



Generation
patient
Annual Report

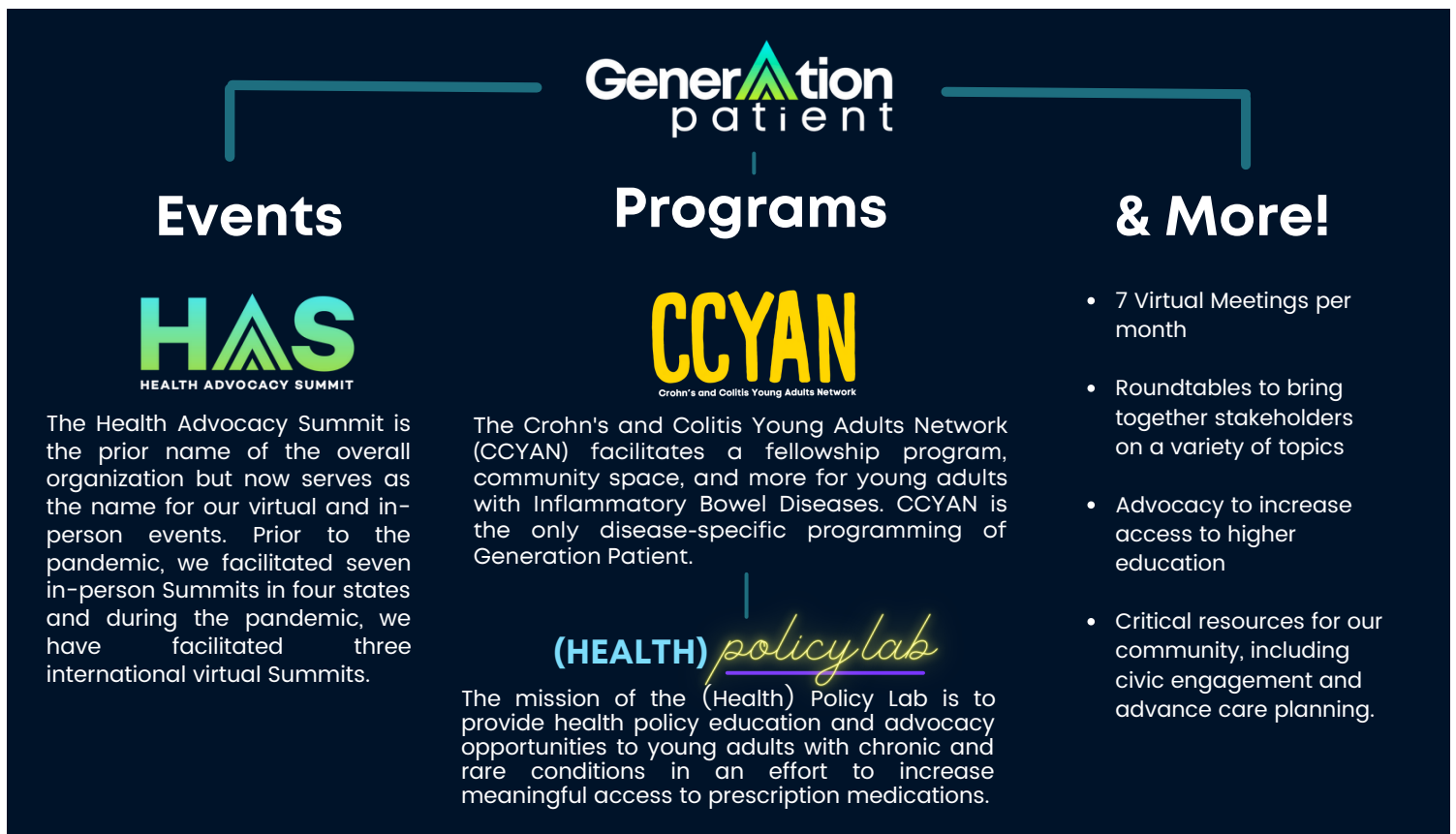
A photograph from one of our 2019 Health Advocacy Summits in San Francisco, CA

2022

Introduction:

In January 2022, we changed our name from the Health Advocacy Summit to Generation Patient. This marked a pivotal point in our growth, as the Health Advocacy Summit was a name created during high school to signify our in-person events in just Indiana at the time. We soon grew to host events in a variety of states, including Texas, North Carolina, and California. But when we were forced to go virtual, it culminated in an opportunity to expand our impact. With that, came a necessary name change to showcase how our impact evolved from events to the extension of programs and meetings.

