

2024  
**IMPACT  
REPORT**



## Elevating the patient experience

**The mission of the Chronic Disease Coalition is to advocate for patients and empower them to advocate for themselves. By understanding and sharing the experiences of people across the country, we have educated hundreds of lawmakers about the need for patient-centered healthcare policy.**

What's more, the amount of direct action taken by our community of patients and supporters continues to increase. Their voices have been instrumental as we advocated in more than 30 states on bills directly impacting those living with chronic conditions.

The Coalition's advocacy network is stronger than ever before. In 2024, regularly communicated with more than 100 other organizations on significant issues and legislation, and our social media engagement is helping us connect with new people in new ways. Our Ambassador program grew significantly this year with the addition of 15 new members—including representatives from five new states: Georgia, Florida, Hawai'i, New Hampshire, and Connecticut. These ambassadors generously volunteer their time to advocate for the CDC and other patients, and we are grateful for their involvement.

To add to their voices, the Coalition commissioned a national poll of 1,000 people with chronic disease. This survey, done as part of Chronic Disease Month, gave us an even more comprehensive view of the chronic disease experience. Together with a robust Roll Call of Champions, a voter scorecard and an "I Vote Because" graphic generator, our awareness efforts illuminated both the challenges and the importance of giving patients access to the levers of government.

Finally, Chronic University had a special focus this year: developing a series of mobile-friendly instructional videos to help patients share their stories with policymakers and other advocates. These videos leverage the insights of legislators, advocacy partners, and patients, making activism accessible to all.

We are proud of what we've enabled patients to achieve this year. People are the heart of an effective democracy, and we will continue to provide meaningful connections and understanding among patients, supporters, experts and elected officials.

Gratefully,



*Mary Kay*  
**Mary Kay Clunies-Ross**  
Executive Director



*Wendy*  
**Wendy Schrag**  
CDC Board Chair  
Fresenius Medical Care



# POLICY In Action

## Our Platform, Their Voice: Patients Were Louder than Ever in 2024

**This year has been transformative for the Chronic Disease Coalition, with more patients than ever stepping up to share their stories with elected officials. We've seen a significant surge in meaningful patient engagement, with our advocates successfully pushing for policy changes that really matter.**

Whether it's sending legislative emails or joining virtual meetings, our advocates have made their voices heard loud and clear — and it's been incredible to see the impact they've had on shaping decisions that affect chronic disease patients around the country.

*"Harmful practices like step therapy, or 'fail first protocols,' cause treatment delays like my son's for millions of Americans,"*

Chrisa Hickey wrote in a letter to the editor of her Wisconsin town's newspaper in support of a step therapy reform bill.

CDC Ambassador Claire Sachs referenced her negative experience with pharmacy benefit management changing access to her medications in testimony to state legislators in Annapolis, Maryland, saying,

*"The real issue [with prescription changes] was that they were implemented in the middle of calendar years without notification. In fact, I knew nothing of any of these changes until I tried to renew the various prescriptions."*

These advocates made their voices heard on issues from PBM reform to Medigap expansion. And it's moving the needle. Several states have moved forward

with legislation that addresses high healthcare costs, including reforms around copay caps and prior authorization. Lawmakers are starting to prioritize these changes, which is a huge win for patients who are still struggling to afford the treatments they need.

We've been working hard this year to not only make sure that chronic disease patients have a seat at the table when healthcare policies are being discussed — but to ensure they can navigate the complexities of voting with a chronic disease. In a tense presidential election year, we remained steadfast in our commitment to putting patients over politics and creating tools to navigate the chaos together.

One of the other major wins in 2024 has been our stronger partnerships with other advocacy groups. Our coalition does not exist in a vacuum; by definition, we're stronger together. This year we established monthly check-ins with more than one hundred state and federal advocacy partners, and it's been a great way to stay in sync, share strategies, and keep the momentum going. By working together more regularly, we've been able to make sure our collective message is stronger and more effective in pushing for policies that prioritize access, affordability, and representation.

Legislators are also continuing to reach out directly to us for input on policy in their states. It's been exciting to see these relationships grow and evolve in service to our larger goals around patient-centered policy.

Looking back on this year, there's so much to be proud of. We've had more patients involved in advocacy than ever, built stronger relationships with our partners, and seen real progress from elected officials. As we move forward, we're excited to keep pushing for policies that make healthcare more accessible for everyone living with chronic disease.





