



Chronic  
Disease  
Coalition

# 2023 IMPACT REPORT



## We strove for visibility and volume... **and we got it!**

**Considering the scale and diversity of the challenges for patients within the healthcare system, the need for advocacy work can feel infinite. That's why it's so crucial to develop a clear strategy and stay focused on tasks that are truly meaningful.**

The Chronic Disease Coalition is a nationwide organization, supporting patients and good policymaking in all 50 states. In our map on page three, you'll see a variety of ways we make our mark.

While working nationally, we're connecting personally. Nothing beats the effectiveness of engaging individuals. Even while we expanded our use of digital media to reach thousands more people, the ultimate goal was still to build relationships and connect patients with advocates, lawmakers and the CDC. As a result, our ambassador program grew, our partnerships with other organizations got deeper, and more legislators participated in our educational work. Perhaps most importantly, more legislators heard directly from their constituents.

Talking to more patients also gave us the opportunity to listen and learn more. We heard dozens of new patient stories that inspired us to expand our video offerings so we could share them in the same raw, human way we hear them. The CDC "Spoonful" series, initially just a bonus feature for Chronic Disease Month, has inspired many and will continue in the new year.

We're going to keep working to ensure that patients have visibility and volume when it comes to healthcare, and we are grateful to the many patients who give their time and energy to this work.

Thank you and onward,



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



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



# POLICY In Action

**The CDC is first and foremost a policy organization. Our advocates, members, and partners gather each year to set a comprehensive policy agenda that tackles the most pressing issues facing chronic patients – primarily, issues of accessibility and affordability.**

It's one thing to set an agenda. It's another to act on it. Throughout the past year, it has been amazing to see our advocates and our team in action every day.

Our ambassadors were instrumental in inspiring the introduction of legislation, advocating for their representatives to sponsor priority bills, and testifying in their state capitols.

Momentum is on the patients' side. The CDC was thrilled to see new proposals at the state and federal level to reform step therapy protocol, shine a light on pharmacy benefit managers (PBMs), protect Medicaid patients, and so much more. Decisionmakers at all levels of government are starting to listen to the patients.

## 2023 POLICY PRIORITIES

All our 2023 policy priorities fell within one of three issue areas: access, affordability, or representation. This year saw hundreds of bills focused on affordability, such as banning copay accumulators and protecting third-party assistance programs. We also saw excellent progress in the fight to expand access to care, through new requirements around Medigap, telehealth, and living donor protections.



**Christina Thielst**  
CDC Ambassador /  
Member Nevada RDAC

Chronic disease patients are also increasingly getting a seat at the table, through new advisory councils or task forces focused on improving care.

As new policy issues emerge, the CDC is positioned to take those on. This year, at the direction of our board and ambassadors, we expanded our policy priorities to include issues impacting the health care workforce and to shine a light on pharmacy benefit management.



