

Generation
patient

Our Team



Sneha Dave

Executive Director



Sydney Reed

Operations & Creative Director



Julia Bartow

Design & Program Coordinator

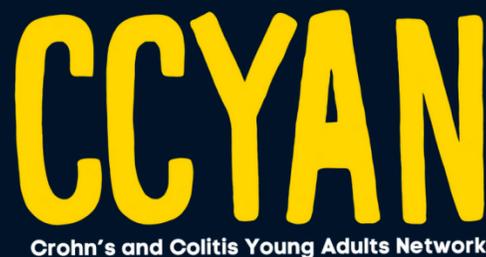


Events



The Health Advocacy Summit is the prior name of the overall organization but now serves as the name for our virtual and in-person events. Prior to the pandemic, we facilitated seven in-person Summits in four states and during the pandemic, we have facilitated three international virtual Summits.

Programs



The Crohn's and Colitis Young Adults Network (CCYAN) facilitates a fellowship program, community space, and more for young adults with Inflammatory Bowel Diseases. CCYAN is the only disease-specific programming of Generation Patient.



The mission of the (Health) Policy Lab is to provide health policy education and advocacy opportunities to young adults with chronic and rare conditions in an effort to increase meaningful access to prescription medications.

& More!

- 7 Virtual Meetings per month
- Roundtables to bring together stakeholders on a variety of topics
- Advocacy to increase access to higher education
- Critical resources for our community, including civic engagement and advance care planning.

Disclosures

We have no disclosure to report.

Our support comes from foundations such as the Helmsley Charitable Trust, Arnold Ventures, the Disability Inclusion Fund, and the Lumina Foundation.

We are independent of **all** industry funding.

Our Virtual Summit Topics

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

SUPPORT MEETINGS



350

The number of virtual support meetings for young adults with chronic conditions.

Our Virtual Meetings

Since March 2020, we have held over 300 virtual meetings to connect young adult patients on a national and international scale. **We currently host at least seven virtual community meetings each month.** Some of these meetings are topic-specific, while others are informal conversations that act as opportunities to connect on a deeper level with others navigating similar experiences.

We currently offer the following virtual support meetings for our community:

- **General Support Meetings for Young Adult Patients**

These virtual meetings are for all young adult patients regardless of their diagnosis. Social engagement and peer support play a crucial role in maintaining hope and resilience, which is why we've created a safe space for young adult patients to come together.

- **Virtual Community Sessions for Young Adults with IBD**

These virtual meetings are hosted through our program, the Crohn's and Colitis Young Adults Network (CCYAN). Each session is based on a specific IBD-related topic as a way for us all to come together virtually and create a safe space to share our emotions, experiences, and ever-evolving IBD journeys.

- **Higher Education Student Support Network**

Our Higher Education Student Support Network is a collective of undergraduate and graduate students who come together virtually to support one another in navigating life with chronic medical disabilities. This support group aims to create a community while also bringing its members real-world tools to navigate life as a college student with a chronic condition.