# ENGAGING With Our Network



## DIGITAL ENGAGEMENT

In 2024, we leveraged Chronic Disease Coalition’s social media platforms to cultivate an engaged and dynamic community, consisting of individuals with chronic diseases, their support networks, and key policymakers. Our focus was on amplifying authentic patient stories, ensuring that voices from within the community were heard directly. Additionally, we prioritized recruiting new ambassadors, continually refreshing our story bank to reflect diverse experiences. This strategy ensured our content remained impactful, fostering deeper connections and driving advocacy efforts for meaningful policy change.

We also utilized targeted campaigns to engage policymakers, advocating for improved legislation and access to care. Through partnerships and collaborations, we expanded our reach, fostering connections between patients, healthcare professionals, and decision-makers. The focus on storytelling not only raised awareness but also empowered individuals to become advocates for themselves and their communities. By amplifying these voices, we ensured that real experiences informed policy discussions, driving meaningful change and building a stronger, more unified coalition dedicated to improving the lives of people with chronic disease.

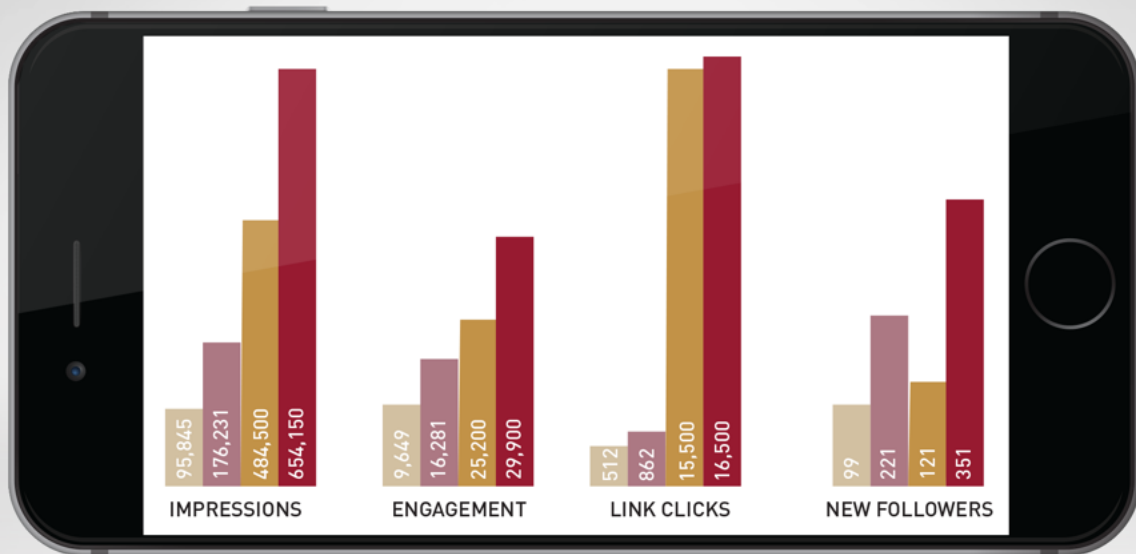
Lastly, we used social media to share the results of our nationwide poll, providing valuable insights into the needs and challenges faced by people with chronic diseases. These findings helped inform policymakers and guide advocacy efforts for more responsive and inclusive policies. By combining data-driven advocacy with personal stories, we ensured that both the voices and the needs of the chronic disease community were front and center in policy discussions, driving meaningful and lasting change.



@chronicrights

## 2023 VS 2024 SOCIAL ENGAGEMENT TRENDS

(Light colors are first half of year, bold colors are Q1-Q3. The bar heights are approximate)





