



**Gener****tion**  
patient  
Annual Report

*A collage of speakers from our Virtual Health Advocacy Summits 2020 - 2023*

**2023**

## A message from our team:

While we are a non-partisan organization, the 2024 election year will be crucial as we recognize how health policy initiatives directly impact our community. We pride ourselves on our commitment to multi-level advocacy and support, highlighting the importance of both peer-based programming and policy-level systemic changes. As young adult patients, we believe that our voices are important in all decisions made about us. In the coming years, we will push harder for our generation of patients - and those that come after us - to have the best possible opportunities to thrive into adulthood.

We remain committed to our organizational values as we continue to grow alongside our community and work to create a more equitable healthcare system. We have continued to decline all funding from the private healthcare industry, ensuring the integrity of our work and programming truly driven by us as young adult patients. We also note that health equity comes with deep internal and external accountability, and we continue striving to ensure our community-driven efforts are led with a racial justice/ anti-oppressive lens.

This annual report is drafted to show our immense gratitude for your willingness to be a part of our community from afar or within. We really could not do it without your support. So, thank you for staying with us in 2023, and here is to an even stronger 2024!

We love to hear from you. If you have any questions, would like to collaborate, or have any recommendations, we look forward to hearing from you at **[admin@generationpatient.org](mailto:admin@generationpatient.org)**!

Sincerely,

The Generation Patient Team

## A message from our team:

This year was important for our team at Generation Patient as we entered a new period of growth and milestones, including hosting our 500th peer support meeting and launching the first cohort of Health Policy Scholars. We are grateful to all of the young adult patients in our community for their commitment to translating their lived experiences into informed, empowered, and independent advocacy. We are excited to begin writing the next chapter of Generation Patient in the coming year as we prepare to expand our leadership team, welcome new community members, and continue our peer support programming.

### Strategy

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graph TD; Strategy[Strategy] --> DirectSupport[Direct Support]; Strategy --> Research[Research and policy]; Strategy --> Leadership[Leadership Programming]; Research --> Roundtables[Roundtables]
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#### Direct Support

- 5 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
- Inflammatory Bowel Disease Medical Student Scholars 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

# Peer Support

## Virtual Meetings:

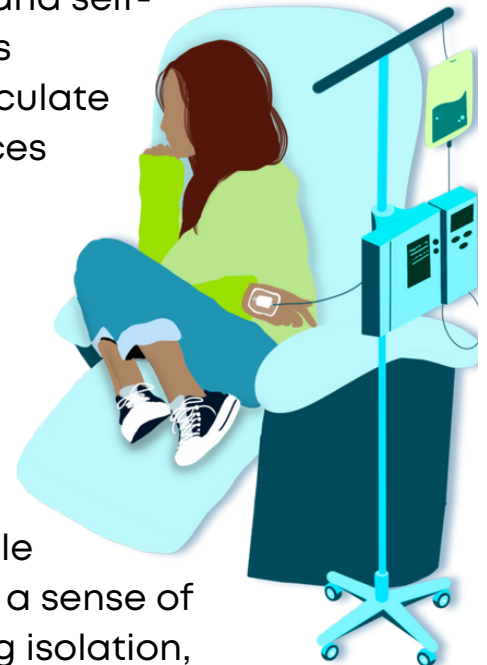
At the start of the pandemic in March 2020, our organization began facilitating **peer-support meetings** for our community of young adults with chronic and rare conditions. Since then, we have held over 500 virtual meetings to connect young adult patients across the U.S. and beyond. As young adult patients, we have witnessed the power of peer support to enhance our demographic's mental and physical well-being, so a significant portion of our work is now focused on the continued facilitation of monthly virtual peer support meetings. We currently host five virtual meetings each month across the following categories:

- **Peer-support for all young adult patients across all disease groups**
- **Peer-support for young adult patients pursuing higher education. This includes graduate, undergraduate, and professional education students.**
- **Community sessions for young adults with inflammatory bowel diseases (IBD)**

These virtual meetings eliminate geographical limitations, giving access to young patients who reside

in remote areas or lack access to transportation and enabling individuals from various locations to participate and benefit from the support network we provide.