- **Virtual Meetings for Siblings of Young Adult Patients**

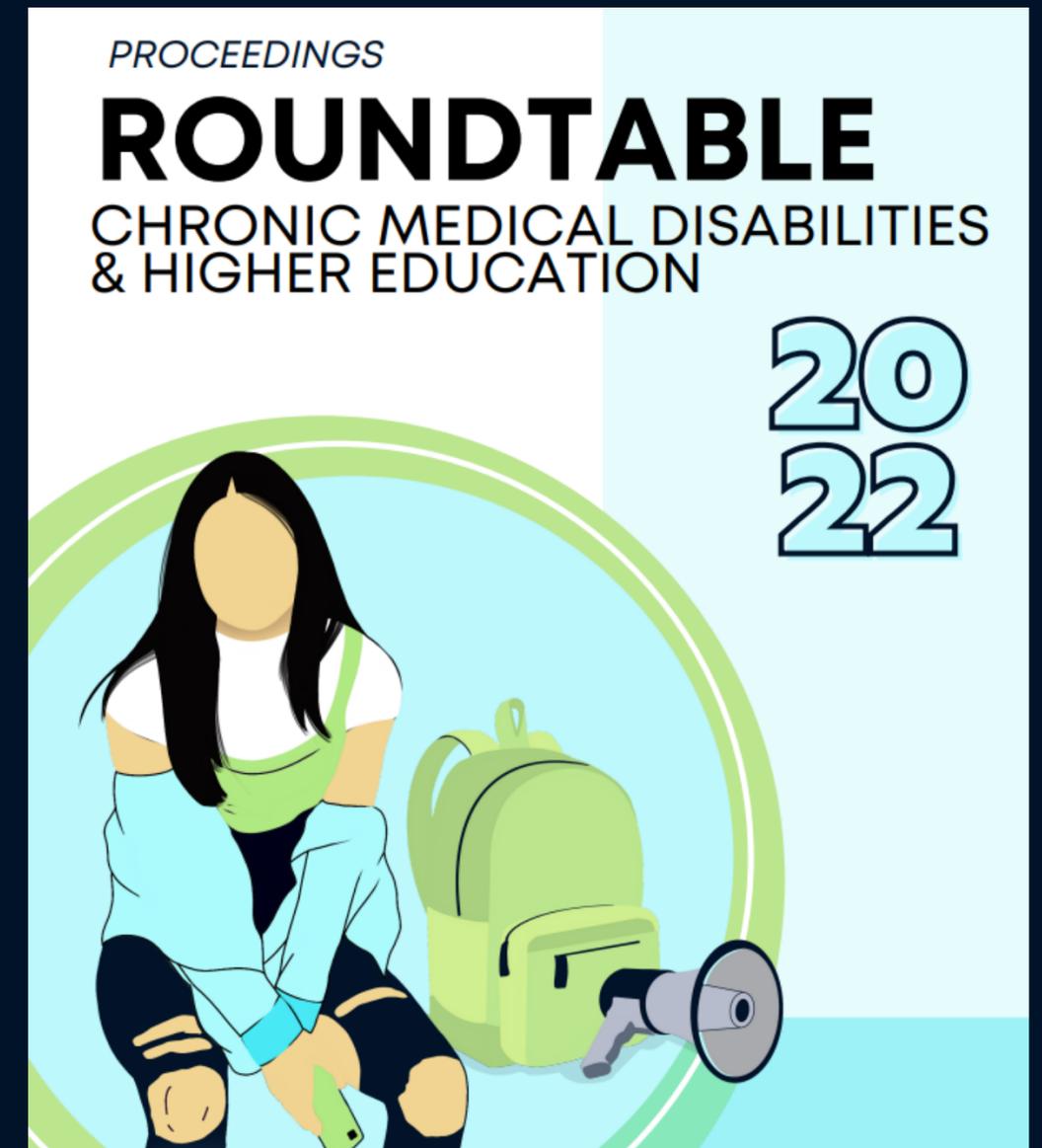
When a family member is diagnosed with a chronic illness, everything in the family changes. There are important issues that can affect a other young family members and it's vital that they have a place where they can speak openly. This support group is open to siblings as well as children of parents affected by chronic illness.

Higher Education

Nineteen percent of undergraduates in 2015–16 reported having a disability.

How many disabilities are underreported, particularly chronic medical disabilities?

Our Roundtable on Chronic Medical Disabilities and Higher Education highlighted the most pressing needs for students who are entering these institutions. We published Proceedings from this Roundtable.



Higher Education

SAT & ACT Experiences Survey for Students with Chronic Medical Conditions

This survey assesses the experiences of students with chronic medical conditions (including chronic illnesses and rare diseases) who have taken the ACT or SAT. This survey was designed by Generation Patient (formerly known as the Health Advocacy Summit). For any questions, please contact Amy Bugwadia, Generation Patient's Higher Education Coordinator at amy@healthadvocacysummit.org.

This questionnaire is focusing on chronic medical conditions (such as chronic illnesses and rare diseases) specifically. For the purposes of this survey, the term "chronic condition" (sometimes referred to as a "chronic medical disability" or "chronic health condition") refers to chronic illnesses and rare diseases, including (but not limited to) Crohn's disease, rheumatoid arthritis, diabetes, POTS, and lupus. You do not have to have a formal diagnosis to complete this survey.

We are aware that other disabilities (such as learning disabilities) can and do affect students' preparation and performance on standardized tests. For the purposes of this survey, we are hoping to specifically capture the impact of your chronic medical condition on your standardized testing experiences. However, we do understand that different disabilities can be difficult to separate and differentiate between.

