



# *CHRONIC DISEASE COALITION*

***2021 IMPACT REPORT***



Chronic  
Disease  
Coalition

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

# PUTTING PATIENTS FIRST

As we slowly come out from the shadow of the pandemic, it has never been so important to increase the visibility of the patient experience.

For chronic disease patients, including those struggling with kidney disease, diabetes, intestinal disorders, MS, arthritis and more, the health care system is not always designed for them to thrive. With constantly changing laws and rules that impact care, access and cost, patients need advocates to tell their story, and a platform of their own.

The Chronic Disease Coalition is designed to be both.

Despite the huge disruption that COVID-19 brought to health care, legislative processes and state and federal priorities, the CDC activated thousands of patients to weigh in on 37 bills in 22 states. We focused our outreach and engagement efforts on copay accumulator programs and step therapy. By partnering with other organizations across the country, we contributed to wins from coast to coast.

Although certainly disruptive to this year's legislative process, the pandemic-driven move to remote hearings helps open the door for more direct participation by patients. That's why we are building our ambassador program and focusing more of our Chronic University education work on policy issues.

Patients have been working alone long enough—we are excited to take up the fight and continue our growth as an organization.

*Wendy Schrag*

Wendy Schrag

CDC Board Chair  
Fresenius Medical Care





# POLICY IN ACTION

2021 was an unprecedented year for the Coalition and chronic disease awareness. We elevated the patient voice in legislatures across the country to protect living organ donors, develop kidney disease task forces, stop copay accumulator programs, reform step therapy practices and more.



**45**

Ambassadors



**15K+**

Patient  
Network



**250+**

Letters sent from  
advocates in 2021



**100+**

Legislative recipients  
in 2021

**Top issues include:**

- Chronic Disease Month
- Safe Step Act (S.464)
- Most Favored Nation Drug Pricing Model



## **Copay Accumulator Reform in 2021:**

- ✓ **KENTUCKY SB 45**
- ✓ **CONNECTICUT SB 1003**
- ✓ **NORTH CAROLINA SB 257**

## **Copay Accumulators: Charging Patients Twice**

A Center for Medicare and Medicaid Services ruling in 2020 allowed the use of copay accumulator programs nationwide. Since then, insurers have been employing accumulator programs in an effort to not count third-party copayment assistance toward a patient's deductible or out-of-pocket maximum.

This year, the CDC joined dozens of patient advocacy organizations across the country in educating, advocating and activating patients on copay accumulators. Working with the All Copays Count Coalition, we've helped bring copay accumulator bans and/or reform to 12 states.

Key copay accumulator successes from 2021 that will influence legislation in other states include Louisiana, Kentucky and Connecticut, while work is ongoing in Pennsylvania, Oregon, New York, South Carolina and others.

## Reaching New Audiences

Although widely used, the CDC found that most chronic disease patients were not aware of copay accumulator programs. To broaden our reach and education, we collaborated with Instagram influencers to educate a more diverse audience.

As we prepare for 2022, copay accumulators continue to threaten patients everywhere. Cohesive messaging and education around these programs are crucial to amplify patient voices.



## Step Therapy

Also known as "fail-first" treatment, step therapy is when an insurance company forces a patient to try and fail on a different treatment before covering the doctor's recommendation.

"I was forced to use Step Therapy & was forced to use treatments that my doctor did not prescribe which wasted not only extra money & time for me but also resulted in harmful side effects to finally get approval for the first medication my doctor had originally prescribed."

-California Chronic Advocate.

Legislators better understand issues when they hear patient stories like this one. That's why we're dedicated to sharing patient testimonials, supporting key state legislative efforts and working with local coalitions to identify in-person and online advocacy opportunities.



### Step Therapy Reform in 2021:

CALIFORNIA AB 347 ✓

OREGON HB 2517 ✓

ARIZONA SB 1270 ✓





# Living Donor Protections

Living donor protections are crucial in the fight against kidney disease and other deadly chronic conditions. With more than 100,000 Americans on the transplant waiting list, ensuring organ donors are protected from workplace, insurance and health care discrimination is this first step in providing this life-saving gift.

CDC Ambassador Mary Baliker was diagnosed with a life-threatening kidney condition at just nine years old when doctors told her she had six months to live. After years of treatment and therapy, her brother Doug donated his kidney to save her life, but lost his job in the process.