## 2023

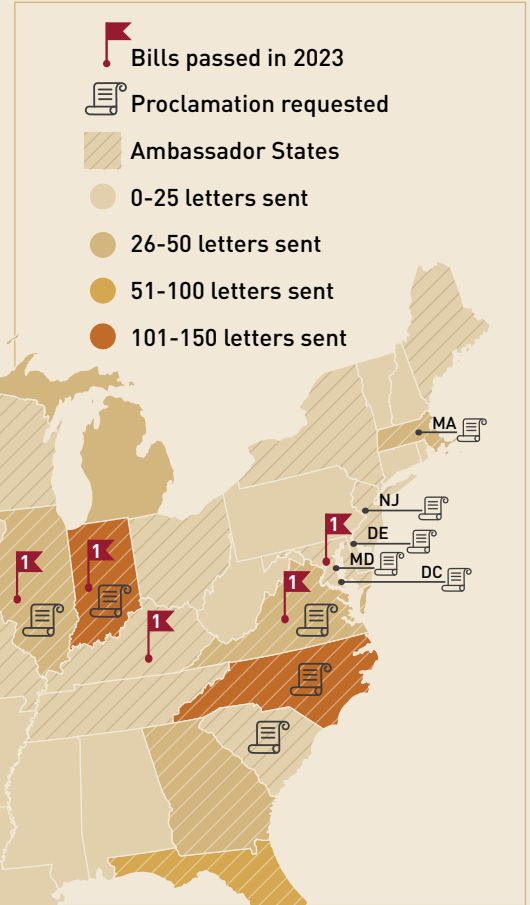
### LEGISLATIVE FOCUS AREAS

- » STEP THERAPY REFORM
- » PROTECTIONS FROM NONMEDICAL SWITCHING
- » PRIOR AUTHORIZATION REFORM
- » REMOVING BARRIERS FOR THE HEALTH CARE WORKFORCE
- » EXPANDING MEDIGAP COVERAGE
- » EXPANDING TELEHEALTH COVERAGE
- » EXPANDING MENTAL HEALTH TREATMENT OPTIONS
- » PROTECTING LIVING ORGAN DONORS
- » BANNING COPAY ACCUMULATOR PROGRAMS
- » REQUIRING TRANSPARENCY FOR PBMS
- » ESTABLISHING RARE DISEASE ADVISORY COUNCILS
- » ESTABLISHING CHRONIC KIDNEY DISEASE TASK FORCES
- » IMPROVING HEALTH EQUITY



## ENGAGEMENT MAP

This year, our coalition advocated for legislation in 35 states and in Congress. For the second year in a row, our network sent more than 1,000 letters to lawmakers around the country on our priority issues, with 12 states successfully passing key bills.



## CDC OUT AND ABOUT

While the threat of COVID-19 remains with us, especially for chronic patients, the CDC was grateful to connect with patients and advocates in-person this year.

Our staff attended the annual **BIO Patient & Health Advocacy Summit** in 2022 and 2023, traveling to Washington D.C. to connect with fellow patient advocacy groups and industry leaders to discuss policy strategies. When legislative sessions kicked off, we testified in person in the **Pacific Northwest**, showing up for the chronic communities in Oregon and Washington. Our advocacy director gave a presentation on coalition-building to industry leaders at the annual **Q1 Life Science Strategic Patient Advocacy Conference** in Philadelphia and spent time with local ambassadors and allies in D.C. shortly after. The best relationships are built on personal connection, and we're looking forward to spending more time face-to-face with advocates and legislators in 2024.