This survey will take about 10 minutes to complete and will be used by Generation Patient to advocate for increased access and equity in higher education for students with chronic conditions. All personally-identifiable information will be kept private, and survey results will be shared in aggregate form (rather than on an individual level).

Our survey on the SAT and ACT Experiences Survey for Students with Chronic Medical Conditions is directed toward College Board and the ACT, because we know anecdotally, the difficulty in accessing accommodations. We are doing this in conjunction with Dr. Ann Shih at Virginia Commonwealth University.

However, we also know things are not going to change without quantitative evidence.

Health Policy



In 1992, Christine Hayes of the Huntington's Disease Society of America said 'hope is no good if a drug is developed and our folks cannot afford it'.

The (Health) Policy Lab is a program through Generation Patient established in January 2022, to provide health policy education and advocacy opportunities to young adults with chronic conditions.

(HEALTH) policy lab



Health Policy

According to the Georgetown University McCourt School of Public Policy, 53% of people ages 18-34 use prescription drugs.

Moreover, **21% of people ages 18-49 years old say** they have difficulty affording their medication (Kaiser Family Foundation, 2019).

The share is likely to be even higher for younger adults as the highest poverty rate in the United States is between the ages of 18-24 (Statistia, 2022).

Health Policy

Why focus on the pharmaceutical industry?

Advocating for change to insurance policies, or PBM policies -none of that will help with drug affordability at the end of the day if a drug price is still \$20,000 a year, for example. Insurance can lower your copays, but premiums will go up, for example, this high drug price will come out of somewhere.

At the end of the day, if we are talking about affordable drugs, everything starts with the base (list) price of that drug, and it is pharma who controls that.

While *MUCH* more advocacy needs to be done regarding insurance, the ACA has created nationwide standards for insurance affordability, but no similar policy has passed regarding prescription drugs and it is urgent.



Health Policy

Health Policy Forums

Our forums are independent education opportunities for young adult patients to get involved in issues affecting them the most.

- **Basics of Prescription Drug Pricing** (February 2022–March 2022)
 - Gerald Posner
 - Andrew York
 - Hemi Tewarson
 - Audrey Baker
- **PDAB General Informational Meeting** (August 2022)
 - Pranav Pinapala (Generation Patient team)
- **Basics of Health Economics** (upcoming)
 - Dr. Rena Conti
 - Dr. Benjamin Rome
 - Yvette Venable

HOW TO EARN A HEALTH ECONOMICS CERTIFICATE

ATTEND OUR **3 HEALTH ECONOMICS FORUMS**

EARN **3/4 BADGES AT EACH FORUM**

social media BADGE **in the chat BADGE** **forum attendee BADGE** **note taker BADGE**

& TAKE AN ACTIONABLE STEP TOWARD ADVOCACY

WRITE AN **OP-ED**,

WRITE A **LETTER TO THE EDITOR**,

OR WRITE YOUR STORY ON **GENERATION PATIENT'S BLOG**

Monopololization

In our current state, there is an abuse of free markets and a consolidation of the industry. The challenge in the 21st century is the high rate of monopolization of these industries, reducing competition and creating market control.

Between 1995 and 2015, 60 pharmaceutical companies merged into 10.

PATENT AND MARKET HIGHLIGHTS FOR THREE TOP SELLING DRUGS						
DRUG	ANNUAL U.S. SALES (2021, \$ BILLIONS)	% OF CO.'S 2021 U.S. PHARMA REVENUE	YEARS ON MARKET (FIRST FDA APPROVAL DATE)	# PATENT APPLICATIONS	% PATENT APPLICATIONS FILED AFTER FDA APPROVAL	# OF GRANTED PATENTS
HUMIRA	\$17.3	40%	19.7 (12/2002)	312	94%	166
REVLIMID	\$8.7	30%	16.7 (12/2005)	206	74%	117
EYLEA	\$5.8	48%	10.8 (11/2011)	135	65%	92
AVERAGE	\$10.6	39%	15.5	218	78%	125

Pharmaceutical Direct-to-Consumer Advertising on TikTok and Instagram

Social Media Usage in Young Adults

- The largest age group using Instagram is aged 25-34 years, at 31.2%, and 18-24 years at 31%.
 - On TikTok, the largest age demographic of users is 10-19. (1)
- In the U.S. 8 out of 10 internet users seek out health information online, with 74% of those people utilizing social media for their search. (2)
 - Around 66-91% of teens using social media report using this avenue for finding their health information. (3)

Who is the most vulnerable?