## Living Donor Protections in 2021:

✓ TEXAS HB 317

✓ PENNSYLVANIA HB 203

✓ WASHINGTON STATE SB

5003



## Navigating a COVID-19 Legislature

Copay accumulators, living donor protections and step therapy reform are just a few of the issues we focused on this past year. COVID-19 brought other key issues to the forefront and promises to continue to do so on issues such as telehealth reimbursement and drug innovation. Some of this year's other policy priorities include:

- Chronic Kidney Disease Task Force
- Rare Disease Advisory Councils
- Telehealth Access and Coverage
- Most Favored Nation Drug Pricing Model
- Drug Pricing and Innovation
- Medigap
- Newborn Screening

"I have been diagnosed with mucous membrane pemphigus and step treatment can contribute to worsening symptoms and possible blindness. [My drug] is the final therapy in the long line of steroid step therapy that can put me into remission. Please help so I and other do not lose the sight we were born with. I would miss the seeing the smile of my daughter and being able to read sheet music to continue with my profession."

- South Carolina Chronic Advocate.





# AMPLIFYING THE VOICES OF PATIENTS

The ambassador program is an integral part of our coalition. Our ambassadors are some of the most engaged advocates with whom we can engage when we need to demonstrate the real life impacts of legislation, policy and other decisions.

In 2021 we overhauled the CDC ambassador program to better identify and activate highly engaged patient advocates. By instituting a more rigorous application and screening process, the ambassador program has new energy and focus for policy issues. The new program creates highly reputable, skilled and engaged chronic disease advocates and positions them at the center of our work.

Through monthly calls with the coalition, ambassadors have more exposure to our policy issues and have more opportunity to give feedback on those and other topics of concern to the community.





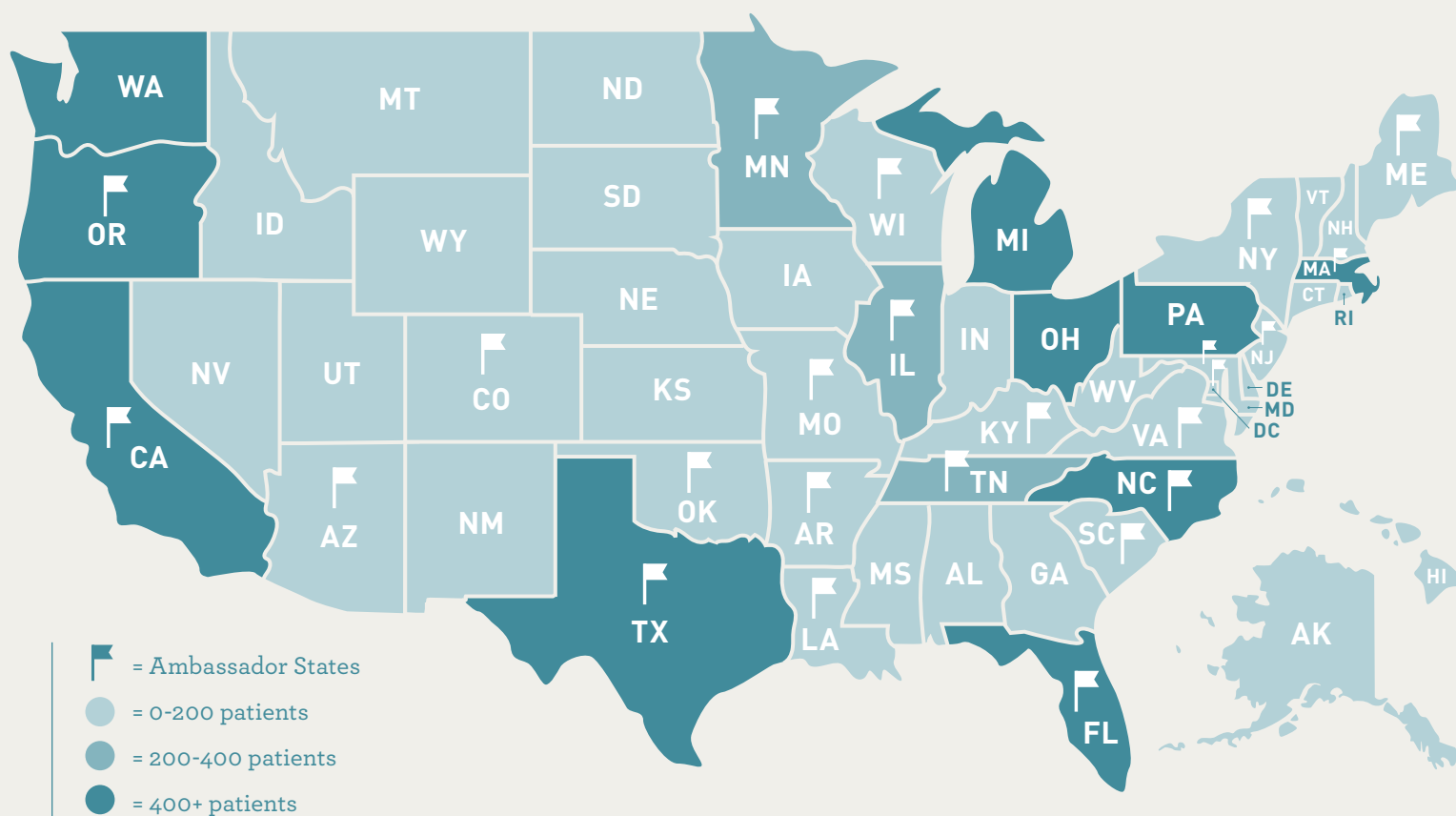
# Who Are Our Ambassadors?