Many of the young adult patients who attend our meetings live with complex, rare, or undiagnosed conditions. Often, their situations are further complicated by overlapping and secondary conditions, as well as treatment challenges. Through these meetings, attendees can connect with others, share their stories, exchange valuable tips and coping strategies, and develop the language and self-advocacy skills needed to articulate their experiences and overcome limitations. We believe that forming such crucial interpersonal relationships plays a vital role in establishing a sense of self, combating isolation, enhancing disease management skills, and overall disease acceptance.



Some of our meetings focus on specific topics, such as medical trauma, disclosure, relationships, and communication strategies, while others offer informal discussions and interactive workshops that allow attendees to forge deeper connections with others who inherently understand the challenges of living with chronic illness.

Evaluation of our work is crucial to us. We are currently working with researchers at Boston Children's to evaluate our peer-support programming. We hope to assess and grow the impact of these meetings in the future, showing the importance of this specific form of support for young adults with complex, lifelong conditions.

### **Roundtable: Peer Support as an Intervention for Young Adult Patients**

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As a team of young adult patients, we recognize the value of peer-support initiatives to alleviate isolation and enhance disease acceptance and management for young adult patients. Unfortunately, there has been a lack of attention given to comparative clinical effectiveness research specifically focused on young patients, particularly regarding the critical role of peer

support in the long-term care of individuals diagnosed with lifelong conditions during their childhood or as young adults.

To address this research gap, we launched our Roundtable on Peer Support as an Intervention for Young Adult Patients in July of 2023. This Roundtable will serve as a collaborative learning community comprising various stakeholders, including young adult patients, caregivers, medical professionals, and researchers. Over the course of two years, roundtable members will convene to engage in meaningful discussions in which they will explore 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 the details of our project [here](#).



## Virtual Summit:

In 2023, we hosted our fourth annual Virtual Health Advocacy Summit, an international event that has brought together a global community of hundreds of young adult patients each year since 2020. This year's summit was held over five days from September 12th through September 16th and was composed of sessions dedicated to the issues that impact our demographic most. Speakers at our virtual summits have included established activists, medical professionals, and young adult patients themselves, providing valuable perspectives and information throughout their individual sessions.

### 2023 Session Topics:

- Ethics in Activism
- Medical Trauma
- Adventure and Travel With Chronic Illness
- Storytelling Workshop: Sharing Your Story to Impact Change
- Self-Advocacy in the Workplace & Higher Education
- Disordered Eating and Body Image
- Becoming a Better Self-Advocate: Identifying Trusted Sources Online
- Navigating your 20s With Chronic Illness
- Isolation & the Value of Peer Support

This event was free to all young adults with chronic and rare medical conditions and featured live closed captioning and ASL interpreters to make the event as accessible to as many patients as possible. Each session was recorded and made available to registered attendees who could not attend the sessions live.

### Session topics from our past Virtual Health Advocacy Summits:

#### 2020

- Global Health Policy: Drug Pricing
- ADA & Accommodations: Self-Advocacy tips for Transitioning From Pediatric to Adult Care
- International Perspectives: Chronic Illness in India
- Mental Health: Emotional Dimensions of Chronic Illness
- Navigating Insurance in the U.S.
- Intersecting Identities & Minority Health
- Mindfulness & Movement
- Navigating Higher Education
- Telling Your Story: Communicating With Peers, Loved Ones, & Medical Professionals
- Chronic Illness & Entrepreneurship

#### 2021

- Global Health Policy: Pharmaceutical Patents
- Advocating for Your Future: Higher Education and the Workplace
- Adaptive Ballet Class
- Digital Activism: Grassroots Patient Advocacy
- Intersecting Identities
- Financial Resources
- Emotional Wellbeing
- International Perspectives: Malaysia, Uganda, and India
- Exploring Art Therapy: An Interactive Session
- Media Representation of Chronic Illness
- Confidence & Body Image