## CHRONIC UNIVERSITY & PARTNERS AND ALLIES



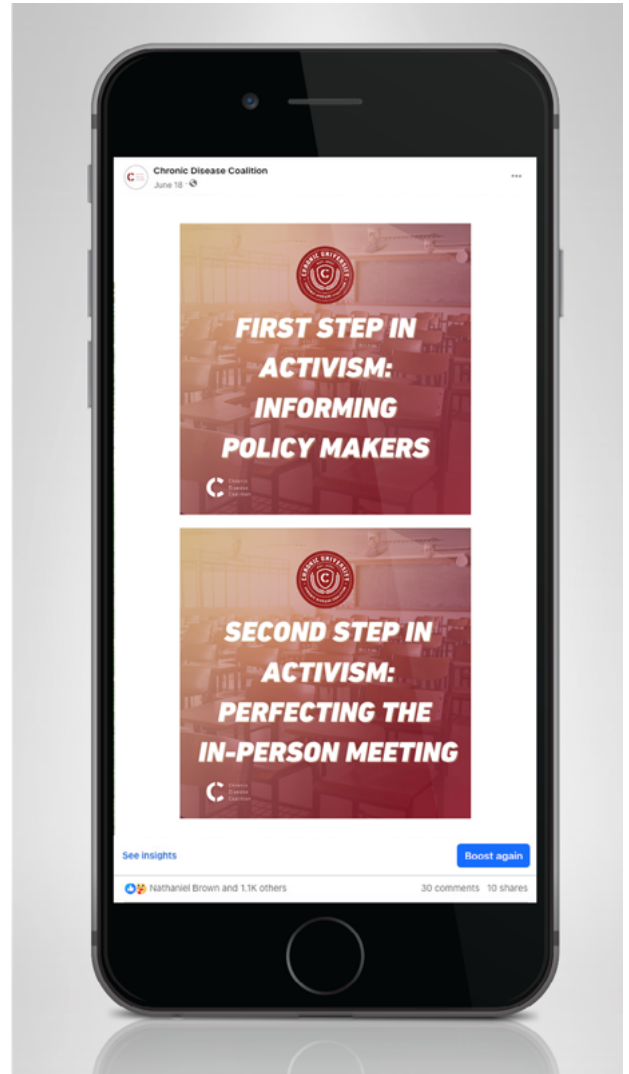
This year, we dedicated Chronic University to creating a phone-friendly series of videos that were a little more instructional. Our goal was to inspire and prepare individuals to advocate for themselves in various settings, particularly in the realm of health care policy.

**#1 First Step in Activism: Informing Policy Makers** In the first episode of the year, we explored the importance of the patient voice in policymaking and provided actionable steps for individuals to share their personal stories effectively.

**#2 Perfecting the In-Person Meeting** is a practical guide to making a real impact with legislators. We covered how to request, prepare and follow up with meetings with legislators, and included the encouraging and practical voices of lawmakers themselves.

**#3 Title forthcoming** illuminates a variety of other ways patients can connect with others in order to amplify their advocacy efforts. Both virtual and in-person connections are important for finding and giving the support needed.

**#4 Making Plans for 2025** sets the stage for the CDC's 2025 policy priorities and how we'll work to keep the public informed and engaged in patient-centered policymaking.



## WOMEN IN GOVERNMENT

In June 2024, the Chronic Disease Coalition was invited to speak to the Women in Government conference. WIG is an outstanding organization that brings together female legislators from across party and state lines. In formal and informal settings, these female legislators are focused on solving our community's most pressing problems.

With other experts, we presented a session titled "Data-Driven, Patient-Centered," to discuss the power of lawmakers engaging with patients and addressing their needs through data-driven policy improvements.



## AMBASSADOR PROGRAM

The ambassador program is made up of amazing patient advocates from all walks of life. We've got everyone — from college students just starting their advocacy journey to experienced, retired advocates who've been making a difference for years. This program helps us connect with patients all over the country who are passionate about standing up for chronic illness rights.

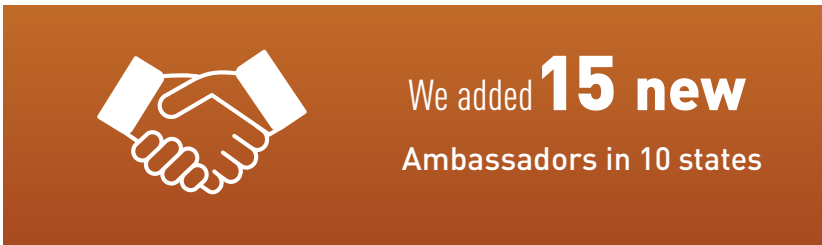
Each year, we welcome new members to the program while keeping some of our most dedicated ambassadors who have been with us since the beginning. Our ambassadors play a critical role in what we do. They join policy calls, help us figure out what issues to focus on, and keep us updated on important policies in their home states. Their work ensures that patients' voices and stories are always front and center.

In 2024, our ambassadors were more involved than ever, making it one of our most successful years yet!



