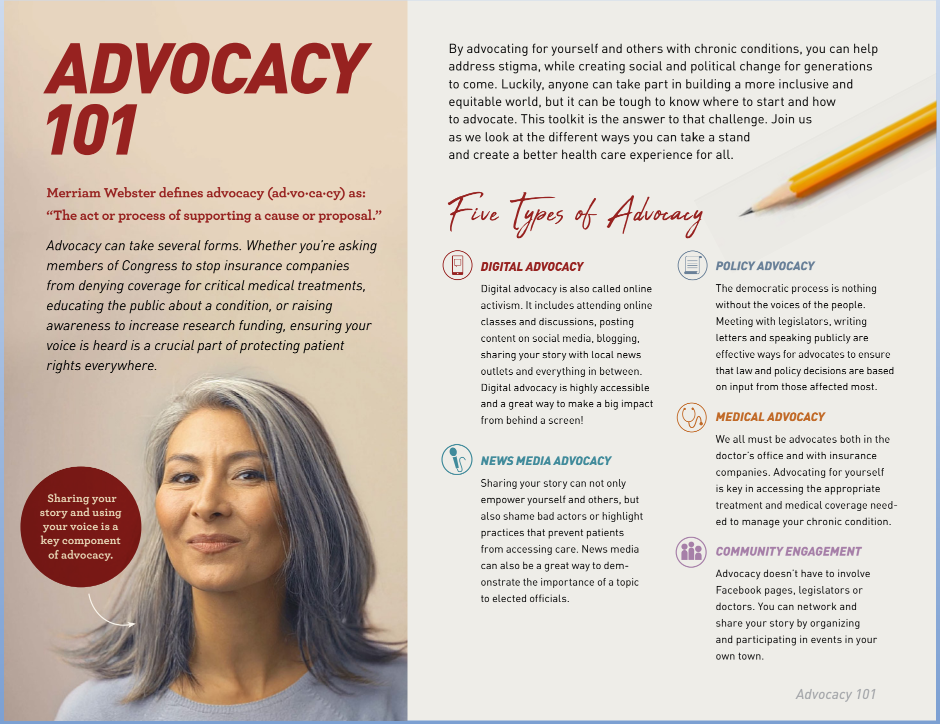
We highlighted the experiences of Patient Advisory Council members Jim Myers and Dustin Miller living with chronic kidney disease in a video called, **Chronic Convos: Then and Now**. Their three-minute conversation offered insight into how they were diagnosed, what their early treatment was like, what they would have told their younger selves, and their hope for the future.



NEW TOOLS

And because there isn't a right way to be an advocate, we updated our advocacy tools and shared the five common types of advocacy with examples of each in action.

We also armed patients with knowledge: for those who couldn't attend the State of the Patient Summit, for example, we shared a timeline for OBBBA implementation and other analysis on our website.



ADVOCACY 101

Merriam Webster defines advocacy (ad·vo·ca·cy) as: "The act or process of supporting a cause or proposal."

Advocacy can take several forms. Whether you're asking members of Congress to stop insurance companies from denying coverage for critical medical treatments, educating the public about a condition, or raising awareness to increase research funding, ensuring your voice is heard is a crucial part of protecting patient rights everywhere.

Sharing your story and using your voice is a key component of advocacy.

By advocating for yourself and others with chronic conditions, you can help address stigma, while creating social and political change for generations to come. Luckily, anyone can take part in building a more inclusive and equitable world, but it can be tough to know where to start and how to advocate. This toolkit is the answer to that challenge. Join us as we look at the different ways you can take a stand and create a better health care experience for all.

Five Types of Advocacy

DIGITAL ADVOCACY

Digital advocacy is also called online activism. It includes attending online classes and discussions, posting content on social media, blogging, sharing your story with local news outlets and everything in between. Digital advocacy is highly accessible and a great way to make a big impact from behind a screen!

NEWS MEDIA ADVOCACY

Sharing your story can not only empower yourself and others, but also shame bad actors or highlight practices that prevent patients from accessing care. News media can also be a great way to demonstrate the importance of a topic to elected officials.

POLICY ADVOCACY

The democratic process is nothing without the voices of the people. Meeting with legislators, writing letters and speaking publicly are effective ways for advocates to ensure that law and policy decisions are based on input from those affected most.

MEDICAL ADVOCACY

We all must be advocates both in the doctor's office and with insurance companies. Advocating for yourself is key in accessing the appropriate treatment and medical coverage needed to manage your chronic condition.