#### 2022

- Dysautonomia & Chronic Illness
- Art Workshop: A Therapeutic, Interactive Session
- Medical Trauma and Growth
- A Conversation With Grassroots Activists
- Decolonizing Patient Advocacy
- Diagnosed: Grief, Identity, Acceptance, & the Unknown
- Neurodivergence & Chronic Conditions
- Global Access to Medicines
- Higher Education, the Workplace, & Self-employment
- Movement & Mindfulness
- A Conversation with Selma Blair and Troy Nankin

# Health Policy

## Health Policy Lab:

Generation Patient's **Health Policy Lab** spearheads our organization's work in health policy, aiming to drive significant change in areas that impact young adult patients, empower young adult patients with policy education and advocacy opportunities, and ensure their voices are heard. In 2023, our team collectively identified three policy areas on which to focus our advocacy and exploration of multifaceted solutions: patent reform, pharmaceutical direct-to-consumer advertising on social media, and clinical trial diversity. While these are our three focus areas, we have also engaged in state-based legislative efforts to lower the cost of our life-saving medicines, such as submitting testimony in support of the Colorado Prescription Drug Affordability Board.

### 1) Patent Reform

**Problem:** Over-patenting prescription drugs creates extended monopolies and market control and inhibits timely access to biosimilars and generics. The lack of new and

clinically improved biosimilars and generics poses an immense financial burden on young adult patients like us, who are navigating a period of life marked by multiple life transitions and financial instability. **Solution:** The U.S. Congress has the power to increase the integrity of the patent system through legislative action. Patent reform should include limits on pay-for-delay tactics (companies offering patent settlements to delay competition), patent thickets (generic companies having to navigate a forest of patents often protecting meaningless enhancements), and product hopping (when the manufacturer switches to a follow-on product). Agencies such as the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the United States Patent and Trademark Office (USPTO), and the Federal Trade Commission (FTC) also have the power to curb patent abuse through regulatory action. Furthermore, the White House has the authority to put pressure on both Congress and federal agencies, as it has done through past executive orders.



### **Our patent reform work:**

- [Patent letter to the Senate Judiciary Committee and Leader Schumer's Office](#)
- [Comments on Transforming Discoveries into Products: Maximizing NIH's Levers to Catalyze Technology Transfer](#)
- [Comments to the U.S. Patent and Trademark Office: America Invents Act Trial Proceedings Before the Patent Trial and Appeal Board](#)
- [Comments to the FDA and USPTO](#)
- Patient-Centered Patents Roundtable (invite-only event for patient advocacy groups)

## **2) Pharmaceutical Direct-to-Consumer Advertising on Social Media**

**Problem:** The Food and Drug Administration's (FDA) Office of Prescription Drug Promotion has the authority to oversee prescription drug advertisements, including those on social media. Unfortunately, the FDA's regulations have not caught up with rapidly-evolving platforms such as TikTok and Instagram. The FDA has not released guidance since 2014 and has not held a public workshop addressing this issue since 2009. In addition, the rapid rise of influencers advertising prescription drugs highlights the need for more aggressive inter-agency

collaboration. Given the power of parasocial relationships that often develop between influencers and their followers and the fact that the majority of social media users on TikTok and Instagram are between the ages of 18 and 34, this is a major concern for young adult patients, who are likely to be most affected.

**Solution:** The FDA and the Federal Trade Commission (FTC) should develop a task force - as they have done in the past with issues such as biosimilar misinformation and promoting competition - focused on DTC advertising on social media. The FTC has regularly updated its endorsement guidelines, which could be adapted by the FDA for applicability of best practices for influencers advertising prescription drugs.