Vulnerable populations, including **adolescents** and individuals with **chronic or hard-to-treat conditions** or those with depression, may be particularly impacted by targeted promotional communications on social media platforms.

Impact of social media

- Virality and viewership, especially on TikTok and Instagram reels.
 - 60-second maximum on Instagram reels
 - 10 minutes on TikTok
- Impact Example: Vagisil recently launched OMV!, a “freshener” aimed at teenagers. Docs all over social media have blasted the product as unhealthy and unkind, calling out Vagisil for vulva-shaming. **On TikTok, though, those slams take on more personality, increasing the likelihood of them going viral.** Dr. Staci Tanouye, an OB-GYN with 1.3 million TikTok followers, characterized the OMV! effort as “**a predatory marketing practice targeting minors.**” (1)

Who is a microinfluencer?

- Accounts with around 10,000-50,000 followers, or less.
- Being leveraged as a more “authentic” avenue to appeal to consumers
- Stronger *parasocial relationships* due to smaller following making the micro influencer seem more like a friend or peer. (1)



(1) Bond, Bradley. (2016). Following Your “Friend”: Social Media and the Strength of Adolescents’ Parasocial Relationships with Media Personae. *Cyberpsychology, Behavior, and Social Networking*. 19. 10.1089/cyber.2016.0355.

Parasocial Relationships +

- Parasocial Relationship: “A parasocial relationship is a one-sided relationship that a media user engages in with a media persona.”
(1)
 - *if an individual has a parasocial connection with a media persona, that persona can influence their political views and voting decisions, their purchasing behavior, attitudes about gender stereotypes, and their trust in various groups of people, such as scientists. (2)*

A doctor in a white coat is examining a patient's hand. The doctor is wearing a white lab coat and a stethoscope. The patient's hand is being held by the doctor. The background is a blurred image of a doctor's hands and a patient's hand.

The Urgency

9 out of 10 patients ask their doctor about a product after seeing influencer-shared information. (1)

Our Concerns

- Expensive medications
 - Patients often face financial instability and being advertised an extremely expensive medication without knowing its price can ultimately be harmful. Promoting such an expensive drug and implying it could help anyone and everyone is deceptive when there are large economic disparities in the US.
- Potential lacking of adequate post-market data to determine **safety**
- To our knowledge, there is currently no understanding of how comment sections or direct messages are regulated by sponsored advertisements that are posted on Instagram stories.
- Confusing definitions for public of “overstatement of efficacy, broadening of drug indication, omission of risks”

Example 1: Celebrities



The image shows a woman with long blonde hair, wearing a wide-brimmed straw hat, a white long-sleeved shirt, and a yellow skirt, sitting on the deck of a sailboat. She is looking towards the camera. The background shows the blue sea and the rigging of the sailboat.

nastialiukin • Follow
Paid partnership with **nurtecodt**

nastialiukin Living life how it should be lived with the help of Nurtec® ODT (rimegepant) 75 mg. Go to [@nurtecodt](#) for more info.

Individual results may vary. Nurtec ODT is for the acute treatment of migraine and the preventive treatment of episodic migraine in adults. Prescription only. Don't take if allergic to Nurtec ODT. The most common side effects were nausea, stomach pain, and indigestion. Talk to your doctor about Nurtec ODT. Swipe for Important Safety Information and see [@nurtecodt_pi](#).

[@nurtecodt](#) [#NurtecODT](#)
[#migrainessuck](#)

4,378 likes
SEPTEMBER 17, 2021

Swipe for Important Safety Information

Example 2: Nurtec ODT

The screenshot shows the Instagram profile for 'nurtecodt', which is verified. The profile picture is a purple circle with the text 'Nurtec® ODT (rimegepant) orally disintegrating tablets 75 mg'. The name 'nurtecodt' is followed by a checkmark, and the bio reads 'Nurtec ODT'. There is a red 'Follow' button. Below the bio, it shows '0 Following', '202.1K Followers', and '500.9K Likes'. A bio note says 'Real people. Real Tok about Nurtec ODT. See House Rules on IG. US only.' and there is a link to 'nurtec.com'. The 'Videos' tab is selected, showing four video thumbnails. The first video shows a woman in a green dress with 1.2M views. The second is a 'Hinge' profile reveal featuring a box of Nurtec ODT with 3132 views. The third shows a woman in a black top and patterned skirt with 4823 views. The fourth shows a woman in a white tank top in a kitchen with 6283 views.

nurtecodt ✓
Nurtec ODT

Follow

0 Following 202.1K Followers 500.9K Likes

Real people. Real Tok about Nurtec ODT. See House Rules on IG. US only.