COMMUNITY ENGAGEMENT

Advocacy doesn't have to involve Facebook pages, legislators or doctors. You can network and share your story by organizing and participating in events in your own town.

Advocacy 101

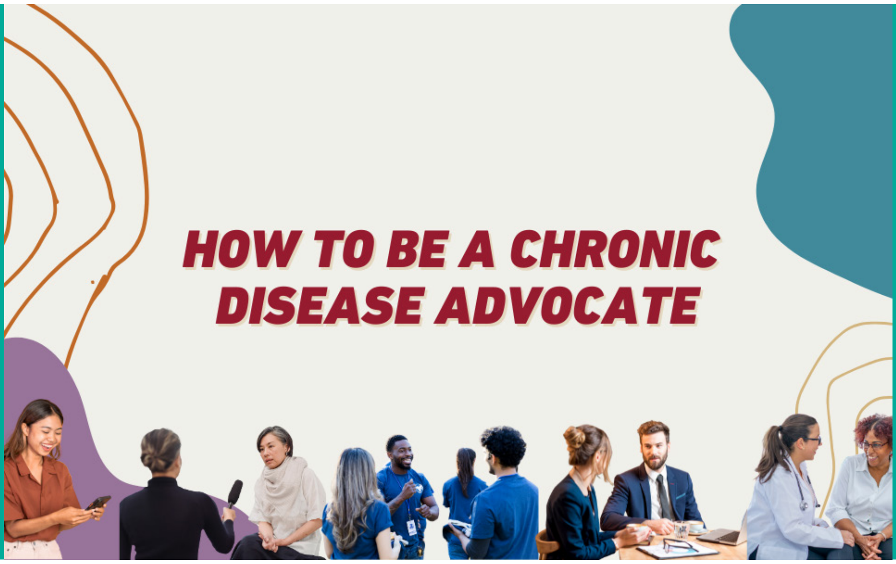
New Champions

During Chronic Disease Month, we recognize the state and federal legislators who in 2025 engaged with us, learned about the impact of policy decisions on chronic disease patients and pushed for healthcare reform in their state or district. This year, we recognized 17 lawmakers who put patients first and made progress toward expanding access to care and reducing healthcare costs

1. Janae Shamp, Arizona Senate Majority Leader
2. Terez Amata, Hawaii State Senator
3. Troy Hashimoto, Hawaii State Senator
4. Kimberly Moser, Kentucky State Representative
5. Carrie Rheingans, Michigan State Representative
6. Jonathan Karlen, Montana State Representative
7. Roberta Lange, Nevada State Senator
8. Michelle McGaw, Rhode Island State Senator
9. Linda Ujifusa, Rhode Island State Senator
10. Jay Dean, Texas State Representative
11. Ryan Guillen, Texas State Representative
12. Ann Johnson, Texas State Representative
13. Lois Kolkhorst, Texas State Senator
14. Charles Schwertner, Texas State Senator
15. Trey Wharton, Texas State Representative
16. Don Scott, Speaker of the Virginia House of Delegates
17. Mark Pocan, U.S. Representative, Wisconsin

ROLL CALL OF CHAMPIONS

Recognizing those who are going the extra mile to move chronic disease care forward for everyone.



New Activism

We also issued a call to action, **"Tell Your Lawmakers to Put Patients First"** and **"Prioritize Progress, Access and Affordability."** More than 250 letters were sent in response asking legislators to make continued investments in public health, medical research and regulatory oversight.

Chronic Disease Coalition

THERE ARE MANY WAYS OF BEING INFORMED AND ENGAGED AROUND PATIENT ADVOCACY.

We invite you to:

Sign up for our newsletter: Twice a month, get the most important news and action items from around the country: https://chronicdiseasecoalition.org/take-action/join-the-fight

Tell your story: Patient stories help us educate elected officials about the challenges of chronic disease. https://chronicdiseasecoalition.org/take-action/share-your-story

Send a letter: We make it easy to take a stand: https://chronicdiseasecoalition.org/take-action/contact-elected-leaders

Join our ambassador program: Our ambassadors represent a wide range of chronic health conditions, all working hard to make a difference. https://chronicdiseasecoalition.org/get-involved/ambassador-program

Learn About Advocacy!

Website
www.chronicdiseasecoalition.org

YouTube
www.youtube.com/@ChronicRights

@ChronicRights on Facebook, Instagram, X and LinkedIn