**Four ambassadors advocated directly on legislation in their home states this year, successfully supporting the passage of three bills. These were active efforts that included writing op-eds and providing in-person testimony.**

### 2024 AMBASSADORS BY THE NUMBERS



**133 MILLION AMERICANS**

are living with chronic disease

Chronic Disease Coalition



### 2024 AMBASSADOR SPOTLIGHT

**Ashlyn Gierling**

Texas, 2024

**Erin Lambert**

Hawaii, 2024

**Jozette Allah-Mensah**

Maryland, 2023

**Tiffany Coles**

Pennsylvania, 2024





# 2024 AMBASSADORS IN ACTION







# CHRONIC DISEASE Month

## THE HIGH COST OF CHRONIC DISEASE

This Chronic Disease Month (CDM) we aimed to spark a nationwide conversation about “The High Cost of Chronic Disease,” highlighting both the personal and financial impacts that chronic illnesses have on patients’ lives. Through this theme, we aimed to amplify patient voices, reveal the depth of their experiences, and advocate for policies that improve care and access for all.

A core feature of CDM 2024 was the release of our study, *The High Cost of Chronic Disease*, which surveyed 1,000 individuals living with chronic illness. These findings, covered in the following pages, spotlighted the challenges patients navigate daily.

This year, we issued five calls to action to encourage patients to “Join the Fight” for their healthcare rights. Our “I Vote Because” initiative empowered patients to share their reasons for voting, while the “Rate Your Candidates” tool encouraged individuals to evaluate local candidates based on their commitment to chronic illness issues. Our “Support a Champion” campaign celebrated pro-patient legislators, and our “Share Your Story” effort underscored the power of personal experiences in shaping public perception and policy. Finally, we encouraged patients to “Contact Your Elected Leaders,” making impactful advocacy accessible to all.

With CDM 2024, we witnessed a growing movement of empowered patients, united to create a healthcare system that prioritizes their rights and well-being.

## CHRONIC DISEASE MONTH BY THE NUMBERS

### State Proclamations



13 States

### “I Vote Because”



21 Submissions

### Legislative Champions



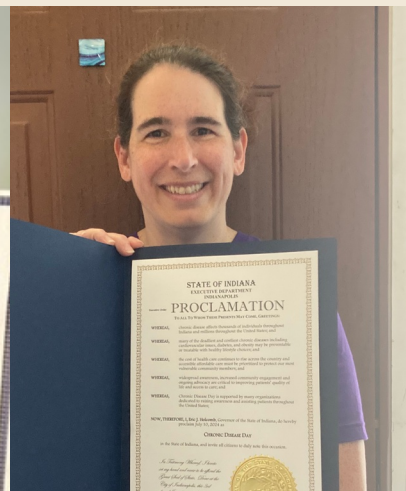
49

### Letters Sent



251

## PATIENT ADVOCATES WITH THEIR STATE PROCLAMATIONS



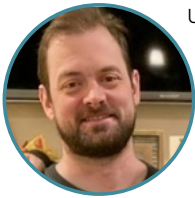


“It is honestly sad... aside from being young, being a woman and being African American, adds on to other layers... It is disheartening when you go to people who are supposed to help you, and their first instinct is, ‘Oh, it’s all in your head.’ A lot of times you get dismissed and that is just something that happens far, far too often. And like what the survey said, it contributes to those feelings of 6/10 people feeling stressed, and feeling overwhelmed and isolated.”



—Tiffany Coles, CDC Ambassador, Pennsylvania

“While I have some amazing friends and family members who provide wonderful support, unfortunately there are others such as medical professionals, employers and past acquaintances who do not understand the struggle we face despite continually explaining what it means to deal with a chronic disease day-in and day-out.”



—Dustin Miller, CDC Ambassador, Wisconsin

*I vote because...*

I believe that combining my voice and story with other patients and advocates, I can make a difference (however small) to make life easier for others with disabilities.

- Kaye Peterson, Patient, Kentucky  
Chronic Disease Coalition



Tiffany and Dustin share their different—but overlapping—experiences with chronic disease. Our cadre of ambassadors tell their stories and help us level the playing field for all patients.

## What is Lost, When Health Fails?

For Chronic Disease Month this year, we commissioned a national survey of more than 1,000 people with chronic diseases, people from all parts of the country, all ages, races, family status and walks of life.

What we wanted to know was this: **What is your health worth? What is lost, when your health fails you?**

In dozens of ways, patients told us that chronic diseases cost financially, professionally, emotionally. Not only that, but the cost of chronic disease is not “paid” just by the person with the disease—their families, friends, employers and communities also suffer.