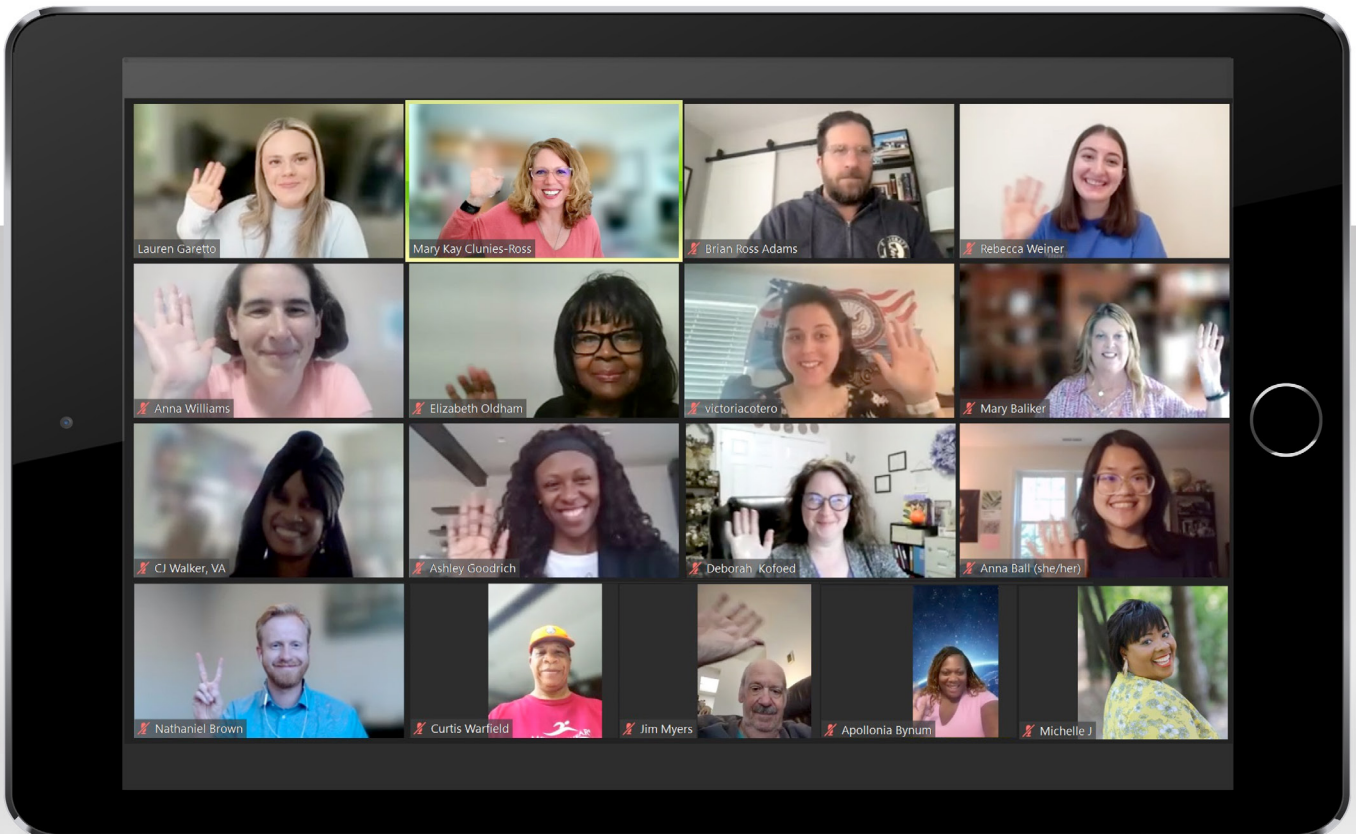
## OUR LEGISLATIVE ADVOCATES

**Our ambassadors are inspiring for many reasons, but their decision to become advocates is an especially brave one – even after navigating the intense challenges of the healthcare system.**

Alongside CDC staff, our ambassadors stepped up time and again this year to testify in person and online, submit letters, and advocate directly with their state and federal representatives.

CDC ambassadors are willing to spend the time and energy to stand up not just for their issues, but for others. A lupus patient will support living donor protections in North Carolina, for example, or a migraine patient will raise their voice on PBM reform in Indiana. Policymakers are also clearly valuing our ambassadors' lived experience, seeking input on draft legislation, and joining them for tours of clinics and hospitals.

The CDC exists to empower patients, and while that work is never done, we have much to be proud of in 2023.





# ENGAGING With Our Network

**We focused on increasing the number and quality of our connections with patients, providers, legislators and more.** We took existing tools like Chronic University, the ambassador program, and social media, and put them together in new ways to expand our networks and advance our policy goals. We also introduced new approaches like the Spoonful series and paid posts to increase the reach and efficacy of our work.

## CHRONIC UNIVERSITY



Our Chronic University lineup featured unique insights from providers, legislators, patients and more. Each session was recorded and saved for advocates to watch at their leisure. This year, we introduced bite-size video highlights of our speaker's most impactful quotes, ensuring that even people who have five minutes to spare can learn something new about patient advocacy.