### **Our pharmaceutical direct-to-consumer advertising work:**

- [Penn Bioethics Seminar \(PBS\): Direct-to-Consumer Pharmaceutical Social Media Advertising](#)
- [Duke Margolis Workshop: The Future of Prescription Drug Promotion and Digital Marketing](#)
- [Responsible Youth Technology Power Fund Grant](#)





### 3) Clinical Trial Diversity

Problem: Young adult patients are a growing demographic, with over half of young adults in the United States living with a chronic condition. Yet, clinical care has often treated young adults (>18) similarly to their older counterparts. In addition, young adults are known to be underrepresented in clinical trials. This is significant because many physiological changes occur between 18 and 39, affecting disease processes and presentation, the response to treatments, and potential complications. Young adults may experience different drug dispositions and adverse events for certain diseases, highlighting the urgent need to investigate this population differently than pediatrics, adults, or older adults.

The lack of focus on age extends to adverse event reporting systems. The Food and Drug Administration (FDA) groups ages 18-64 as one demographic in their adverse event reporting, while the Centers for Disease Control (CDC) has narrower subgroups, such as ages 18-29, in their adverse event reports.

### Solution:

It is critical to disaggregate data for young adults, beginning with sponsors making this data more readily available and the FDA mandating data disaggregated public reporting through its diversity efforts. Furthermore, conditions affecting young adults should be investigated for potentially differing disease epidemiology, and trial data should be available for disaggregation by at least five years.

#### **Our clinical trial diversity work:**

- [STAT News article: If Pharma Can Market to Youths by TikTok, it Should Include Them in Clinical Trials](#)
- [University of Pennsylvania's Research Ethics and Policy Series \(REPS\): Representation of Adolescents and Young Adults in Clinical Trials](#)
- [Presentation at Duke-Margolis Center for Health Policy on Advancing Representative Enrollment in Clinical Trials](#)

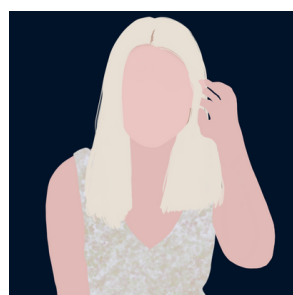
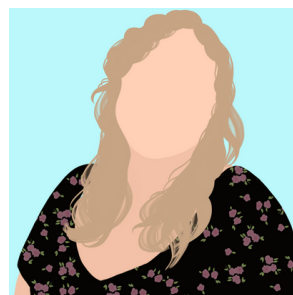
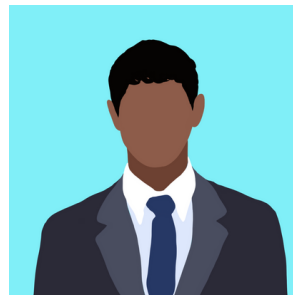
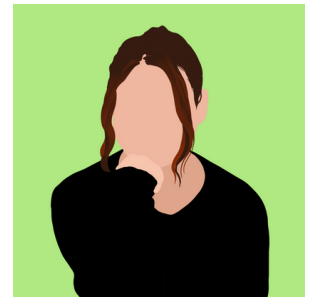
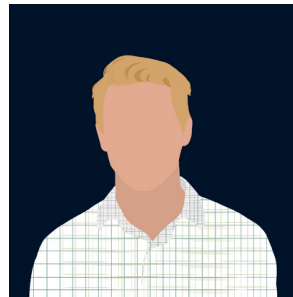


## Health Policy Scholars:

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In March of 2023, we launched our first class of Health Policy Scholars, comprised of nine young adults with chronic and rare conditions who represent a critical perspective in the health policy space and 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. Over their scholarship year, our scholars work on several advocacy projects and attended workshops focused on subjects such as patents, op-ed writing, value-based pricing and health technology assessments, as well as current drug pricing legislation and the implementation of the Inflation Reduction Act. See examples of op-eds by our 2023 scholars including **“Medicating Inequality: A Feminist Examination of Drug Costs,”** by Anna Ball, and **“Access Denied: My Battle with Gastroparesis and the High Price of Essential Medication,”** by Grace Shults.

