



Generation patient

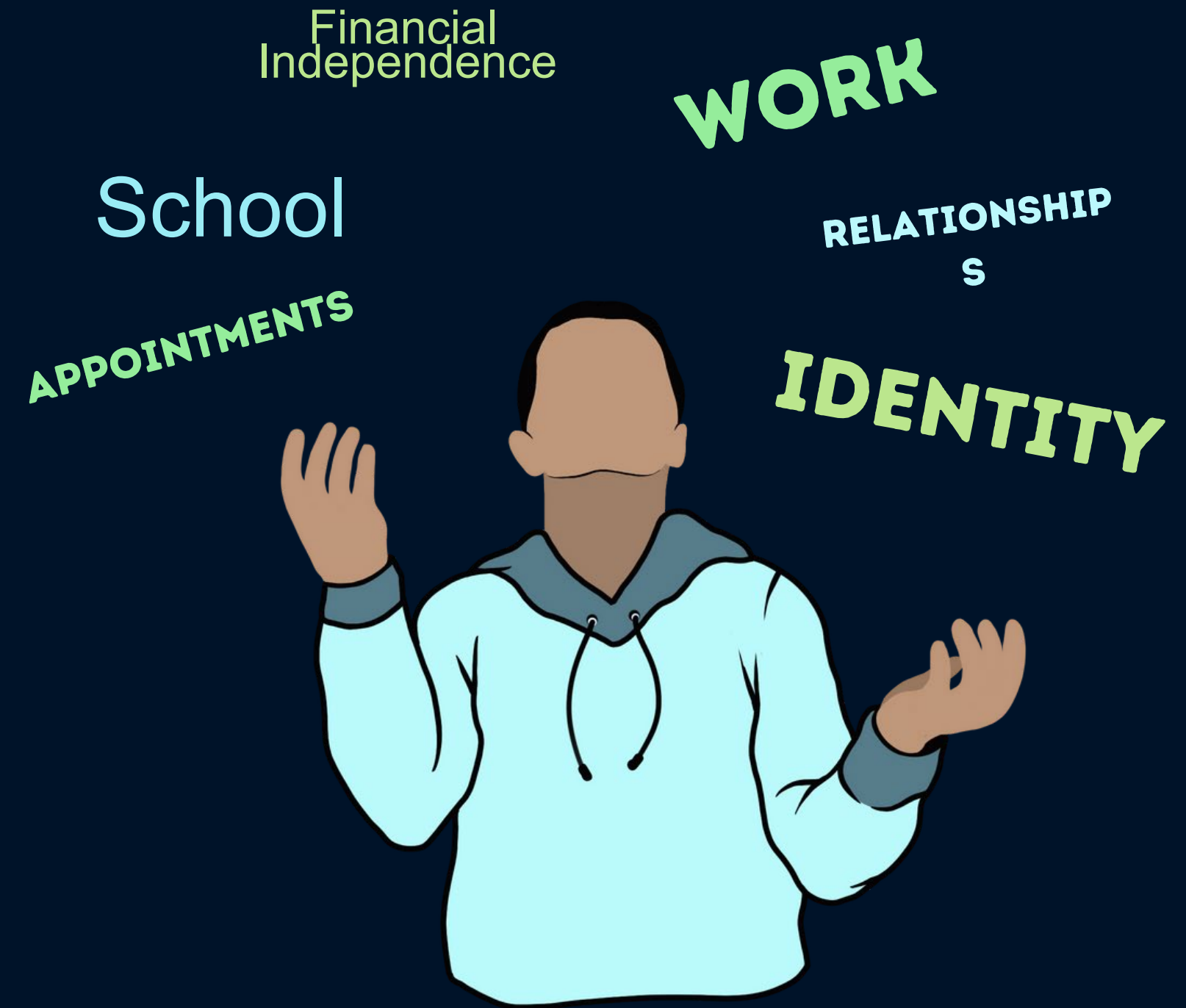
Disclosures

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

We are independent of all private healthcare industry funding.

Social considerations for adolescents and young adults

- The transition and transfer of care from pediatric to adult care
- Unique socioemotional challenges
- Financial instability
- Competing priorities such as higher education, work, family caregiver duties



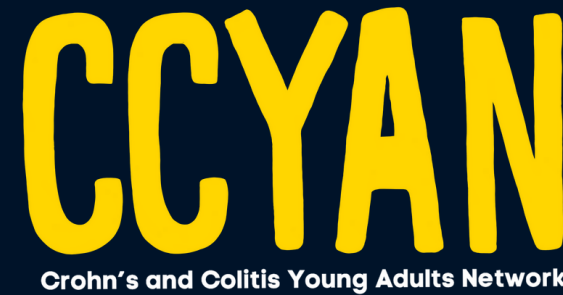


Events



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

& More!

