Our Projects & Their Impact
Kimberly
Reynaud’s Syndrome
Ella
Cystic fibrosis
Welcome to Patients Rising. We are immensely proud to share with you this breakdown of our different programs and their impact on patients and policy.

At its core, Patients Rising is about healthcare access and affordability for patients, and we accomplish this by actively participating in policy and access discussions while simultaneously elevating the patient voice in the healthcare conversation. For such a seemingly simple mission, we have many working parts.

We provide patients a platform to share their voice on Patients Rising Stories. We connect with individual patients in need through Patients Rising Concierge. We tap into our social channels to initiate and establish meaningful relationships with patient support organizations and providers.

We address patient concerns with access and affordability in several ways. At Patients Rising University, we curate information from the most reputable sources we can find, then turn that into tools that patients can use to overcome specific barriers to care. Through the Patient Access and Affordability Project, we take a deeper dive into those issues to find the truth and identify solutions.

Patients Rising Now works closely with advocates and with patients on the path to advocacy, to hand them tools that will assist their noble work. For those who want to take their advocacy to the next level, we have our Advocacy Master Class. Additionally, we give patients a public platform and help clarify complex issues by speaking with experts on the Patients Rising Podcast.

We invite you to browse through our various offerings and to lend your support to our mission.

**Terry Wilcox**
Co-founder and Executive Director
Patients Rising & Patients Rising Now
Patients Rising was founded in 2015 by Terry and Jonathan Wilcox to focus on the access and affordability needs for all patients that live with chronic and life-threatening illnesses. They believed that by default, healthcare in the U.S. should be about getting the right treatment to the right patient at the right time. This simple motto drove their advocacy.

Terry and Jonathan knew from first-hand experience that a plastic card in the wallet did not guarantee coverage for a patient’s needs. It did not guarantee access to the doctor they wanted to see or the treatment that doctor prescribed. Patients living with chronic and life-threatening illnesses often had to fight harder to get what they needed. They learned this through stories from others, but ultimately, they learned it by caring for their own parents.

In 2007, Terry and Jonathan spent more than a year traveling, telling America the stories of cancer patients. This inspiration, coupled with the exasperation they felt from meeting these patients and their families, stuck with them for years. Both Terry and Jonathan’s dads have since passed away. Today they find themselves homeschooling two kids, navigating care for their aging Moms, and still looking in awe at the patients they serve wondering how they manage it all? Their hope is that through the programs offered via Patients Rising and Patients Rising Now, they can give those patients and their families the support, education, and tools of empowerment they need.

In 2015 the couple found themselves as an active part of the Sandwich Generation— they had young twin boys they were caring for on one hand, and aging parents on the other. When Jonathan’s mother and father moved into their home, it became abundantly clear that without self- and family-advocacy, patients can get lost and fall through the cracks. Even with great insurance, everything took work and follow-up and diligence. Terry brought her stepmother, living with dementia, and her dad, who was living with type 1 diabetes and advanced stage renal disease, from Denver to an assisted living facility near them.
Terry and Selma

Jackson and James with their Nanny

Jackson, Terry, Granny, Jonathan, and James
Mission

Patients Rising Now is dedicated to advocating for the rights of patients with chronic and life-threatening illnesses. We work at community, state, and federal levels to educate patients so they can actively advocate for reforms and legislation aimed at advancing patient access to, and affordability of, healthcare.

Vision

We envision a healthcare system where no patient is deprived of access to the treatments they need when they need them.

We engage in policy discussions that impact the access and affordability of care for patients. We create our position statements following a careful review of the issues, weighing opinions from experts, and speaking with patients.

- We stand up for patients’ rights and dignity
- We advocate for the importance of medical innovation and timely access to treatments that patients need
- We engage with patients, medical professionals, policy experts, and legislators to have solution-oriented discussions and to keep healthcare transparent
- We give a platform to patients and advocates to raise awareness of chronic and life-threatening illnesses

patientsrisingnow.org
@PatientsRisingNow
@patientsrisingnow
Lindsey
Narcolepsy
Since its founding in 2015, the mission of Patients Rising—a 501(c)(3) nonprofit organization—has been providing education, resources, and advocacy for all people living with chronic and life-threatening illnesses to ensure they have access to treatments and care.

Access to healthcare is heavily impacted by a patient’s race, ethnicity, gender, age, and other social determinants, creating disparities and inequities for a broad range of patients. As part of our commitment to ensure that all patients have access to treatments and care, we have created the Patients Rising Diversity, Equity, and Inclusion Council.