We are proud that our scholars have spoken at the United States Patent and Trademark Office and have contributed to drafting Congressional and regulatory testimonies. In this way, young adult patients are not just “sharing their stories” but leading the necessary policy change.



## 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.

### **Fellowship:**

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2023 marked the fifth year of our fellowship program for young adults with IBD. The CCYAN 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 successfully brought together a diverse group of 35 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. In its initial five years, this program has transformed the lives of young adults worldwide who are living with inflammatory bowel disease (IBD). This one-year

fellowship program provides crucial support, a platform for advocacy, and a sense of community to young adults facing the unique challenges of IBD.

Our fellows actively contribute by producing monthly content shared across multiple online platforms. This content encompasses a wide range of topics, including personal experiences, surgical journeys, travel with IBD, dietary challenges, emotional struggles, and more. Through these engaging narratives, our fellows connect with fellow patients and raise awareness about the multifaceted aspects of living with IBD. To continue the relationships with our fellows and provide them with advocacy opportunities beyond the conclusion of their fellowship, we have created a database of all our fellowship alumni. This database promotes the young adult patient voice through consulting and collaborative initiatives with other organizations and institutions we work with in the IBD space.

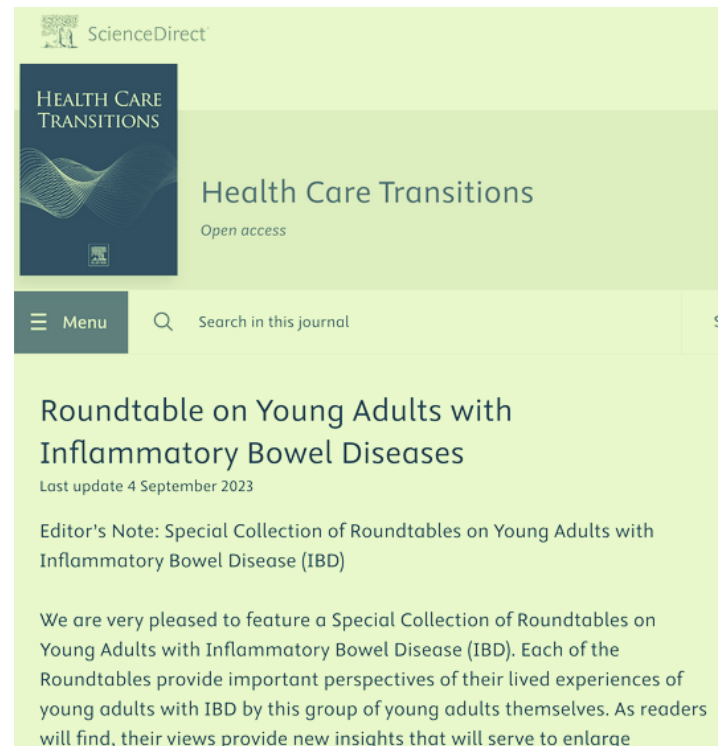
## Roundtable on Young Adults with IBD

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This year, we launched our Roundtable on Young Adults with IBD, a yearlong learning community comprised of monthly discussions between patients and providers to improve outcomes for the young adult IBD-patient population.

We partnered with **Health Care Transitions**, a peer-reviewed journal, to publish the roundtable's findings and insights in a special collection. This collection serves as a vital resource for both IBD patients and their care teams, offering insight into the unique experiences of young adults with IBD and providing guidelines for effective, patient-centered treatment.

This patient-centered approach extends to the publication process, with patients themselves actively involved in collaboration with expert clinicians.