We hope you can check out the below graphic to see some ways we have organized ourselves after the name change.



Introduction:

We encourage you to read until the end and especially note our supporters. Our supporters allow us to remain independent of funding from the pharmaceutical, insurance, and hospital industries. As an entirely young adult patient-led organization, this has been a crucial part of the integrity of our organization. We are ecstatic to continue this work together throughout 2023 and beyond.

Many of our team members wrote a section, so if you read ahead, you will get to hear their summary of our 2022 programming!

Sincerely,

The Generation Patient Team

Sneha Dave,
Executive Director

Sydney Reed,
Operations Director

Amy Bugwadia,
**Higher Education
Coordinator**

Leah Clark,
CCYAN Program Coordinator

Erin Ard,
CCYAN Program Coordinator

Julia Bartow,
**Social Media
Coordinator**



If you'd like to contribute to our movement, you can [donate here](#). Every little bit helps our organization grow.

Peer Support

Virtual Meetings:

My name is Sydney and I'm the operations director of Generation Patient. I am truly amazed to see how much our community has grown, especially over the last two years, and to witness so many young adult patients join together in support of one another across the globe. Since March of 2020, Generation Patient has held over 350 virtual meetings to connect young adult patients in our community, of which more than 80 meetings were held in 2022 alone. Currently, we offer general meetings for all young adult patients regardless of their individual diagnosis, as well as specialized peer-support meetings for young adult patients in higher education and those living with IBD. Furthermore, we also offer quarterly peer-support meetings for siblings and young adult family members of patients with chronic conditions.

The majority of young adults that attend our community meetings live with complex, rare, or undiagnosed

conditions. During these meetings, attendees have the opportunity to share their stories, often for the first time, as well as exchange tips and coping strategies. They begin to develop the self-advocacy skills and language to describe their experiences which can act as a catalyst to disease acceptance and embracing disability as not only a strength but as an identity. While some of our meetings are topic-focused with discussions centered around themes such as medical disclosure, intersecting identities, navigating relationships, stress management, and even interactive poetry and neurographic art workshops; other meetings consist of more informal conversations and opportunities to connect on a deeper level with people who inherently understand the challenges of chronic illness without explicitly having to discuss it.

Virtual Summit:

This year we held our third annual Virtual Health Advocacy Summit

across three days from September 29th through October 1st. This free, virtual event brought together the global community of adolescents and young adults living with chronic medical conditions. For three years, our Virtual Summit has involved more than 300 attendees and featured incredible speakers such as actress and advocate Selma Blair and former American gymnast Katelyn Ohashi. This year's summit was comprised of sessions focused on important subjects including decolonizing patient advocacy, medical trauma, dysautonomia, neurodivergence, health policy, and more. Each year we recruit established activists, influencers, and medical professionals from the chronic illness/disability community to speak on such topics, while simultaneously providing valuable perspectives and information throughout their sessions. We make an effort to recruit speakers that represent the various identities that make up our demographic, including BIPOC and LGBTQIA+ communities. We would also like to note that live closed captioning and ASL

interpreters were provided for all sessions of our Virtual Summit to make the event as accessible to as many people as possible. Additionally, all of the sessions were recorded, allowing us to share the critical insight garnered from these discussions with an untold number of patients for years to come.



Bio: *Sydney Reed (she/her) is a patient advocate from northern California who has worked as the operations and creative director of Generation Patient since 2018. Her work is driven by her personal experiences living with a rare autoimmune disease since she was a teenager. In addition to her advocacy work, Sydney is also a passionate artist and digital illustrator.*

Higher Education

Roundtable: Chronic Medical Disabilities Higher Education

Greetings! My name is Amy, and as Generation Patient's Higher Education Coordinator, I am excited to share with you the many strides that we made in supporting and advocating for students with chronic medical disabilities this year.