The Council is composed of healthcare stakeholders from a variety of cultural, ethnic, and socioeconomic backgrounds, including youth and patient advocates, health educators, writers and consultants, as well as case workers and nonprofit leaders—several of whom live with rare or chronic diseases.

Our goal is to establish an atmosphere of belonging and inclusion for all patients by considering all of their unique needs. Patients Rising plans its programs in a way that is meant to celebrate the diversity of our patient community. Through open communication and outreach, we aim to better understand the many needs of the diverse communities of America and work together to ensure every patient has access to appropriate care.

The Patients Rising Diversity, Equity, and Inclusion Council

Patients Rising’s Diversity, Equity, and Inclusion Council (“Council”) has been created to support our efforts to provide patients with the tools they need for self-advocacy. The Council does this by reviewing Patients Rising’s programs and providing data, patient stories, case studies, and counsel to ensure that the needs of every patient are met.

How Patients Rising is fostering diversity, equity, and inclusion

Our Patients Rising Concierge program provides the same exceptional level of assistance to every person who contacts us, regardless of their circumstances. See Patients Rising Concierge to better understand how the program works.
To help Patients Rising identify potential partner organizations that share our passion for diversity, equity, and inclusion (DEI), the Council refers organizations and individuals who hold themselves to high DEI standards in the work they do or the service they provide.

The Patient Access and Affordability Project (PAAP) and the Patients Rising University (PRU) are partnering with patient support organizations that also prioritize diversity, equity, and inclusion. This helps ensure that participation in or results from PAAP or PRU research is fundamentally diverse and inclusive, and that the unmet needs of a wider population are addressed in educational modules.

Patients Rising Stories is being shared with all of our partners and coalitions and welcomes all patients. The Patients Rising Podcast has interviewed several patients and policy makers on the topic of disparities in healthcare, and has plans to continue seeking these voices.

Our Advocacy Masterclass and Advocacy Chats are tackling issues that are universal to all communities. We are actively striving for diverse participation in these programs so we can better learn what unique issues are affecting various parts of society so we can customize advocacy efforts accordingly.

Meet the Team

Rachel Westlake, Woven Health Advocacy
Ronetta Stokes, Case Manager
Isabel Mavrides-Calderon, Student
Meridith O’Connor, The Merit Option
Surabhi Dangi-Garimella, SDG AdvoHealth, LLC
CarmenRose Fiallo, Community Manager
Mission

At Patients Rising we believe that patients and caregivers hold the power to move the needle in healthcare and create a better tomorrow for all patients and caregivers by raising their voice. The Advocacy Master Class is designed to train patients and caregivers in the art of healthcare advocacy.

Vision

To have delegates serving in each district across the country to advocate for policies that put patients first.

This 14-week, immersive experience is designed to teach patients and caregivers all about advocacy on and off the hill to provide them with the tools and tactics they need to be an effective healthcare advocate. Designed as a mini-college course, students receive a curriculum with weekly reading, watching, and listening to be completed at their own pace. Course participants from across therapeutic areas come together for live virtual sessions to engage with fellow classmates and hear from leading advocates.

Upon completion of the program, delegates will be able to:

• Communicate their patient/caregiver story in a compelling manner that will help drive change in healthcare

• Learn how to tie their personal experiences to healthcare policies they want fixed

• Understand key healthcare legislation seeking to stop dangerous practices negatively impacting patients and what they can do to help ensure it gets passed

• Learn how to effectively advocate “on the hill” by leveraging meetings with your representatives and the power of social media to affect change

• Learn how to effectively advocate “off the hill”— From testifying for the FDA approval of a new therapy or speaking at an ICER or DUR meeting to push for equitable access to a therapy

patientsrisingnow.org/advocacy-master-class
Anthony
Non-alcoholic Steatohepatitis
Marissa
Gastroparesis
Mission

Patients Rising University aims to empower patients and caregivers by presenting them with the information they need (never to be confused with medical advice, ever) to make informed decisions and advocate for themselves or others.

Vision

Our vision at Patients Rising University is that visitors will find value in the content and leave with a better chance for success in healthcare.

A big part of what we do at Patients Rising is listening. That is how we learn what works and where healthcare is failing patients. Focused on that patient need, we seek answers and end up with valuable tools and resources for our readers. We pass on what we learn through our Patients Rising University*.