*A screenshot of the special collection in Health Care Transitions where all proceedings for our roundtable sessions have been published.*

### **The Roundtable has conducted nine sessions, each focusing on critical aspects of young adult IBD care and support:**

- Understanding Emerging Adults with IBD
- Higher Education, the Workplace, & Financial Challenges
- What Adult GIs Should Know About Young Adults with IBD
- Peer-Support Interventions
- Clinical Trials & Young Adults With IBD
- Providing Affirming IBD Care to Young Adults in the LGBTQ+ Communities
- Sexual Health, Reproductive Health, and Family Planning for Young Adults with IBD
- Medical Trauma & ACE's
- Men's Health and IBD



## The IBD Medical Student Scholars

Running adjacent to our Roundtable on Young Adults with IBD is our **IBD Medical Student Scholars Program**, a unique program for medical students who are interested in the field of gastroenterology and internal medicine to learn about the global challenges and needs of adolescents and young adults with IBD.

Five prestigious and highly motivated scholars were selected from almost 250 applicants worldwide. These scholars helped our team to develop comprehensive proceedings documents from each of our roundtable discussions over the past year and were empowered as future medical professionals to understand and engage with young adults with IBD as they begin their careers as healthcare providers.

## Advances in Inflammatory Bowel Diseases (AIBD) Conference

In 2020, the CCYAN has established a unique partnership with the Advances in Inflammatory Bowel

Diseases (AIBD) Conference to amplify the voices of patients in clinical spaces, conversations, and research. For the past four years, the CCYAN has been invited to participate in this conference, providing young adult patient perspectives on IBD management and other critical issues, such as the transition of care from pediatric to adult care.



CCYAN booth and materials at the 2024 AIBD Conference.



Two images of our team members Sneha Dave and Erin Ard interviewing healthcare professionals.



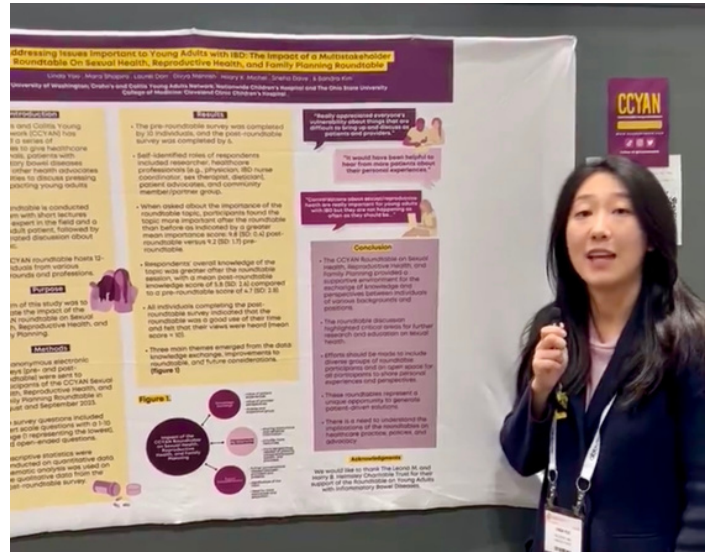
As Dr. Miguel Regueiro, esteemed gastroenterologist and Co-Chair of the AIBD Conference, recognized, “The involvement of these wonderful young adult patients was highly impactful, and we look forward to partnering for years to come.”

Additionally, Advances in Inflammatory Bowel Diseases accepted two conference abstracts written and presented by our team: "Overcoming Patent Barriers in IBD Therapeutics: A Path to Affordable Access" and "Addressing Issues Important to Young Adults with IBD: The Impact of a Multistakeholder Roundtable On Sexual Health, Reproductive Health, and Family Planning Roundtable.” We are proud of our past and current CCYAN fellows for leading the effort and grateful for our partnership with gastroenterologists who equally believe in patient-led research.

## AIG IBD Summit 2023

This year, we were thrilled to partner with the Asian Institute of Gastroenterology to host the first patient advocacy day for patients with inflammatory bowel diseases in India! This was an incredible event, and we were honored that

members of our fellowship alumni living in India had the opportunity to present their patient advocacy experiences as part of this conference.



The poster for our abstract "Addressing Issues Important to Young Adults with IBD: The Impact of a Multistakeholder Roundtable On Sexual Health, Reproductive Health, and Family Planning Roundtable," presented by 2023 fellow Linda Yoo at the 2024 AIBD Conference.



