



Generation patient Annual Report

A collage of members from our Generation Patient community 2020 - 2024

2024

Generation Patient is a nonprofit organization created by and for young adults with chronic conditions. As young adults, we are at a pivotal life stage: navigating the transition to adulthood while simultaneously managing unpredictable health conditions along with our personal, educational, professional, and psychosocial needs.

At Generation Patient, we facilitate peer-support meetings for our young adult patient community while driving systemic change through policy work, leadership programming, and evidence-generation initiatives. We amplify young adult patient voices in critical conversations where real change can occur. Through this strategy, we envision a future where young adults with chronic medical conditions can live with greater quality of life, access, dignity, and fulfillment.

Lastly, we do not accept funding from pharmaceutical or insurance industries—especially at a time when patients across the U.S. and internationally struggle to access life-saving medication and care. As an organization founded by young adult patients, maintaining our ability to advocate for the needs of our community (independent from industry influence) is extremely important to us.

Strategy

Direct Support

- 6 Virtual peer-support meetings
- International Virtual Health Advocacy Summit
- Peer-led resources in higher education and advance planning

Research and Policy

- Patent reform
- Pharmaceutical direct-to-consumer advertising on social media
- Representation of adolescents and young adults in clinical trials

Leadership Programming

- Health Policy Scholars Program
- Crohn's and Colitis Young Adults Network Fellowship Program

Roundtables

- Peer Support Interventions for Young Adult Patients
- Young Adults with Inflammatory Bowel Diseases
- Higher Education and Medical Disabilities
- Social Media Direct-to-Consumer Advertising

Our Peer-Support Work

Our peer-support meetings are community-led, meaning that all of our facilitators are also young adult patients living with chronic medical conditions.

Since March 2020, Generation Patient has facilitated nearly 600 virtual peer-support meetings. Our main focus for these groups is support and solidarity with fellow young adult patients. We want to foster community and provide tools to navigate real-world challenges.

Virtual Meetings

Our meetings address a variety of topics tailored to the needs of our community, such as:

- medical disclosure
- coping with unpredictability
- navigating outside perceptions of chronic illness
- medical trauma
- relationships and communication strategies.

We also host more informal conversations, interactive workshops, games, and other activities. This mix of styles allows participants to forge deeper connections with their peers, who inherently understand the challenges of living with chronic illness even when it's not explicitly being discussed.

"I never felt like there was a place to talk so openly about chronic illness and different topics that weighed so heavily on my mind in my group around me.

These support groups make it easier to foster connections with others which have made a really positive impact on my life."

"...Sharing advice and knowing I'm not alone has kept me alive."

"I really love the support and how everyone wants to uplift each other, this community is so amazing and as given me opportunities I would've never thought of achieving as a chronic illness patient."

Anonymous feedback from those who have participated in our peer-support groups

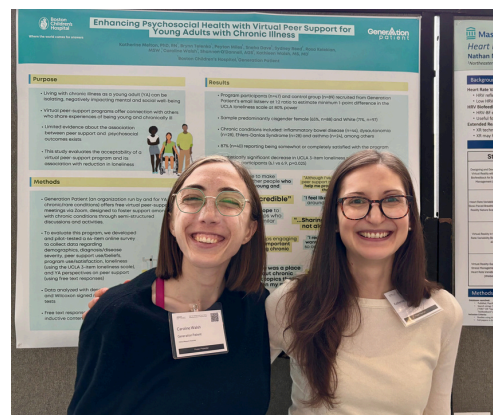
We offer six virtual meetings per month across the following areas:

- **General peer-support meetings for all young adults with chronic and rare medical conditions**
- **Higher education peer-support meetings for young adult patients who are current or prospective students in undergraduate or graduate school**
- **Peer-support meetings for young adults with IBD (our only disease-specific groups)**

Learn more about our approach to peer support [here](#).

Peer support is still underutilized in healthcare settings, and there is a further lack of research promoting its inclusion in the standardized long-term care plans for young adult patients with chronic conditions, a gap that, if addressed, could significantly bolster disease acceptance and reduce isolation for young adult patients across disease groups.

We worked with researchers at Boston Children's to evaluate the impact of our peer-support meetings and presented our findings in an abstract at the Osher Network Forum: High-Tech Medicine & Soft-Touch Healing – Advancing Innovation in Integrative Health at Harvard Medical School in Boston, MA.