[nurtec.com](https://www.nurtec.com)

Videos Liked

▶ 1.2M
With prior authorization te...

▶ 3132
#Hinge profile reveal. See ...
For the acute treatment of migraine and the prevention of episodic migraine in adults. Prescription only. Individual results may vary.

▶ 4823
Are you a sun-lover like Sa...

▶ 6283
Tell me you take Nurtec® ODT (rimegepant) 75 mg without telling me you take Nurtec ODT
With Nurtec® ODT (rimege...



Health Union (formerly WEGO Health): Micro-influencers

“Why would a company choose to work with regular people when they could be working with celebrities like Kardashian? In the age of social media, it’s all about establishing a *relationship*,” Barrette said.

“It may seem intuitive, but someone with 1,000 dedicated followers has a more personal connection with consumers than someone with hundreds of thousands. *The smaller audience influencers often personally respond to comments and answer questions.* The bonus for pharma companies is outreach to a much more targeted audience.”

Example 4: Microinfluencer

- Lack of regulation of comment sections
- Lack of regulation of direct messaging



use it to treat or prevent migraines, especially when a migraine attack is triggered during that time of the month.

Individual results may vary. @nurtecodt is for acute treatment of migraine and preventive treatment of episodic migraine in adults. Prescription only. Don't take if allergic to Nurtec ODT or its ingredients. Most common side effects were nausea and stomach pain/indigestion. Talk to your doctor about #NurtecODT. Swipe for Important Safety Information and see @nurtecodt_pi.

Edited · 24w

- ilana.dunn** Influenced
24w 1 like Reply Send
- itsgigirobinson** @ilana.dunn you won't regret
24w Reply Send
- seeingotherpeople** Need this!!!
24w 1 like Reply Send
- amy_marietta** YES QUEEN
24w 1 like Reply Send
- itsgigirobinson** @amy_marietta we love this for us
24w 1 like Reply Send
- amy_marietta** @itsgigirobinson LOVE
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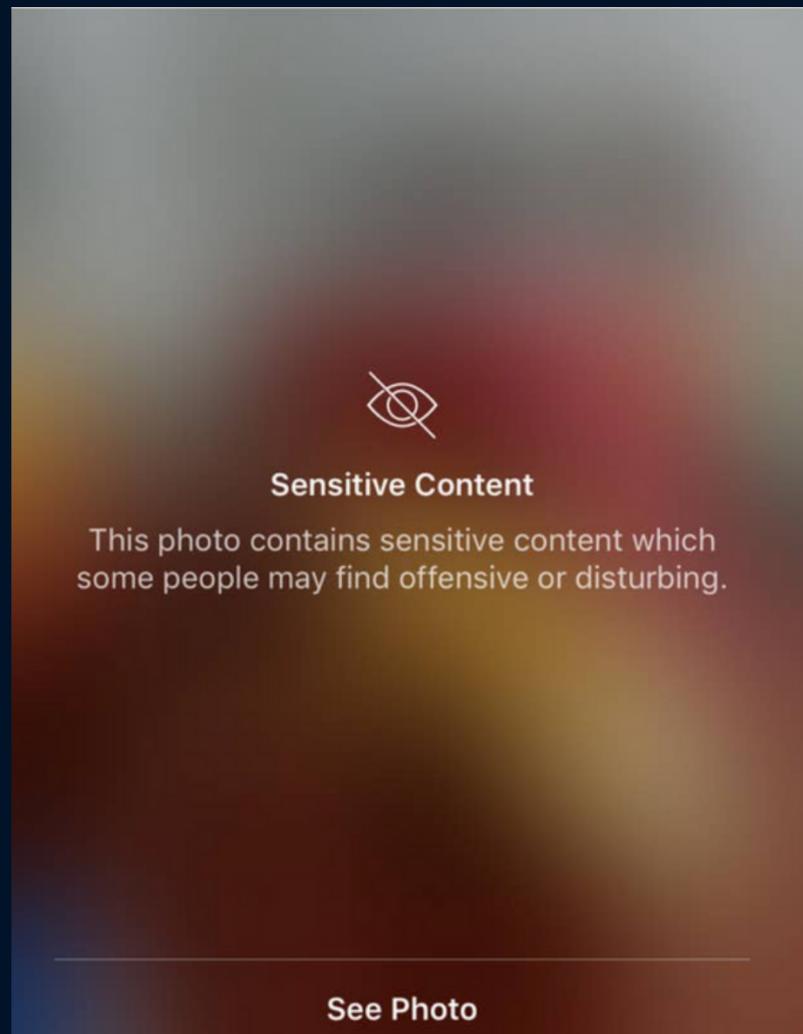
New York Fashion Week x Nurtec ODT