We kicked off 2022 (and the Winter quarter/Spring semester) with our first-ever ***Roundtable on Chronic Medical Disabilities and Higher Education***. Over two days, we brought together folks from varying experiences, including students with chronic medical disabilities as well as University and Disability Services professionals.

As someone who's been navigating life with a chronic illness since 5th grade and through undergraduate, a master's program, and now medical school, I've experienced firsthand the unique learning and socioemotional learning needs that college students with chronic medical disabilities can

have - and this Roundtable was an incredibly important step in understanding current barriers and collaborating on solutions. We pulled together some key discussion points and findings from the Roundtable in a [44-page proceedings document](#). Whether you're a current/former student or a higher education professional, I promise it's worth the read!

Research:

Though our Roundtable was primarily focused on the experiences of students during their higher education journey (whether that's undergraduate or graduate school), we recognize that the process of beginning college isn't without its challenges - which is why we launched our ***SAT & ACT Experiences Survey***. Given the lack of research on the standardized testing experiences of students living with chronic medical conditions, we developed an online survey questionnaire to better understand these folks' experiences when taking the SAT or ACT as they

relate to accessibility, challenges, accommodations, or lack thereof. We appreciate the number of responses we received from our Generation Patient community. We're excited to publish the findings of this survey in the coming year. Subscribe to our newsletter and follow us on social media so you don't miss future surveys!

And speaking of upcoming higher education work: stay tuned for our **Commentary on Accommodations!** In our community, we often talk about registering for accommodations as one important step to creating a support system at school - and university Disability Offices are often the first step for students to access these accommodations. So, we conducted a "secret shopper" study in which we made phone calls to various Disability Offices, in order to understand the accessibility of this process for a prospective student. Our team has written a commentary piece for higher education and student affairs professionals based on our findings which we are currently working to publish.

Stand by for more resources to come in 2023! In the meantime, I encourage you to check out our guides on [the Higher Education portion of our website](#), where we provide information about accommodations, campus engagement, and more.



Amy Bugwadia
Higher Education Coordinator

Bio: Amy Bugwadia (she/her) is a patient-advocate and M.D. Candidate at Stanford University School of Medicine. Her lived experiences with ulcerative colitis and chronic illness has fueled her passion for patient empowerment and increasing representation, access, and support for students with chronic medical disabilities.

Health Policy

Health Policy Lab:

As our executive director, one area in particular that I am very proud of is our team's continued work in health policy. In January of 2022, shortly after our name change, we established our **Health Policy Lab**, a program in which we aim to provide education and advocacy opportunities with regard to health policy and prescription drug pricing. The work of this program is focused primarily on three areas: pharmaceutical direct-to-consumer advertising on social media, clinical trials, and lowering healthcare costs through timely legislation. We have also created numerous educational resources and infographics to educate our community that can be accessed through our [program's website](#).

Forums:

During the last year alone, we held six educational forums, three focused on drug pricing and three dedicated to health economics. You can view the

recorded sessions [here](#). Our drug pricing forums included discussions with author and investigative journalist Gerald Posner, executive director of the Maryland Prescription Drug Affordability Board Andrew York, executive director of the National Academy for State Health Policy Hemi Tewarson, and communications director at Patients for Affordable Drugs Audrey Baker.

Our three-part series on health economics centered on the intersections of health economics and the impact of policy decisions on prescription drug pricing. This series involved conversations with Dr. Hussain Lalani from the Brigham and Women's Hospital of Harvard Medical School, Yvette Venable of the Institute of Clinical and Economic Review (ICER), and Dr. Benjamin N. Rome, a general internist and health policy researcher at Harvard Medical School. We also submitted a variety of comments to the FDA as well as the FTC regarding our concerns with pharmaceutical direct-to-consumer advertising on social media. Furthermore, we submitted

several testimonies on behalf of the prescription drug user fee agreements where we continued to push for clinical trial diversity, especially pertaining to the diversification of age groups. We also engaged in outreach about the importance of the Inflation Reduction Act. We even got to visit the White House twice!