- 6 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.

SUPPORT meetings



450

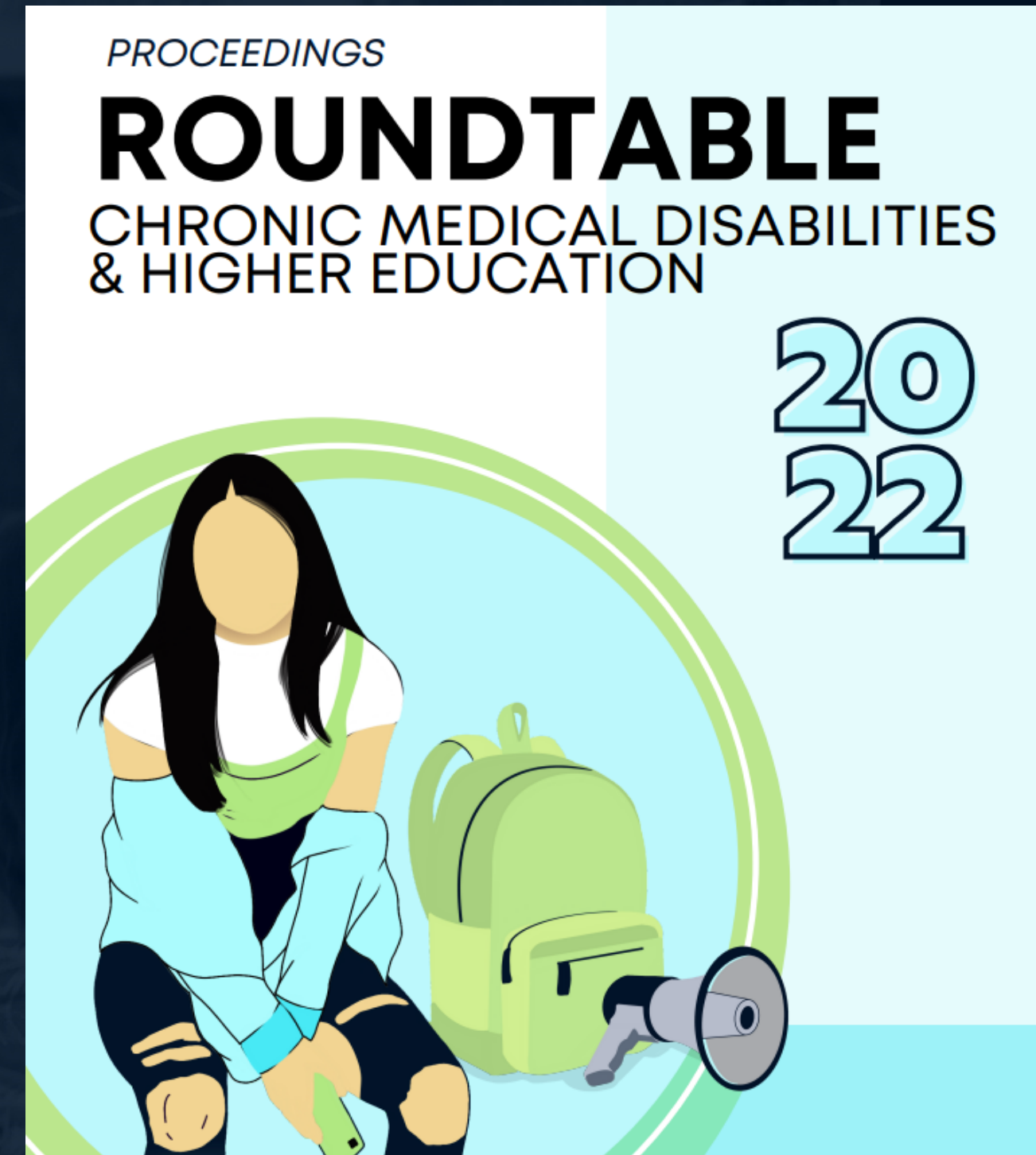
The number of virtual
support meetings for
young adults with chronic
conditions.

Higher Education

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

How many disabilities are underreported, particularly dynamic disabilities, such as IBD?

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.