Our ambassadors span the entire country and various chronic diseases. We work with 45 ambassadors in 19 states covering more than 50 chronic diseases including kidney disease, psoriasis, diabetes, endometriosis and epilepsy.

We're looking to grow our network in states with high legislative priorities in 2022:

## Our Patient Network

*We exist to unite patients across state lines and disease experiences*



## Ambassadors' Chronic Diseases

### Chemical sensitivities

Crohn's  
Diabetes  
Dysautonomia  
Endometriosis  
Fibromyalgia  
Gastro  
Graves disease

### Guillan Barre Syndrome

Hereditary Lymphedema  
Hypersensitive nerves  
Hyposensitive nerves  
Hypothyroidism  
Inflammatory Bowel Disease  
Indeterminate colitis  
Interstitial cystitis

### Kidney Disease

Mast Cell Activation  
Myalgic encephalomyelitis/  
chronic fatigue syndrome  
Ehlers-Danlos syndrome  
Multiple Sclerosis  
Neuritis  
Neurogenic bladder

### Neuropathy

Polycystic ovary syndrome  
Postural orthostatic  
tachycardia syndrome  
Psoriatic arthritis  
PTSD  
Pudenda neuralgia  
Sickle Cell

# Chronic University

This year, we launched Chronic University, a free educational webinar series focused on chronic disease advocacy. Chronic University not only serves as an important patient recruitment and education tool, it also provides valuable networking opportunities to connect patients and thought leaders.

Through this programming, our goal is to increase the voices of chronic disease patients as influencers and advocates. It also allows us to educate and activate new patients and ambassadors. More than 350 people attended 2021's premiere events; the 2022 series will be even more robust as we continue to explore chronic policy and lifestyle issues.



## July is Chronic Disease Month

f t i @ChronicRights

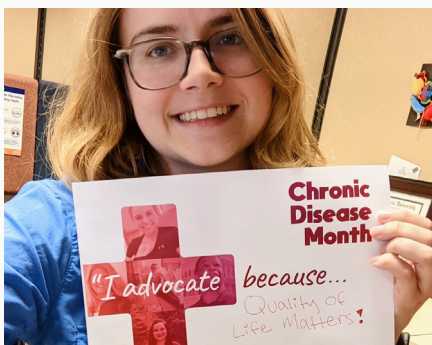
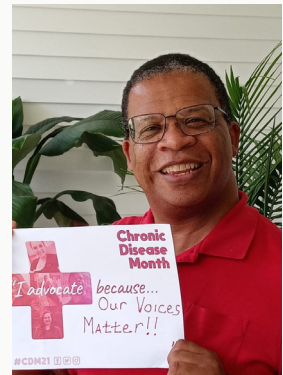
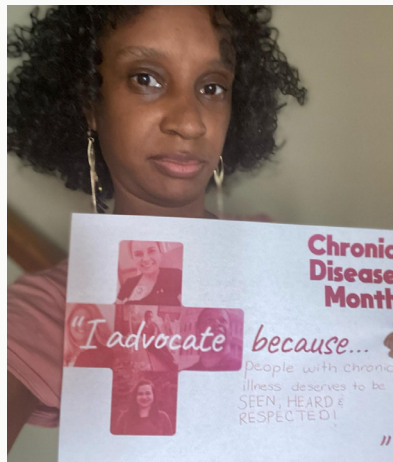
Join the conversation!