Sneha Dave
Executive Director

In 2023, we are thrilled to continue some of these priorities, while also working for increased patent reform to close loopholes that limit the production of novel medications and greatly reduce the affordability of the prescription drugs we rely on.

Bio: Sneha Dave (she/her) is the executive director at **Generation Patient** where she is proud to work with a team composed entirely of young adult patients. Sneha graduated from Indiana University in May 2020 where she majored in chronic illness advocacy as well as journalism. Besides working at Generation Patient, you can find Sneha on a trail, carving small pieces of wood, or spending time searching for new coffee shops!

Click on the images below to view some of the educational resources regarding health policy

WHO ARE THE MAIN PLAYERS IN DRUG PRICING?

Drug pricing can be a tough topic to understand, but once you know the basics, you will learn as you go! You are not alone if you find yourself having to look up the majority of drug pricing terms in any news article about this topic. Please note – these topics are far more complex than can be explained in a paragraph, but this resource can help you understand the basics of who different players in drug pricing are and what roles they play. We encourage you to refer back to this document to refresh yourself on these terms!

PHARMACEUTICAL BENEFIT MANAGERS (PBMS)

The role of the Pharmaceutical Benefit Managers (PBMs) is to negotiate with the pharmaceutical industry to get discounts on the medications on behalf of insurance companies or employers, and ultimately patients. Some common PBMs that you might recognize include CVS Caremark, Express Scripts, OptumRx, and others. The main role of a PBM is to negotiate with the pharmaceutical company to bring down the cost down of a prescription drug for the insurer. However, some argue that PBMs lack transparency and that it is unclear if the negotiated savings are fully passed on to the patient.



PAYERS

Payers pay providers (like doctors and hospitals) for medical services and pay for medical products their covered patients receive. The terms payers and insurers are often used interchangeably. However, payers may include private insurance companies or public payers like Medicare or Medicaid. Insurers, or payers, are the vehicle through which people pay for their drugs. Insurers develop formularies of covered drugs and determine co-pays for medication. Insurers work with PBMs to determine how much to charge the patient based on the medication and its place on the formulary.



FEDERAL DRUG PRICING

This infographic provides a general overview of the federal drug pricing landscape, but there is so much more that we will address in the future. Note that this infographic is published in January 2022 and we will update the information when possible.



MEDICARE NEGOTIATION

What is Medicare?

Please check out this [link](#) for Medicare basics!

- Part A: Inpatient medical coverage
- Part B: Outpatient medical coverage
- Part C: Medicare Advantage Plans
- Part D: Prescription drug coverage

The Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3) is the bill that passed the U.S. House of Representatives in 2021 and would allow Medicare to negotiate drug prices. Given that Medicare is the largest health care program in our country, lowering prices under Medicare through negotiation would mark a significant victory against pharmaceutical profiteering. **According to Edwin Park at the Commonwealth Fund**, Medicare negotiation is expected to reduce government spending by \$455 billion over 10 years.

WHAT IS AN HTA?

Health technology assessment (HTA) is a holistic, multidisciplinary process that evaluates the social, economic, and ethical impacts of health technologies (Ciani and Jommi, 2014).

Health technologies are considered to be any sort of medical intervention (drugs, vaccines, medical devices, etc.)

HTA bodies perform health technology assessments (HTA). Depending on the specific purpose of the HTA bodies, criteria may vary, but generally, all HTA bodies consider the **clinical effectiveness and cost-effectiveness** of the particular drug, medical device, etc.

COMPARATIVE EFFECTIVENESS:

A term commonly used by HTA agencies to compare the effectiveness of new interventions against those that are already in the market. For example, an HTA agency might compare the effectiveness of two different asthma medications and determine whether the drug is fairly priced or if its price should be lowered depending on a variety of factors such as clinical trial data, benefits to patients and caregivers, and overall benefits to society as a whole.

HOW MUCH POWER DO HTA BODIES HAVE?