The University is made up of modules, which are self-run parcels of curated knowledge that grow around a theme or subject. The seed of any module begins with what we hear from patients.

* Patients Rising University is not an accredited institute of learning that conveys degrees. We just thought the name was cool.

patientsrising.org/patient-education
One of the modules we developed is on **Biologics and Biosimilars** wherein we demystify biologics and help patients have informed conversations with their doctors. This particular module includes:

- An e-book featuring foundational information on biologics, written for patients
- A survey on patient’s attitudes about and experiences with biologics, conducted in cooperation with several patient support organizations
- An episode of the Patients Rising Podcast that discusses the policies that impact biologic access, cost, and production
- A patient story presented in video format by a patient, wherein they explore the decision-making process that went into using a biosimilar as a treatment option
- Several key articles on issues pertaining to biologics and biosimilars

Modules are multi-media and based on the most effective way to share information to the broadest audience.

Modules are a lot of work, and we cannot build them in a vacuum. We make inquiries with patients, caregivers, and support organizations; we ask experts in the field for input and critiques; we curate the best quality information from the most reliable resources we can find. Then we package that together in a way that honors the people who will use it.
**Mission**

Develop an advocacy platform that is accessible to the average patient and caregiver and to use that platform to have a measurable impact on awareness and advocacy activities nationwide.

**Vision**

That this tool will become an effective way for patients to build the foundations of community and for legislators and advocates to collect information on disease conditions and healthcare issues at the local, State, and Federal level.

We present real patient stories about healthcare in America.

There are insurance barriers to access and affordability concerns. Expensive markups by secretive pharmacy benefit managers and callous value frameworks that value everything but the patient. We believe that the true measure of value in our healthcare system starts with the concerns and goals of patients—not payers, providers, or manufacturers.

The best way to see through all the obstacles and noise...**The Patient Story.**

Every day, patients living with rare diseases and chronic conditions face real barriers to accessing the right treatment.

- A retired grandmother who loses access to her arthritis treatment because of a midyear bait-and-switch by her insurance company.

- A working mom who must live with migraine pain because of step therapy requirements by her pharmacy benefit manager.
• A toddler who must overcome a flawed value framework before accessing a life-saving treatment.

By sharing their stories, patients will be able to shine a light on these issues and how they impact geographical areas, congressional districts, disease communities, and much more.

Patients Rising Stories attracts story entries from across the country. Visitors have the freedom to share whatever is meaningful to them, including their inspirations, their social media links, and photos of their choice. But similarities to traditional social media end there. There is no advertising or partisanship, only true patient stories narrated with sincerity for the sake of advocacy and awareness.

The freedom to choose the kinds of policy issues they have encountered shows users and visitors just how influential policy decisions can be. This will spawn grassroot extensions of the Stories program, and lend data and power to patient support efforts everywhere.

As Patients Rising Stories grows, develops, and patterns emerge it will be able to inspire reports and advocacy efforts to legislators, media, medicine, and patient support communities.
Carol
Cancer
Mission
Patients Rising Concierge helps patients and caregivers find solutions when they don’t know how to find help on their own.

Vision
Construct a library of curated services and programs that meet the stated need of clients we have encountered, which will then be made available to the public.

Finding help can be frustrating and time consuming, and many are hesitant to ask for it. We offer clients three ways to get help: by phone voicemail, by email, or by visiting PatientsRisingConcierge.org directly. These offerings address hesitancy by allowing clients to determine how they want to interact with us. Concierge staff can respond by calling them back or emailing with the resources we find. We believe that by offering these options (as opposed to a “hotline”) we give some power back to those who (experience tells us) often feel powerless.

Every client in the Concierge service will get a customized response to their query. The Concierge staff are experienced in healthcare, social programs, and customer service. We pride ourselves on listening carefully to a person’s needs and getting them the information that will take them to the next step in solving their problem.
Impact

In 2020, Patients Rising Concierge responded to 610 unique voicemail queries and 138 email queries.

The website landing page received 41,610 pageviews with 2 minutes 20 seconds average time spent on the site. This was sufficient for them to find their way to the Patients Rising Concierge website.

That Patients Rising Concierge website received:

- 63 distinct identified users (people who set up an account)
- 6,053 distinct anonymous users
- 7,193 sessions
- 10,984 database searches

This is precisely how the Concierge service is meant to work. A significant number of searches were done without staff assist. Individuals who set up user profiles were contacted by Concierge staff to see if they needed assistance. Testimonials and lack of follow up inquiries from clients both indicate the needs are being addressed.