Here at the Chronic Disease Coalition, every month is Chronic Disease Month, but July is our opportunity to further amplify patient voices and continue to advocate for patient rights.

Each week in July, we highlighted a different area of chronic disease advocacy to help bring people along in the journey. These themes – awareness, education, access and action – provided a deeper look into not only how to be an advocate, but why. Chronic Disease Month provides a valuable opportunity to build awareness of the Coalition and engage a new network of advocates.

## I Advocate Because...

Building strong advocates is the core of what we do at the CDC. As part of Chronic Disease Month 2021, we asked our network to share why they advocate through our "I advocate because..." campaign. Check out all the social action from this year's campaign using #CDM21.





# 2021 Rollcall of Champions

Legislators across the country are partnering with us and other advocates to support patients. This year, we recognized all of them through the Rollcall of Champions.

## Copay Accumulators

### Connecticut

Sen. Saud Anwar

Rep. Michael A. Winkler

Rep. Jillian Gilchrest

Sen. Martin M. Looney

### Florida

Sen. Jason Brodeur

Sen. Shevrin Jones

Sen. Gary Farmer

### New Mexico

Rep. Alonzo Baldonado

Rep. Kelly Fajardo

Sen. Daniel Ivey-Soto

### Louisiana

Sen. Jimmy Harris

### New York

Sen. Gustavo Rivera

Asm. Richard Gottfried

### North Carolina

Sen. Jim Perry

Sen. Danny Earl Britt

Sen. Todd Johnson

### Kentucky

Sen. Ralph Alvarado

Rep. Kimberly Moser

### Oregon

Sen. Sara Gelser

Sen. Tim Knopp

### Pennsylvania

Rep. Barbara Gleim

Sen. Judith Ward

### Maryland

Del. Pat Young

Sen. Joanne Benson



**Sen. Gustavo Rivera**  
New York's 33rd District