### 2023 SESSIONS:

- » **February:** Covid Long-Hauler: The Newest Wave Of Chronic Disease Patients
- » **March:** Amplifying the Kidney Patient Experience
- » **April:** Engaging with Legislators 101
- » **May:** Demystifying Mental Health
- » **June:** The Case for Whole Health Care
- » **August:** Representation for Rare Diseases
- » **October:** Navigating Insurance Open Enrollment
- » **November:** Caring For Our Caregivers
- » **December:** Our 2024 Policy Priorities

**“ THE POWER OF SHARING OUR STORIES CANNOT BE OVERSTATED. ”**

—Nadine Gartner, Founding Executive Director, Boost Oregon



## THE SPOONFUL

As we engage with advocates from across the country, we saw a need to share their stories in short, snackable videos – which we call “Spoonfuls.” It started as a new offering during our annual Chronic Disease Month, but with lots of positive feedback, it evolved into a permanent offering.



- » **How we Care for Our Caregivers** – Cristol Barrett O’Loughlin, Angel Aid
- » **Breaking Down Copay Accumulators** – Madonna McGuire Smith, Pacific Northwest Bleeding Disorders
- » **The Importance of Expanding Medigap Coverage** – Andrew Conkling, Dialysis Patient Citizens
- » **Caretakers and Advocates: The Taylors** – Jim & Geri Taylor, Memory Advocates Program
- » **Navigating Prior Authorization with Providers and Insurers** – Dr. Amish Dave, MD, Virginia Mason Medical Center



Scan the QR code to see all our Spoonfuls and Chronic University sessions



# DIGITAL ENGAGEMENT

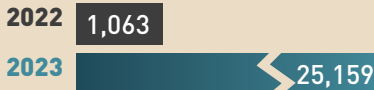
This year we adeptly leveraged the power of social media advertising to forge a more direct and impactful connection with our target audience. Recognizing the vast potential of platforms like Facebook, Instagram, and Twitter to reach a diverse group of individuals, the CDC initiated ad campaigns tailored to resonate with those affected by chronic illnesses, as well as their families, caregivers, and legislators.

These campaigns were strategically designed with compelling visuals, powerful narratives, and calls-to-action, prompting users to learn more, share their stories, and get involved in the coalition's initiatives. The precision targeting capabilities of social media platforms enabled the CDC to find and engage with users who were previously unidentified, but who had shown interest in or had affiliations with related topics. By employing these techniques, the CDC not only amplified its outreach, but fostered a sense of community and support among those managing chronic diseases.

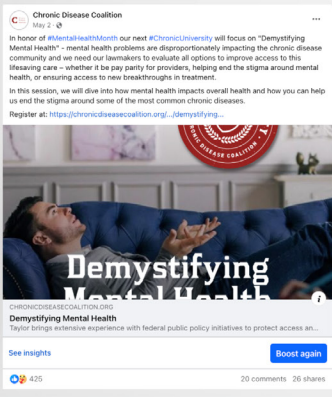


### The value of paid media amplification:

ENGAGEMENTS - 2,266% INCREASE



IMPRESSIONS - 3,490% INCREASE



425 IMPRESSIONS  
26 SHARES



706 IMPRESSIONS  
23 SHARES



1,100 IMPRESSIONS  
10 SHARES



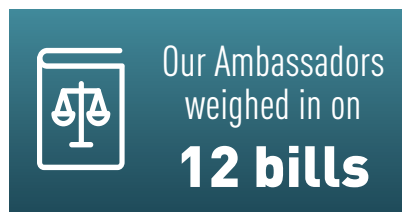
1,000 IMPRESSIONS  
104 SHARES

## AMBASSADOR PROGRAM

The ambassador program is a diverse group of patient advocate superstars. From new advocates in college to retired veteran advocates and everything in between, this program allows us access to patients across the country who want to make a difference in the fight for chronic rights. Each year we not only recruit new members to the group, but have also maintained some of our strongest advocates since the creation of the coalition.

This group is essential to the work we do. Ambassadors participate in policy calls, advise us on policy priorities, and keep us up to date on important policies in their home states. All of this is to ensure that the patient voice is at the forefront of everything we do. 2023 was one of our most successful ambassador years, with the group more engaged than ever.