- “Biohaven, the company that manufactures the migraine drug Nurtec[®] ODT (rimegepant) 75 mg, partnered with Horwell to collaborate on the jacket’s design in hopes of speaking to people with migraine from the runway. They also connected Horwell with lifestyle content creator and influencer Amy Marietta— who’s lived with migraine since high school —who modeled the buzzed-about bomber jacket in the Hardware LDN show.”
- Instagram stories versus posts
 - Amy Marietta’s instagram stories all tag NurtecODT but there is no apparent safety information in any of these stories.

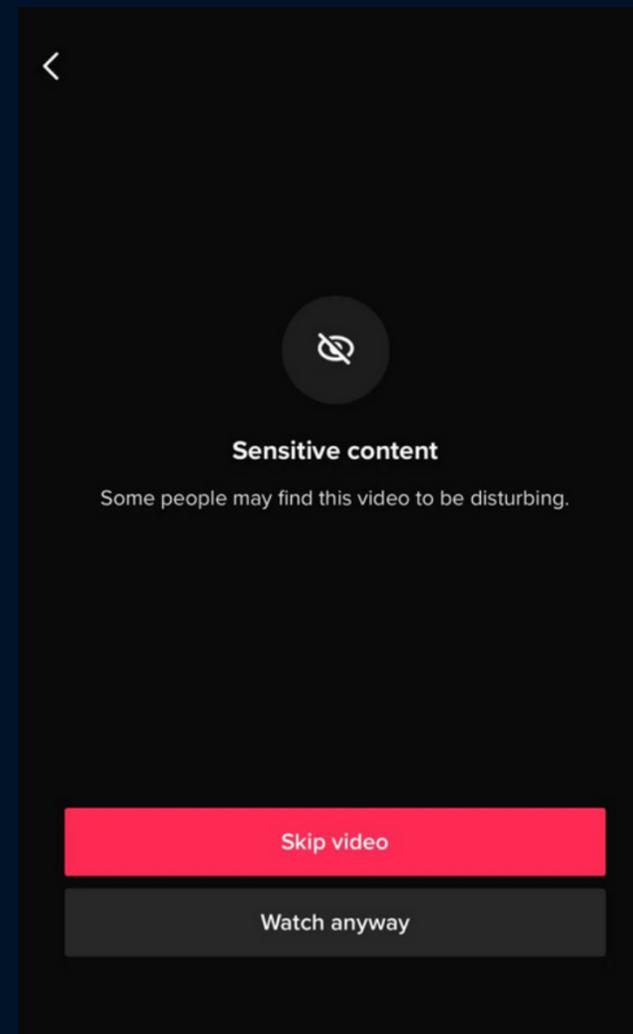


Our Recommendations for Social Media Companies

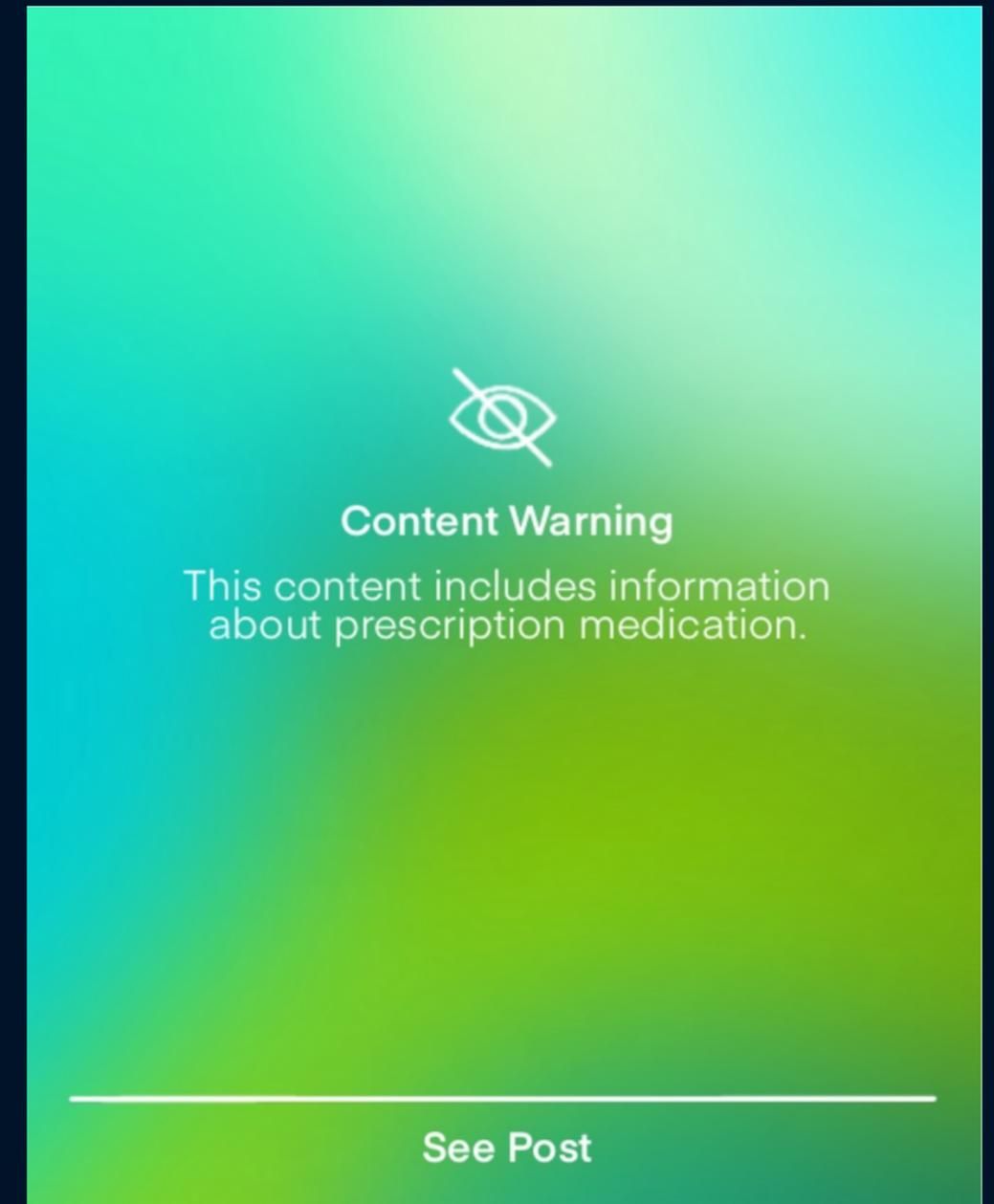
- A form of social media “flagging”
 - similar to the “sensitive content” warnings seen across various social platforms, we recommend a flag stating:
- “this content includes information about prescription medications”



Instagram Warning



TikTok Warning



Mock-up of our suggestion

Our Recommendations for FDA

- Facilitate a public workshop with *independent* stakeholders
- The FDA should work with patients and influencers to issue updated guidance on specifically pharma DTCA within social media. More oversight and research are necessary for social media DTCA.
- “Help-Seeking” or disease awareness advertisements are currently being leveraged by pharmaceutical companies. We ask that there is more clarity on what actually constitutes a “Help-Seeking” Ad, and more transparency on how these ads are regulated/determined to be appropriate or not.
- The Office of Prescription Drug Promotion should extend studies to increase an understanding of the impact of DTCA on TikTok and Instagram.
- For patient groups funded by the pharmaceutical industry, we believe that for transparency’s sake, they should be an explicit requirement that they have received funding from a prescription medication that they are discussing. This funding from the pharmaceutical industry might be in the form of unrestricted grants or sponsorships, regardless, this should be explicitly stated on each social media post that shares about a prescription drug
- Independent advisory board on prescription drug promotion composed of patient/consumer advocates.
- Update the Drug Advertising Glossary to include social media more prominently.