**Sen. Sara Gelser**  
Oregon's 8th District

## Living Donor Protections

### Ohio

Rep. Erica Crawley

Rep. Jon Cross

### Pennsylvania

Rep. Tarah Toohil

### Texas

Rep. Andrew Murr

Rep. Brad Buckley

Rep. Ryan Guillen

Sen. Borris Miles

## Chronic Kidney Disease Task Force

### Colorado

Rep. Mary Bradfield

Rep. Brianna Titone

Sen. Janet Buckner

Sen. Dennis Hisey

### Oklahoma

Rep. Chris Sneed

Rep. Randy Randleman

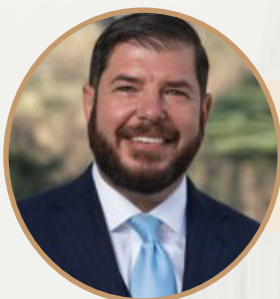
### Nevada

Sen. Pat Spearman

### Oregon

Rep. Raquel Moore-Green

Rep. Andrea Salinas



**Asm. Joaquin Arambula**  
California's 31st District

## Step Therapy

### Arizona

Sen. Nancy Barto

### California

Asm. Joaquin Arambula

### Florida

Sen. Gayle Harrell

### Connecticut

Sen. Martin Looney

### Oregon

Rep. Susan McLain

Rep. Rachel Prusak

Sen. Bill Hansell

### New Jersey

Rep. Ronald Dancer

Rep. Herbert Conaway

Rep. Anthony Verrelli

## Rare Disease Advisory Councils

### New Jersey

Sen. Vin Gopal

Sen. Thomas Kean

Rep. Ronald Dancer

Rep. Daniel Benson

### Florida

Sen. Dennis Baxley

### California

Sen. Susan Eggman

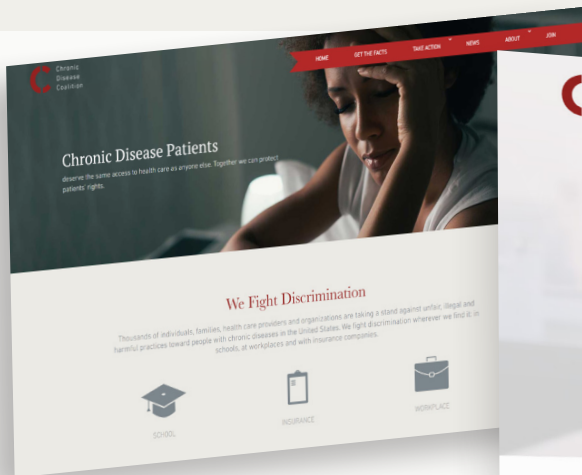


**Rep. Barb Gleim**

Pennsylvania's 199th District

# BUILDING FOR THE FUTURE

In 2021 the Coalition positioned itself for years of growth with new digital and communication assets. We created a new website, with a patient-forward portal for engagement, action and information.



Before

After

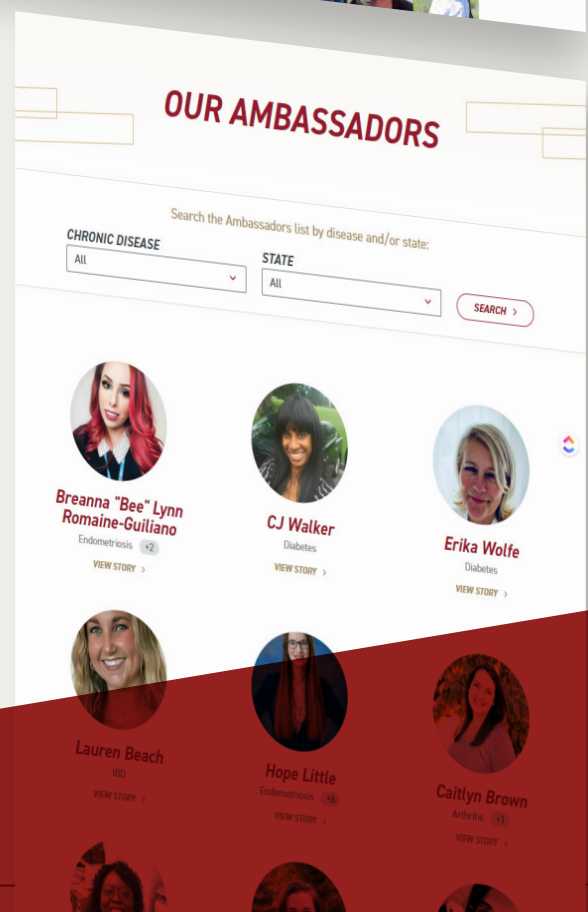
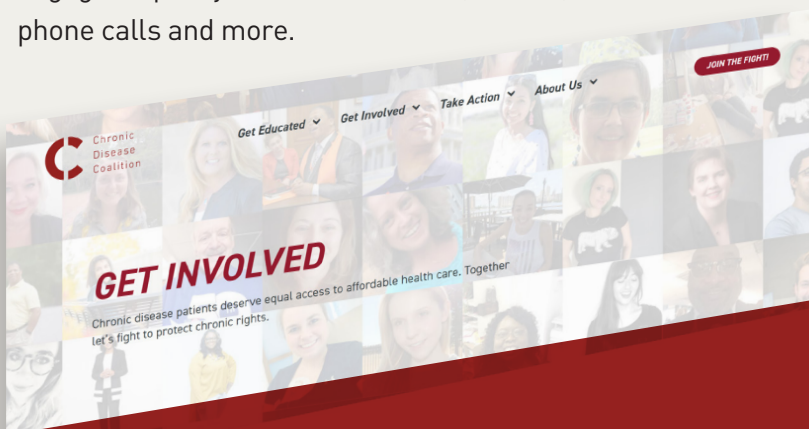


## Ambassador Profiles

Our new ambassador profile pages elevate powerful stories and build patient credibility.

By elevating the voice of patients on our new website, we can more effectively navigate and activate on complex health care policies through powerful stories.