The Patients Rising Concierge program had 41,670 pageviews and 10,984 database searches in 2020.

“We’re not the last stop on the road to solving your problem, but we’re really good at giving directions.”
**Mission**

To provide patient-powered pathways to help both public and private payers as they make critical coverage decisions for patients with rare and chronic diseases. As scientific innovation advances and evolves, it is imperative that we look beyond the one-size-fits-all approach to identify ways to promote access and maintain affordability. PAAP evaluates the various frameworks used to assess and demonstrate the value of new treatments to ensure that the patient is kept at the center of these decisions.

**Vision**

Thought leaders in the delivery of healthcare will make treatments that are available to the most vulnerable patients—the rare, chronic, and underserved—regardless of socioeconomic status. Access and affordability to patients will be reasonable, delivery will happen quickly, and patient dignity will be preserved. The measure of a successful healthcare system will be the satisfaction of patients.

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[Image of Ariel with text indicating she has gastroparesis]
The Patient Access & Affordability Project (PAAP), a program of Patients Rising, is a policy institute that evaluates healthcare policies to understand their impact on patient access to treatments and their ability to afford paying for those treatments. Policies evaluated by PAAP include, but are not limited to, those at the federal, state, and local government level; those used by insurers to determine coverage; and those developed by non-government stakeholders.

PAAP’s work is carried out by a team that includes a health economist, health policy experts, researchers, and educators. The PAAP Advisory Board includes patients and patient advocates, industry experts, and other healthcare professionals. PAAP conducts a series of events on relevant topics, including Policy Working Group meetings, an annual policy summit, and an annual patient and industry forum.

Publications from PAAP include blog posts on relevant policy issues, ICERWatch analysis and commentary, current issues reports on relevant policy topics under discussion, and more. PAAP also produces a regular e-newsletter to share the latest updates with subscribers.

Meet the Team

Terry Wilcox, Executive Director of Patients Rising

Paul Langley, B.Sc. (Econ), M.A., Ph.D., Lead Researcher

Jim Sliney, Jr., Director of Patient Content

Joe Keenan, Digital Director

Joelle Sokolic, Advocacy Manager
Mission

The Patients Rising Podcast combines patient voices, healthcare industry experts, and timely news commentary to educate listeners about the current healthcare policy landscape and solutions being considered to address their biggest concerns. From access to affordability, no topic is off-limits. Each Friday, Terry Wilcox and Dr. Bob Goldberg examine the latest health policy news, exposing the obstacles to accessible and affordable healthcare: pharmacy benefit managers, co-pay accumulator programs, and more. Every episode highlights patient struggles and the ways policymakers can pursue meaningful pro-patient legislative reforms. The end goal? Driving adoption of healthcare solutions that work for patients, not against them.

Patients Rising brings its established brand of patient advocacy to a weekly podcast, featuring honest and helpful discussions about issues impacting those with chronic illness. Executive Director Terry Wilcox hosts the show, with Robert “Dr. Bob” Goldberg, Co-Founder and Vice President of the Center for Medicine in the Public Interest.

Every week, Terry and Dr. Bob explain the true impact of Washington, D.C. healthcare policy decisions on patients across America. The podcast features interviews with patient advocates, government officials, and policy experts. Past guests include former FDA Commissioner Dr. Mark McClellan, Congressman Fred Upton, and vaccine expert Dr. Paul Offit.

Additionally, field correspondent Kate Pecora talks with patients about their challenges with access to treatments, navigating care, and more. And because patient voices are at the heart of Patients Rising’s advocacy work, members of the chronic disease community also contribute to the podcast with personalized messages detailing their healthcare journeys.
Meet the Hosts

**Terry Wilcox**, Executive Director of Patients Rising

**Robert “Dr. Bob” Goldberg**, Co-Founder and Vice President of the Center for Medicine in the Public Interest

**Kate Pecora**, Patients Rising Field Correspondent

**Robert Johnson**, News Host

What Listeners Are Saying

“The Patients Rising Podcast highlights issues and topics that we need to be discussing in a way that is understandable and relatable!”

—Amaiello3

“Patients Rising is a tool for chronically ill and disabled folks, by chronically ill and disabled folks! Our voices are heard, valued, and amplified. This podcast should be shared with everyone!”

—Carolannemaria