FDA and FTC

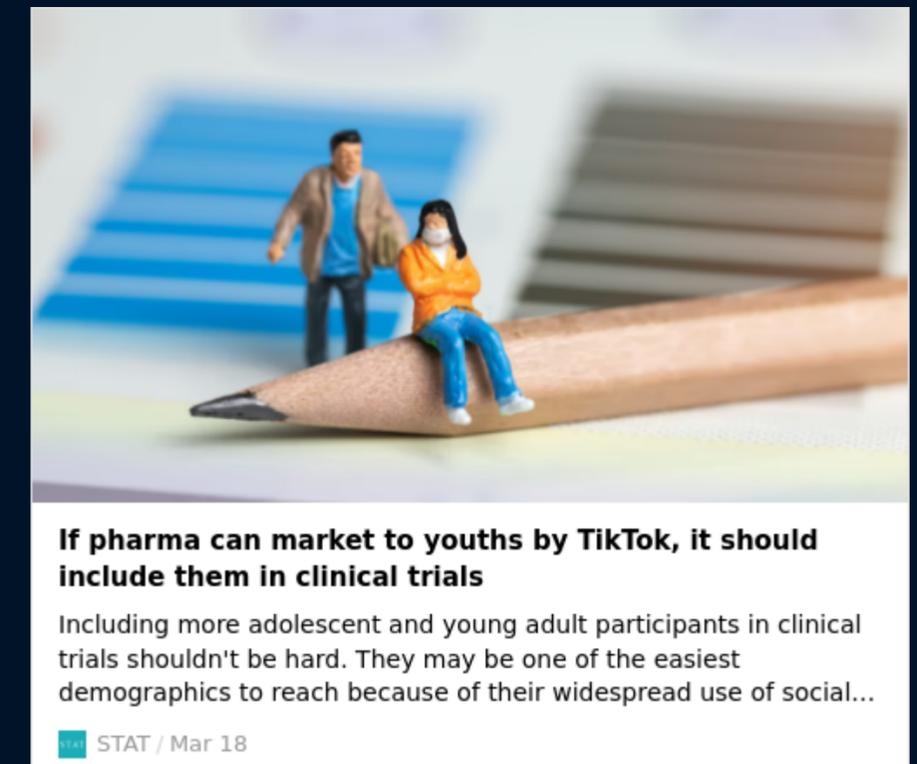
The FDA and FTC should work together to draft an updated memo of understanding that is focused on pharmaceutical advertisements on social media. This memo of understanding between the FTC and FDA was created in 1971, which indicates that it must be updated or a new version should be more publicly apparent.

Similar to the FDA and USPTO collaboration, FTC should increase working with FDA.

Clinical Trials and Adverse Event Reporting

- FDA Adverse Event Reporting System
 - 18 and 64-year-olds are grouped together.
 - What would a more reasonable age stratification look like?

3-11 Years	12-17 Years	18-64 Years	65-85 Years	More than 85 Years
12,541	15,116	387,938	239,150	19,936
22,693	32,177	733,734	459,485	37,138
21,237	40,473	688,228	442,969	38,898
23,413	42,233	703,170	445,420	38,966
23,633	33,855	689,096	473,622	41,736
20,769	23,200	567,051	393,642	36,857
17,921	21,392	570,690	356,013	33,017
17,694	19,946	591,356	350,327	32,553
17,737	14,118	440,178	234,671	23,179



270

The number of articles or videos created by and for young adults with IBD since 2020.

4

Countries represented in our 2022 Fellowship Program.

WHO WE ARE

The CCYAN is a community and international fellowship program for young adults with IBD.

OUR FELLOWSHIP

We facilitate a yearlong fellowship that brings together a select group of young adults with IBD from around the world. Our fellows produce monthly content, convene virtually to hear from influential speakers, engage in speaking opportunities and receive a stipend for their participation.

AND MORE...

- **Virtual community meetings for young adults with IBD**
- **Roundtable on Young Adults with IBD** - a yearlong learning community comprised of monthly discussions between patients and providers
- **IBD Medical Student Scholars** - a unique program for medical students interested in gastroenterology and internal medicine to learn about the global challenges and needs of adolescents and young adults with IBD