Crohn's and Colitis Young Adults Network

Who we are

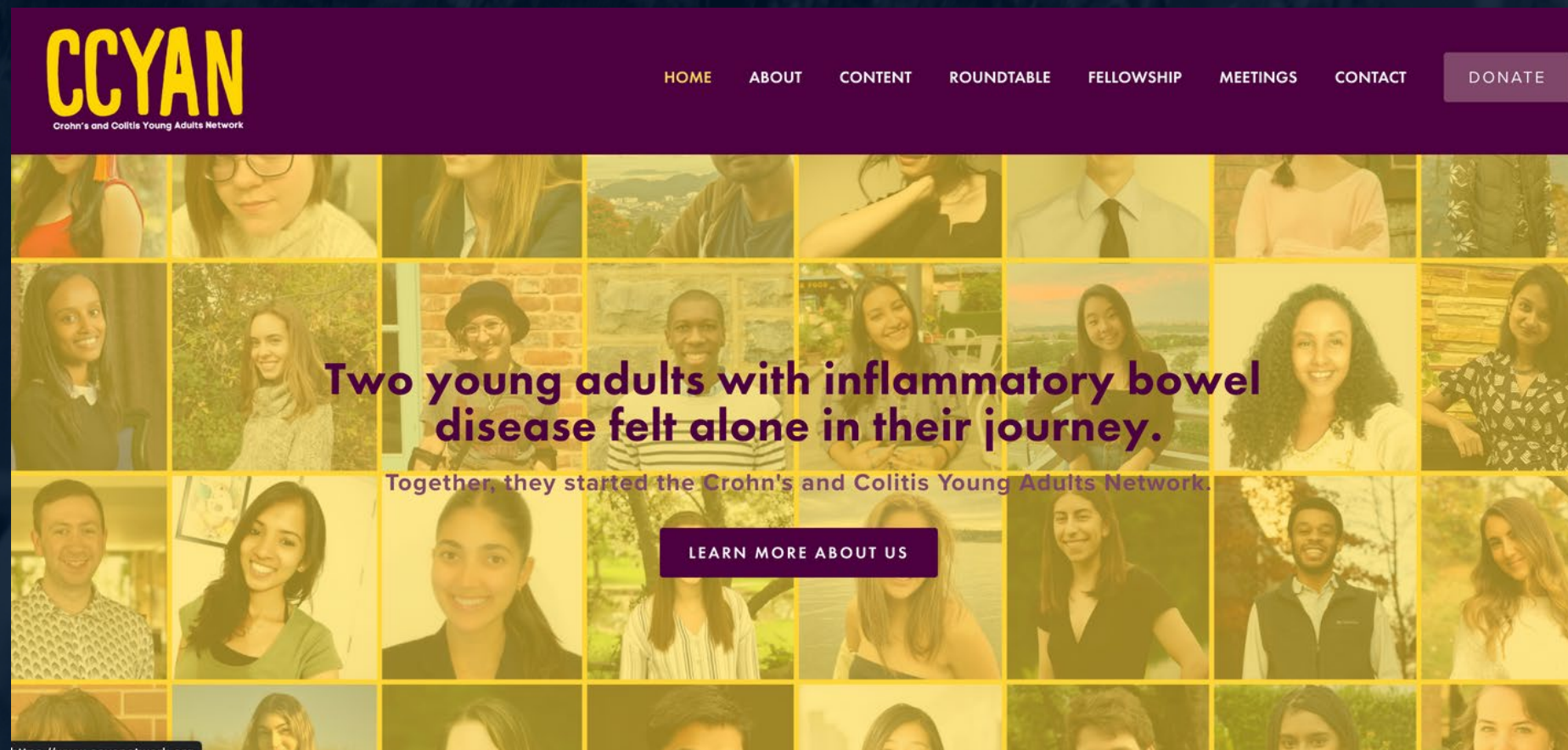
The CCYAN is a community and international fellowship program for young adults with IBD.

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



Health Policy



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

- Pharmaceutical direct-to-consumer advertising on social media
- Adolescents and young adults in clinical trials
- Patent reform
- Health policy scholars program



Defining adolescents and young adults

A lack of consensus among decision-making agencies about age and terminology:

- Food and Drug Administration
 - adolescents are defined as 12-17 years
 - no definition for young adults
 - Pediatrics are defined as children younger than 17.
- World Health Organization
 - adolescents are defined as 10-19
 - "youth" are 15-24 years old
- American Academy of Pediatrics
 - Considers up to 22 as pediatrics

The problem: Clinical care treats young adults similarly to their older counterparts, despite mounting evidence that young adults experience different outcomes. Adolescence and young adulthood has not been well-defined in the medical context and a consensus is lacking.