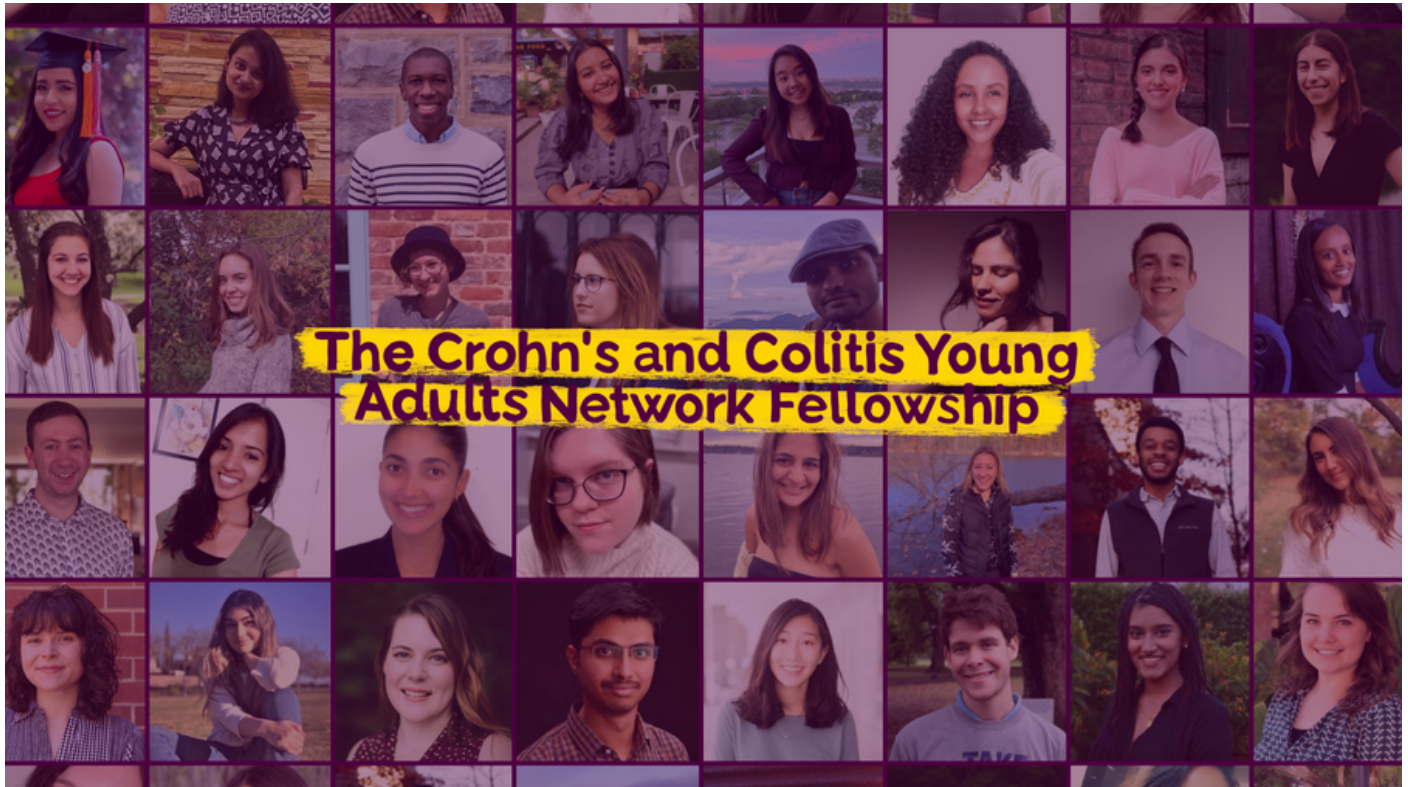
HTA bodies can determine market access for a particular medication in countries that have nationalized health plans. Some HTAs determine whether a medication has enough value to warrant entry to the market based on its evidence and cost.