Our abstract was presented by qualitative researcher and community member Katherine Melton as well as another member of our young adult patient community, Caroline Walsh.

Roundtable on Engaging Adolescents & Young Adults With Chronic Conditions in Research for Peer Support Interventions

To further address this research gap, we created the **Roundtable on Engaging Adolescents & Young Adults With Chronic Conditions in Patient-Centered Comparative Effectiveness Research (CER) for Peer Support Interventions**. This two-year roundtable explores the opportunities, barriers, existing data, and the pressing need for further patient-centered outcomes research and comparative effectiveness research related to peer support in the treatment of young adult patients. This roundtable is supported by the Eugene Washington PCORI Engagement Award Program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI).

You can learn more about this roundtable [here](#).

In connection to our work, our Program Manager, Rosa Kelekian, traveled to D.C. to speak on a panel about "Engaging Youth, Igniting Change: Exploring Youth Engagement" at the PCORI Annual Meeting!



Virtual Health Advocacy Summit

In September, we hosted our fifth annual Virtual Health Advocacy Summit! This free, international event has brought together a global community of hundreds of young adult patients annually since 2020.

This year's sessions focused on the evolution of our work, how members of our community began their advocacy journeys as young adults, and how other young adult patients can get involved in the regulatory and legislative process to be a driving force for meaningful, systems-level change!

Health Policy Lab

Generation Patient's (Health) Policy Lab spearheads our organization's work in health policy, aiming not only to drive significant change in areas that have the most impact on young adult patients, but also to empower young adult patients with policy education and advocacy opportunities to ensure that their voices are heard.

Health Policy Scholars:

Leadership programming conducted under this arm of our organization includes our *Health Policy Scholars*, a group of young adults with chronic and rare conditions, who share a keen interest in actively engaging with health policy matters, particularly those related to lowering healthcare costs and the prices of prescription medicines.

Our scholars engage in drafting testimony, feedback to regulatory agencies, and breaking down complex health policies for our broader community!



Adam Koch



Peyton Miles



Giovanna Burno



Rachel Litchman



Casey Doherty



Genna Goist



Sneha Dave and 2024 Scholar Peyton Miles the White House! Read more about Peyton's experience [here](#).

Areas of our policy work:

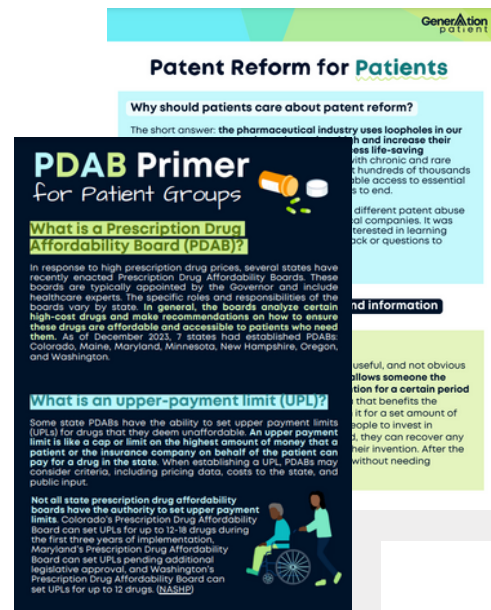
Our team has collectively identified three policy priority areas:

- **Patent reform** ([Read more](#))
- **Increasing oversight of pharmaceutical advertisements on social media** ([Read more](#))
- **Clinical trial representation of young adult patients** ([Read more](#))

Patent Reform

Recent work in this area:

- [Patent Reform Primer](#) - This primer is meant to educate young adult patients on the patent reforms needed to increase the affordability of prescription medicines.
- [Prescription Drug Affordability Board \(PDAB\) Primer](#) - We created a primer for patient groups on the increasing importance of PDABs in ensuring patients can afford medicines.
- [Letter](#) in support of S. 2780, the Medication Affordability and Patent Integrity Act
- [Comment](#) to the U.S. Patent Trade Office: Terminal Disclaimer Practice To Obviate Nonstatutory Double Patenting Proposed Rule
- [Comment](#) on Patent TAB Rule
- [Comment](#) for the Record Submitted to Senate Committee Hearing