### 2023 AMBASSADORS BY THE NUMBERS



### 2023 AMBASSADOR SPOTLIGHT

**12 ambassadors advocated directly on legislation in their states this year, successfully supporting the passage of four important bills.**

CJ Walker supported	<b>Medigap expansion in Virginia</b> (HB 1640)
Brooke Epps supported	<b>Mental health access in Colorado</b> (HB 23-1130)
Michelle Johnson supported	<b>Mental health access in Illinois</b> (SB 1568)
Anna Williams supported	<b>PBM reform in Indiana</b> (SB 8)

**Jim Myers**  
Indiana  
joined in 2018

**CJ Walker**  
Virginia  
joined in 2021

**Deborah Kofoed**  
North Carolina  
joined in 2022

**Casey Doherty**  
Washington D.C.  
joined in 2023





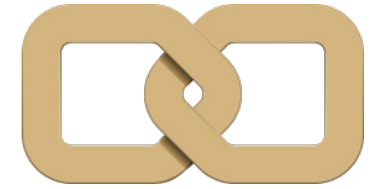


# CHRONIC DISEASE Month

## DON'T FIGHT ALONE – CHRONIC DISEASE MONTH 2023

Our goal during Chronic Disease Month (CDM) is to raise awareness about the challenges that chronic disease patients face and transform that awareness into actionable steps that advance policy objectives benefiting patients.

This year's theme was "Don't Fight Alone," showcasing the power of numbers in the fight for patient rights. To support that theme, we increased the number of opportunities people had to engage with us – and it paid off! 2023 was one of our most engaging Chronic Disease Months yet.



# DON'T FIGHT ALONE

### CHRONIC DISEASE MONTH BY THE NUMBERS

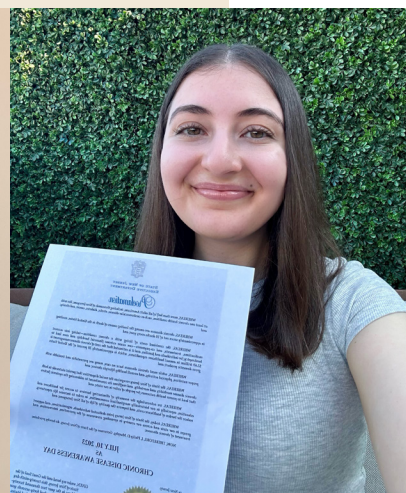


One of our new 2023 CDM programming was the "Chronic Disease Day Symposium." In this two-hour virtual gathering, discussions with health journalists, patient ambassadors, partner organizations, legislators and more all came together to discuss topics paramount to chronic patients.



Scan the QR code to watch our symposium highlights

### PATIENT ADVOCATES WITH THEIR STATE PROCLAMATIONS



# LEGISLATIVE LEADERS FOR CHRONIC DISEASE MONTH

Political leaders across the country are working to make positive change in the lives of chronic disease patients. We are grateful for the legislators across the country who fight every day for patient rights. Thank you!