Crohn's and Colitis Young Adults Network

Fellowship:

My name is Leah and I was a Crohn's and Colitis Young Adults Network (CCYAN) Fellow in 2019 and have since served as an advisor helping to continue the expansion of the program! The CCYAN is a fellowship program and community space for young adults with Inflammatory Bowel Diseases (IBD). In total, the fellowship program has hosted 27 IBD fellows since its start in 2019, including international fellows from countries all over the world such as Canada, the United Kingdom, India, Greece, Dubai, Ethiopia, Malaysia, and across the United States. Our fellows have created an entire archive of content with articles and videos for the IBD community in which they share their plethora of personal knowledge and experiences while also collaborating on group projects, and engaging in community support groups. The program is designed to encourage each fellow through their own unique IBD advocacy journey, with mentorship tailored to their specific goals and ideas for learning.

This year, each fellow was paired with another to work on a year-long project supporting IBD advocacy for young adults. As an example, two of this year's fellows created an IBD International Student Guide aimed at providing resources, comfort food recipes, and more for students studying abroad. Written and visual content created by our fellows included reflections on medical disclosure, the pandemic, social media influence, boundaries and communication, personal surgical and treatment experiences, and so much more. This content was distributed on the **CCYAN website** and social media platforms to increase awareness of IBD. Each fellow worked hard on breaking out of their comfort zones and grew as advocates through their content, such as Dr. Fasika Teferra with her article series, **My Leadership Journey with IBD**, and Natasha Kacharia's personal video diary **To the Girl Staring Back at Me**. We were also proud to note that 2022 Fellow Dr. Teferra was featured in the Guardian for her efforts in building Crohn's and Colitis Ethiopia!



A collage with photographs of all our fellows from 2019 to 2023

IBD Medical Student Scholars:

Our leadership team selected the participants for our IBD Medical Student Scholars Program, starting in 2023. From almost 250 applications from all over the world, five prestigious and highly motivated scholars were selected to participate in this program. This program is a particularly unique opportunity for medical students interested in the field of

gastroenterology and internal medicine because they will get the chance to connect and receive mentorship from faculty, including the CCYAN Medical Advisory Board. These scholars all receive a travel stipend to attend a US-based IBD conference to further their careers in medicine and network with leading experts in the field. We are very eager to implement this program this year in 2023!

Roundtable: Young Adults with IBD

CCYAN is also pleased to announce the creation of the Roundtable on Young Adults with IBD sessions in 2023. The Roundtable is a yearlong learning community of monthly discussions between providers and patients to improve the quality of life for those living with IBD. These monthly sessions are open to the public to allow the greatest access and exposure. Notable discussion topics include medical trauma and behavioral health, understanding emerging adults with IBD, body image and disordered eating, sexual health and family planning, and peer support interventions. Our Medical Student Scholars will also play an integral role in these sessions, and we are very excited for their participation and leadership during these. Through these sessions, we hope to fill the gaps in treatment plans, physically, mentally, and emotionally, for adolescents and young adults with IBD.



Leah Clark
CCYAN Coordinator

Bio: Leah Clark (she/her) is a patient advocate currently based in Washington, DC that has worked with the Crohn's and Colitis Young Adults Network since 2019. Starting in the first class of fellows, she is now a program coordinator for the fellowship program and has managed 25 fellows, including 10 international advocates. As a child, she herself was diagnosed with Crohn's disease and understands how important patient advocacy work is for the community. Along with her work through Generation Patient, she works as a full-time research analyst for a grant and government relations firm in Washington, DC.

Engagements & Supporters:

While we spoke at many events and conferences, as well as have had various publications, we wish to highlight the following!

- [Aspen Ideas Health](#)
- [Journal of Pediatric Nursing Editorial](#)
- [Stat News Op-Ed](#)

We thank the following foundations for their support in making our work possible in 2022:

- Arnold Ventures
- Lumina Foundation
- Disability Inclusion Fund
- Kazanjian Economics Foundation
- The Leona M. and Harry B. Helmsley Charitable Trust
- Barnraisers
- Third Wave Fund
- Connecting to Cure
- WITH Foundation
- Advances in Inflammatory Bowel Diseases

Connect with us on Instagram at [@generationpatient](#) and [@ccyanetwork!](#)

And as always, reach out to us anytime at [virtual@healthadvocacysummit.org!](mailto:virtual@healthadvocacysummit.org)

If you'd like to contribute to our movement, you can [donate here.](#) Every little bit helps our organization grow.