Pharmaceutical Direct-to-Consumer Advertising on Social Media

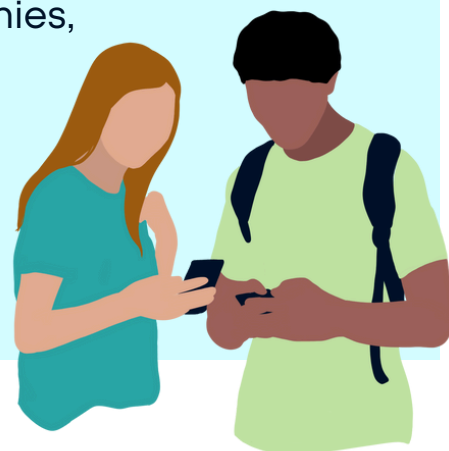
Recent work and features in this area:

- We were featured in the *British Medical Journal (BMJ)* for our work in the development of the Protecting Patients from Deceptive Drug Ads Online Act, introduced by Senator Durbin (D-IL) and Senator Braun (R-IN).
- Our executive director was invited to speak on the *Medical Marketing & Media podcast* for our work at Generation Patient to increase oversight of pharmaceutical advertisements on TikTok and Instagram.
- Our *STAT News Article*: The FDA and FTC need to crack down on TikTok and Instagram influencers pitching prescription drugs
- *Comment*: Addressing Misinformation About Medical Devices and Prescription Drugs
- *Letter* on Prescription Drug Advertising to the Food and Drug Administration

2024 was a big year for us as we drove the first legislation addressing increasing oversight of pharmaceutical advertisements on social media!

The Protecting Patients from Deceptive Drug Ads Online Act, introduced by Senators Durbin (D-IL) and Braun (R-IL), directs the FDA to update and enforce its regulations for how prescription drugs are promoted on social media, focusing the agency's attention specifically on deceptive or misleading communications by telehealth companies, social media influencers, and healthcare providers.

In September, we held a briefing with the Young People's Alliance and the U.S. Public Interest Research Group on the this bill an its potential impact!



Clinical Trial Representation

Recent work in this area:

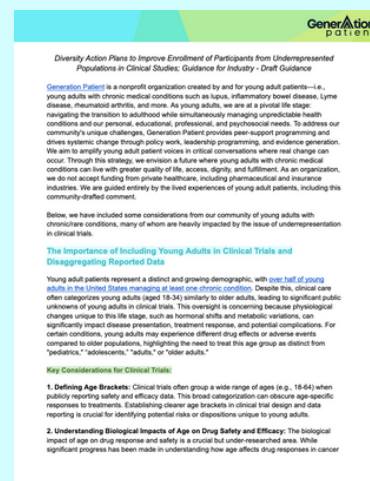
- We were thrilled to have an abstract at UEG - United European Gastroenterology Week in Vienna through our only disease-specific program at Generation Patient, the Crohn's and Colitis Young Adults Network. Our abstract examines the need to subgroup young adults with IBD in research rather than adults ages 18-60.

Our aim is to continue spotlighting young adults to be considered a specific subgroup within disease areas that impact our age demographic.



Check out our guidance on the FDA's Diversity Action Plans to Improve Enrollment of Participants from Underrepresented Populations in Clinical Studies!

Considerations for clinical trials from our community of young adults with chronic/rare conditions, many of whom are heavily impacted by the issue of underrepresentation in clinical trials.



Crohn's and Colitis Young Adults Network

The **Crohn's and Colitis Young Adults Network** is an international community space and fellowship program for young adults with inflammatory bowel diseases (IBD) and is the only disease-specific programming at Generation Patient.

Our International Fellowship

2024 marked the **sixth year** of our fellowship program for young adults with IBD. Our fellowship program is a unique patient advocacy initiative with a primary goal of elevating young adult patient voices within the IBD space.

Since 2019, the CCYAN Fellowship Program has brought together a diverse group of 41 young adults with IBD worldwide. Over the years, our fellows have represented various countries, including the United States, India, Ethiopia, the United Kingdom, Dubai, Greece, Malaysia, and Canada.

This one-year fellowship program provides support, a platform for advocacy, and a sense of community for young adults facing the unique challenges of IBD.