### THE HIGH FINANCIAL COST

**29%**

Sometimes **have to make choices between medication, and other basic necessities** like rent, food, or school.

**24%**

**Take less of their medication than is prescribed** to save money.

### THE HIGH PROFESSIONAL COST

**50%**

About half of people said **their condition impacts their ability to work**

**22%**

22% of respondents, or almost **30 million Americans, have felt discriminated at work** because of their medical needs.

### THE HIGH EMOTIONAL COST

**60%**

Often **feel stressed** in dealing with their condition.

**50%**

Feel a **significant negative impact on mental health** including isolation or depression.

**40%**

Often **feel isolated** because of their condition.

**50%**

Half **worry about the impact of their condition** on their children and partners.

**1-in-5**

Nearly 1-in-5 respondents **have been told “it’s all in your head”** or have been otherwise dismissed by a healthcare professional.

**30%**

About 30% **feel they receive a different standard of care** because of age, gender or ethnicity.



As we build on the progress achieved in previous years, it is important that we recognize the efforts of legislators across the country who tackled health care reform this year. Their bipartisan support for legislation aimed at enhancing access to essential health care services for chronic disease patients marks a vital step forward for our communities.

This year, we highlighted more champions than ever before, many of whom were nominated for this recognition by CDC ambassadors in their states.

CHRONIC DISEASE COALITION PRESENTS

## 2024 ROLL CALL OF CHAMPIONS

1. California Asm. Akilah Weber (D)
2. Florida Rep. Lindsay Cross (D)
3. Montana Sen. Mike Bernskoetter (R)
4. Ohio Rep. Susan Manchester (R)
5. Oregon Rep. Emerson Levy (D)
6. Oregon Rep. Cyrus Javadi (R)
7. Oregon Sen. Sara Blouin (D)
8. Tennessee Rep. Ryan Williams (R)
9. Tennessee Rep. Shane Reeves (R)
10. Utah Sen. Michael McKell (R)
11. Alaska Sen. David Wilson (R)
12. California Sen. Scott Wiener (D)
13. Kentucky Sen. Jimmy Higdson (R)
14. Maine Rep. Margaret Craven (D)
15. Michigan Rep. Mike McFall (D)
16. Maryland Sen. Mary Washington (D)
17. Oregon Rep. Nancy Nathanson (D)
18. Oregon Rep. Christine Goodwin (R)
19. Washington Rep. Marcus Riccelli (D)
20. Colorado Senator Barbara Kirkmeyer (R)
21. Colorado Sen. Joann Ginal (D)
22. U.S. Rep. Abigail Spanberger (D)
23. Indiana Sen. Jean Breaux (D)
24. South Carolina Rep. Joseph Jefferson (D)
25. Massachusetts Rep. Bill Driscoll (D)
26. New Hampshire Rep. Jose Cambrils (R)
27. U.S. Sen. Kirsten Gillibrand (D)
28. Connecticut Rep. Jillian Gilchrest (D)
29. Washington Sen. Phil Fortunato (R)
30. Vermont Rep. Mary-Katherine Stone (D)
31. Arizona Rep. Daniel Hernandez (D)
32. California Asm. Rick Chavez Zbur (D)
33. Oklahoma Sen. Carri Hicks (D)
34. Oklahoma Sen. Jeff Boatman (R)
35. California Sen. Catherine Blakespear (D)
36. Georgia Sen. John Albers (R)
37. Nebraska Sen. Mike Jacobson (R)
38. Ohio Rep. Jamie Callender (R)
39. Ohio Rep. Bride Rose Sweeney (R)
40. Arizona Rep. Steve Montenegro (R)
41. Florida Sen. Gayle Harrell (R)
42. New Jersey Sen. Vin Gopal (D)
43. New York Asm. Aileen Gunther (D)
44. Wisconsin Sen. Jesse James (R)
45. Rhode Island Sen. Linda Ujifusa (D)
46. Rhode Island Sen. Elaine Morgan (R)
47. U.S. Sen. Lisa Murkowski (R)
48. Colorado Rep. Shannon Bird (D)
49. Colorado Rep. Lisa Frizell (R)



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 team:** 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](http://www.chronicdiseasecoalition.org)

**YouTube**  
provide channel links

**@ChronicRights** on Facebook, Instagram, X and LinkedIn