A photo of a few of our team, fellowship alumni, medical student scholars, along with caregivers and medical professionals at the AIG IBD Summit in Hyderabad, India.

## Resources for Young Adult Patients

Another way Generation Patient has continued to provide direct support to our community is by providing resources focused on **advance care planning** and **higher education**.

Advance care planning allows individuals to establish their wishes regarding their medical care and treatment if they cannot do so in the future. Typically, advance planning is geared toward seniors, but we believe it is critical for all ages, particularly our demographic. As adolescents and young adults with chronic conditions, we represent a distinct patient population with unique medical and psychosocial needs. This is why we must understand and discuss what is important to us regarding quality of life and complete the necessary legal documents to ensure our wishes are respected.

Additionally, our team has created several higher education resources that help students living with chronic medical conditions advocate for themselves as they pursue undergraduate, graduate, and professional education.

### A few of our higher education resources include:

- [Accommodations 101](#)
- [Accommodations Letter from Your Doctor – Template](#)
- [Transitioning from Pediatric to Adult Care \(While Transitioning to College\)](#)
- [Ease of Access to Accommodation Information: Assessment and Commentary](#)
- [Campus Engagement: Advocating for Chronic Medical Disabilities within Student Life](#)
- [Considerations for Starting a Disability-Related Student Organization](#)



## Our commitment to health equity:

**Racism is a public health crisis, and as the next generation of patients, we are compelled to continue working toward health equity where all can thrive.**

At Generation Patient, we are committed to adopting a racial plus lens in our work, fully acknowledging the stark disparities in healthcare access and affordability. Statistics reveal that people of color are disproportionately affected, often finding essential medicines financially out of reach. This inequity is not accidental but rooted in systemic bias and discrimination entrenched in various structures. Understanding that achieving health equity is an ongoing journey, we are dedicated to incorporating cultural perspectives in our programs to dismantle these systemic barriers. In our work, we continue to explore how race plus other identities impact access, affordability, and coverage for young adults with chronic conditions.

In 2024, our focus will intensify on identifying and implementing systemic solutions to these deeply ingrained health inequities. We plan to elevate and amplify the narratives of those most affected yet frequently overlooked, ensuring their voices lead the way in shaping equitable healthcare solutions. Our goal is to channel more resources and support towards our peers, fostering a new era of advocacy that is not only inclusive but also actively addresses and rectifies racial injustices.

This endeavor will be driven by an expanded dialogue with our community, engaging in meaningful conversations that pave the way for a future built on the foundations of racial justice. By listening to and learning from those directly impacted, we aim to create a healthcare landscape where equity and accessibility are not aspirations but realities for all.



# Thanks to our supporters!

## We thank the following foundations for their support in making our work possible in 2023:

- Arnold Ventures
- Commonwealth Fund
- Lumina Foundation
- Disability Inclusion Fund
- The Leona M. and Harry B. Helmsley Charitable Trust
- Third Wave Fund
- Responsible Technology
- Youth Power Fund
- Connecting to Cure
- WITH Foundation
- Patient-Centered Outcomes Research Institute (PCORI)

## We would also like to thank our incredible team:

### **Amy Bugwadia**

Higher Education Coordinator

### **Rosa Kelekian**

Peer Support Coordinator

### **Erin Ard**

Program Coordinator for the CCYAN

### **Leah Clark**

Program Coordinator for the CCYAN

### **Natalie Litton**

Health Policy Lab Coordinator

### **Julia Bartow**

Design and Social Media

### **Sneha Dave**

Executive Director

### **Sydney Reed**

Operations and Creative Director

## And the members of our board:

### **Barbara Bierer, MD**

Harvard Medical School

### **Stephen Plank**

Annie E. Casey Foundation

### **Leah Clark**

McAllister & Quinn

### **Kevin Corcoran**

Lumina Foundation

### **Pretima Persad**

American Cancer Society

If you'd like to contribute to our movement, you can **donate here**. Every little bit helps our organization grow.