Vedolizumab for patients under 35 years of age.

Demographics of C13011

Baseline demographic characteristics were generally similar between the treatment groups in the Overall ITT Population. Among all patients, there was a higher proportion of female patients than male patients (57% vs. 43%). Most patients were White and non-Hispanic. The mean age was 37.9 years; most patients were ≥ 35 years of age (54%) and few patients were ≥ 65 years (2%). More placebo-treated patients (51%) than vedolizumab-treated patients (42%) were ≥35 years. The mean body weight was 70.4 kg and the mean body mass index (BMI) was 24.3 kg/m². With respect to geographic distribution, 28% were enrolled at sites in the US and 72% were enrolled at sites outside of the US, including 21% at Central European sites, 19% at Canadian sites, 18% at Western/Northern European sites, 8% at sites located in Asia, Australia, and Africa, and 6% at Eastern European sites.

The demographic characteristics of the TNFα Antagonist Failure ITT Subpopulation were similar to those observed for the Overall ITT Population, except that the difference between the treatment groups in patients < 35 years of age was less pronounced (placebo 46%; vedolizumab 41%). In addition, the TNFα Antagonist Failure ITT Subpopulation had greater proportions of patients enrolled at sites in North America and smaller proportions of patients enrolled at sites in Central Europe than the Overall ITT Population.

Baseline Crohn's Disease Characteristics C13011 Induction

Images from multi-disciplinary review of vedolizumab

Clinical Remission at Week 52 in Crohn's Disease (C13007)			
Clinical Remission	Placebo	Vedolizumab300 mgQ8W	Vedolizumab300 mgQ4W
N	153	154	154
Number (%)	33 (21.6)	60 (39.0)	56 (36.4)
95% CI	(15.1, 28.1)	(31.3, 46.7)	(28.8, 44.0)
Difference from placebo		17.4	14.7
95% CI for difference from placebo		(7.3, 27.5)	(4.6, 24.7)
P value for difference from placebo		0.0007	0.0042

For patients under 35 years of age, there was a trend toward less treatment failure, highlighting the importance of age stratification for better studies of efficacy and safety.

FDA Adverse Event Reporting System vs. CDC Vaccine Adverse Event Reporting System

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
12,737	14,118	440,128	234,621	23,129

Image from the FDA Adverse Event Reporting System

Age
3-5 years
6-17 years
18-29 years
30-39 years
40-49 years
50-59 years
60-64 years

Image from the CDC Vaccine Adverse Event Reporting System

Key points:

- We need consensus on age subgroups beyond the age of 18.
- Co-create solutions with patients on transitions and transfer of care within the medical system and the social systems young patients encounter.
- Focus on changing the system, not the person!
- Consider peer support integral to all aspects of the medical system and beyond.
- Go beyond solely seeking feedback from young adult patients, we can drive the change!

Our Team



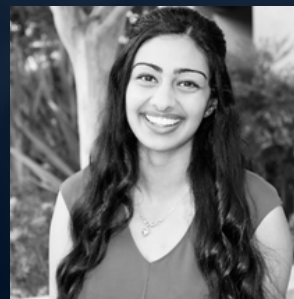
Full-time staff: Sneha Dave, Sydney Reed,
and Cade Johnson.

Part-time staff:

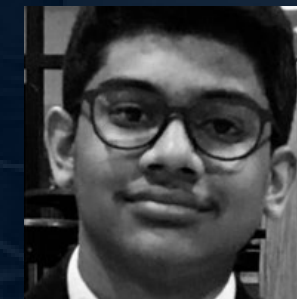


Julia Bartow (Social Media
Coordinator)
College student, Bentley
University

Programmatic staff:



Amy Bugwadia (Higher
Education Coordinator)
Medical Student, Stanford
University



Prana v Pinapala (Health
Policy Lab)
Freshman at the University
of North Carolina at
Chapel Hill



Erin Ard (CCYAN)
Research Dietitian
UW School of Medicine and Public
Health



Leah Clark (CCYAN)
Senior Research Analyst,
McAllister & Quinn

Contact:

✉ sneha@generationpatient.org

🐦 [@genpatient](https://twitter.com/genpatient)

📷 [@generationpatient](https://www.instagram.com/generationpatient)

🌐 generationpatient.org