During their fellowship year, our fellows have opportunities to:

- produce monthly content shared across multiple online platforms
- hear from monthly speakers and participate in various advocacy initiatives
- facilitate peer-support meetings for our patient community



Zahraa Chorghay,
Canada



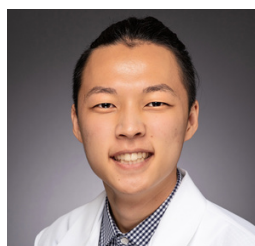
Selan Lee,
United Kingdom



Maria Rouse,
United States



Yeabsira Taye,
Ethiopia



Peter Park,
United States



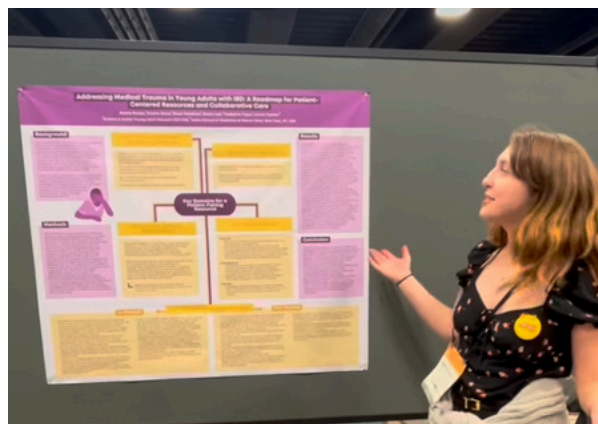
Giana Formica,
United States

Check out our [database](#) (which includes all our fellow alumni) to promote the young adult patient voice through consulting and collaborative initiatives with other organizations and institutions we work with in the IBD space.

AIBD Conference

For the past four years, the CCYAN has partnered with AIBD (Advances in Inflammatory Bowel Diseases) to provide young adult patient perspectives on IBD management and other critical issues, such as the transition of care from pediatric to adult care.

Our team works with our fellows to lead an abstract related to their experiences of inflammatory bowel disease in young adulthood. This year we had two abstracts on medical trauma and a clinician checklist for young adult patients!



2024 CCYAN Fellow Maria with her abstract on medical trauma in young adults with IBD.



A few of our fellows, team members, and healthcare professionals at AIBD 2024!

Webpage for Clinicians

Take a look at our [webpage for clinicians](#)! Here, clinicians can access educational handouts, video resources, peer-reviewed publications, and opportunities to get involved in our work.

Opportunities for Clinician Involvement: Delphi Consensus & Expert Panels

To enhance support for young adults with IBD, we are launching a modified Delphi consensus panel to identify key challenges and recommendations in patient-clinician interactions, research, and system-wide support. We are [continuing to recruit](#) in 2025!

Additional Highlights: Grants, Speaking Engagements, & Publications

Grant from the Lucile Packard Foundation for Children's Health

We were awarded a grant from the **Lucile Packard Foundation for Children's Health** to support an initiative to identify current systemic challenges and opportunities for young adults living with chronic and rare conditions!

We convened a series of meetings with both patient and medical advisory boards, which met to explore various systems-level issues impacting young adult patients (aged 18-30). The outcomes of these meetings will shape a series of Roundtable discussions scheduled for next year.

Articles & Media Features

How Young Voices Can Shape Prescription Drug Policy

The Generation Patient Team worked with our Health Policy Scholars from 2023 and 2024 to write this article for The Commonwealth Fund blog focused on the importance of young voices in health policy reform!

Medicaid Unwinding Unfairly Puts Patients at Risk By Rachel Litchman

One of our 2024 Health Policy Scholars, Rachel Litchman, has published an op-ed in *The Progressive*. In her piece, Rachel highlights the devastating impact of recent Medicaid rollbacks on vulnerable patients. Her insights emphasize the urgency of protecting access to healthcare, especially for those with chronic conditions. This article is a must-read for anyone passionate about health equity and policy reform.

The FDA and FTC Need to Crack Down on TikTok and Instagram Influencers Pitching Prescription Drugs

An opinion piece by Generation Patient's executive director Sneha Dave and operations director Sydney Reed, with Dartmouth professor Dr. Steven Woloshin published in STAT News.