## ROLL CALL OF CHAMPIONS

1. Minnesota Sen. Liz Boldon
2. Oregon Sen. Sara Gelser Blouin
3. California Sen. Steven Bradford
4. Utah Sen. Curt Bramble
5. Indiana Sen. Jean Breaux
6. New York Sen. Neil Breslin
7. Indiana Sen. Ed Charbonneau
8. U.S. Rep. Lori Chavez-DeRemer
9. Massachusetts Rep. Edward Coppinger
10. Massachusetts Sen. Brendan Crighton
11. Massachusetts Rep. Josh Cutler
12. U.S. Rep. Diana DeGette
13. Indiana Sen. Dan Dernulc
14. Florida Rep. Karen Gonzalez Pittman
15. U.S. Sen. Maggie Hassan
16. South Carolina Rep. Patricia Henegan
17. New Mexico Rep. Dayan Hochman-Vigil
18. Nebraska Sen. Mike Jacobson
19. Nevada Asm. Sandra Jauregui
20. South Carolina Rep. Joseph Jefferson
21. Colorado Rep. Dafna Michaelson Jenet
22. Georgia Rep. Todd Jones
23. U.S. Sen. Tim Kaine
24. North Dakota Rep. Karen Karls
25. Hawaii Sen. Jarrett Keohokalole
26. Virginia Rep. Tom Kilgore
27. Maryland Sen. Clarence Lam
28. Rhode Island Sen. Valarie Lawson
29. U.S. Sen Roger Marshall
30. U.S. Rep. Lucy McBath
31. U.S. Rep. Mariannette Miller-Meeks
32. Iowa Rep. Gary Mohr
33. Illinois Sen. Julie Morrison
34. Kentucky Rep. Kimberly Moser
35. U.S. Sen. Lisa Murkowski
36. Oregon Rep. Nancy Nathanson
37. Oregon Rep. Rob Nosse
38. Wyoming Rep. Kevin O’Hearn
39. Texas Rep. Tom Oliverson
40. Virginia Rep. Israel O’Quinn
41. Nevada Sen. Julie Pazina
42. Texas Rep. Four Price
43. Washington Sen. Ann Rivers
44. Texas Rep. Toni Rose
45. North Carolina Rep. Phil Shepard
46. Washington Rep. Tara Simmons
47. New Mexico Sen. Elizabeth Stefanics
48. Oklahoma Rep. Kevin Wallace
49. California Asm. Akilah Weber
50. Utah Rep. Mark Wheatley
51. Missouri Sen. Dale Wright
52. Florida Sen. Tom Wright



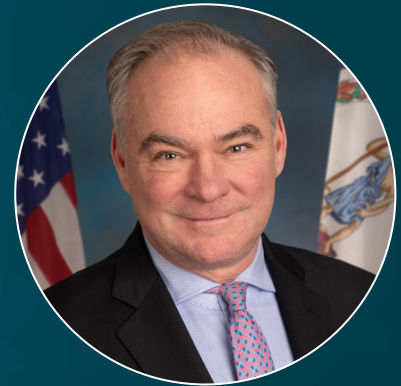


**“ IT’S BECAUSE OF ALL OF YOU – PATIENTS, PROVIDERS, CAREGIVERS AND ADVOCATES – WHO ARE BRAVE ENOUGH TO SHARE YOUR STORIES, THAT WE WILL CONTINUE TO MAKE CHANGES FOR THOSE LIVING WITH CHRONIC DISEASES. ”**

—U.S. Senator Lisa Murkowski, Alaska

**“ THANK YOU TO THE CHRONIC DISEASE COALITION FOR CONVENING PATIENTS, ADVOCATES AND CAREGIVERS SO THAT ALL CAN SHARE THEIR STORIES AND EXPERIENCES. ADVOCATES LIKE YOU INSPIRE POLICY MAKERS TO PROPEL CHANGE. ”**

—U.S. Senator Tim Kaine, Virginia



**“ I HAVE USED THIS AS THE CALLING OF OUR LIVES. BOTH MYSELF AND MY SON, WILL, WILL NOW FOR THE REST OF OUR YEARS ON EARTH DO EVERYTHING WE CAN TO HELP IMPROVE THE ACCESS TO CARE THAT PEOPLE NEED NO MATTER WHAT DISEASE THEY ARE SUFFERING FOR SO WE CAN DO THINGS BETTER. ”**

—State Senator John Albers, Georgia







# JOIN THE FIGHT FOR PATIENT RIGHTS!



[chronicdiseasecoalition.org](https://chronicdiseasecoalition.org)

JoinUs@chronicdiseasecoalition.org  
Chronic Disease Coalition  
6605 S. Macadam Ave #200  
Portland, OR 97239

@ChronicRights  
[chronicdiseasecoalition.org](https://chronicdiseasecoalition.org)  
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