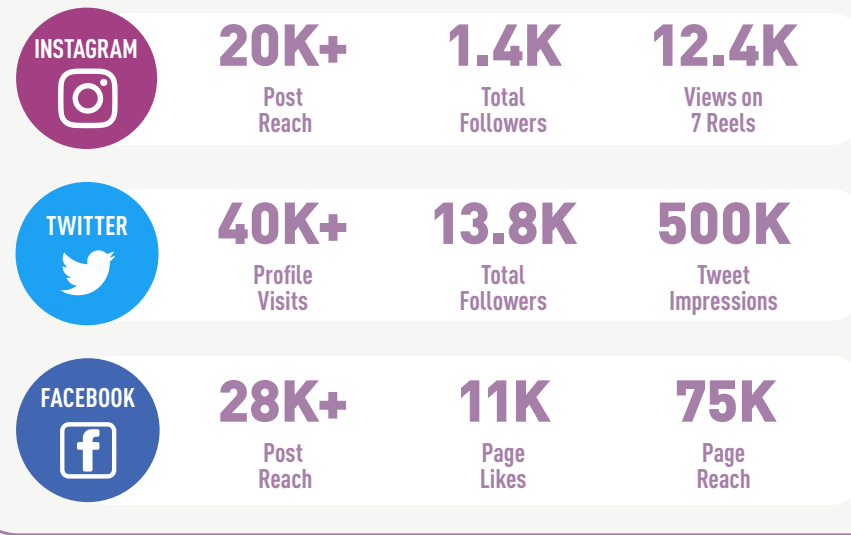
The new platform includes robust tools to enable patients to engage on policy issues with letters, tweets, phone calls and more.





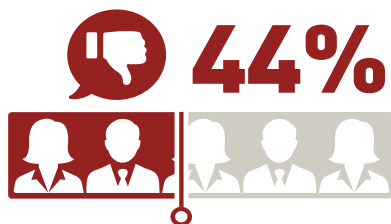
# Social Media: Targeted Impact

In 2021 we set out to increase the quality of the Coalition's online content in order to identify and engage highly active ambassadors.

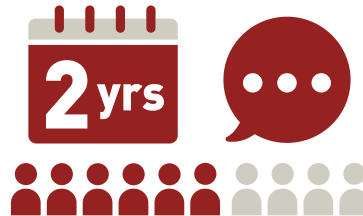


# National Chronic Disease Patient Survey

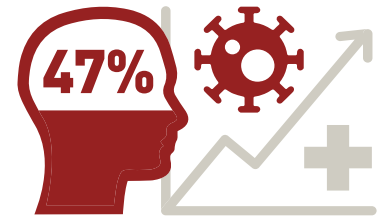
This June, to better understand the experiences of people with chronic diseases and begin to explore connections with our policy agenda, we conducted our first ever national survey of more than 2,000 patients.



More than two in five who are employed feel discriminated because of their medical needs in the workplace.



69% of those who struggled to get a formal diagnosis waited up to two years.



47% of those living with a chronic disease feel there has been greater national awareness since COVID-19.

Other key findings include:

- One third (33%) of those employed have not disclosed their chronic illness to their employer.
- Nearly half (46%) of those suffering from a chronic disease are still worried about COVID-19 as certain physical distancing and mask mandates are being eliminated.
- Of those who have had a COVID-19 diagnosis and are already living with a chronic disease 69% are worried that COVID-19 might cause another chronic condition.

This data helps us to be better voices for patients on public policy issues, and potentially identify new issues where our efforts can be effective. The data can be shared publicly to support policy work in target states, highlight coalition allies and ambassadors, and strengthen our position as an essential voice for patients on policy issues.

# JOIN THE FIGHT

## FOR PATIENT RIGHTS!

The Chronic Disease Coalition accomplished a lot this year, and we're excited about doing more in 2022. For too many chronic disease patients, the struggle to access high-quality, affordable health care is a full-time job. Insurance rules and state laws might seem like common sense at first, but they can create extraordinary burdens for those with chronic conditions. That's why it's crucial for us to be at the table.

It's our mission to advocate for those patients and to empower them to advocate for themselves. That means giving them the information and tools they need to tell their story. As we head into 2022, we're focused on our strategic impact: where can we do the most good for patients?

Inform.

Engage.

Activate.

Win.

We're getting ready for a strong 2022; we're also building for the future by developing a clear policy agenda and lasting patient-engagement programs. If you'd like to know more about the CDC, please don't hesitate to reach out.

Sincerely,



Mary Kay Clunies-Ross

Executive Director

Chronic Disease Coalition

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