The Connection Between Patents and High Drug Prices

A Q&A in POLITICO featuring our executive director along with other experts who shared their perspectives on the connection between pharmaceutical patents and high drug costs—and, more importantly, what can be done about it through patent reform.

Notable Presentations and Speaking

ICHOM ([More Information](#))

Keynote Plenary Session: "The Patient-led Revolution for Better Outcomes" and a panel discussion on "Patient Perspectives Matter: What Has More Impact – Outcomes or Experiences?"

ISPOR—The Professional Society for Health Economics and Outcomes Research ([More Information](#))

Webinar focused on "Patient Involvement in Value and Health Technology Assessment"

FDA's Public Workshop on Enhancing Diversity in Therapeutics Development for Pediatric Patients

Duke-Margolis Institute for Health Policy ([More Information](#))

Spoke on regulatory gray areas in pharmaceutical marketing on social media and preventing misleading advertisements.

Panel Discussion Hosted by Senator Welch with Senator Klobuchar, Health Care Experts, & Patients

Focus: Dismantling patent walls and new patent legislation addressing patent thickets.

Health Technology Assessment International (HTAi) Global Policy Forum

AARP and I-MAK's Webinar on Patent Reform

White House Convening

Panel Discussion on the impacts of President Biden's Prescription Drug Law from a gender and intergenerational perspective, focusing on inflation rebates and effects on young adult women.



Sneha Dave speaking on breaking down big pharma patent walls.

Thanks to our supporters!

We thank the following foundations for their support in making our work possible in 2024:

- Arnold Ventures
- Responsible Technology Youth Power Fund
- Disability Inclusion Fund
- The Leona M. and Harry B. Helmsley Charitable Trust
- Patient-Centered Outcomes Research Institute (PCORI)
- Third Wave Fund
- Commonwealth FundConnecting to Cure Crohn's and Colitis
- Lucile Packard Foundation for Children's Health
- Nightingale Advocacy

We would also like to thank our amazing team:

Rosa Kelekian
Programs Manager

Sneha Dave
Executive Director

Amy Bugwadia
Research Consultant

Sydney Reed
Operations &
Creative Director

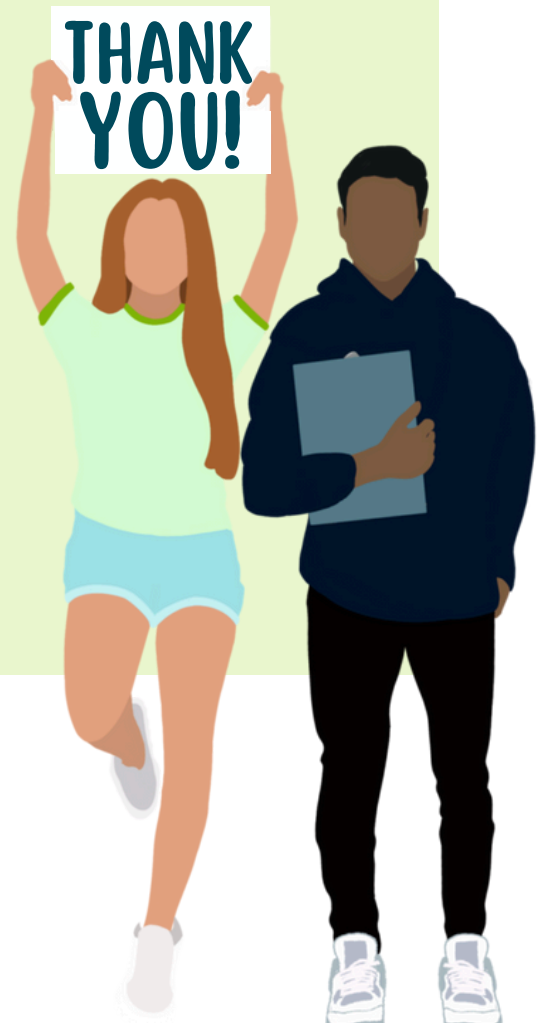
Erin Ard
Content Consultant
for CCYAN

Julia Bartow
Social Media
Intern

And the members of our board:

Barbara Bierer
Stephen Plank
Keely Cat-Wells

Pretima Persad
Leah Clark



As an organization independent of all private healthcare industry, your donation makes a big difference for us. You can **donate here**. Every little bit helps our organization grow.