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## Editorial

## Promoting self-advocacy for young adults with chronic and rare conditions

We are pleased to publish this editorial authored by two young adult patients, Sneha Dave and Sydney Reed of *Generation Patient*. The messages conveyed in this editorial are timely as evidenced by the growing numbers of individuals with childhood acquired conditions entering adulthood. The importance of what is presented in this editorial cannot be understated as it comes from the most experienced experts themselves—those who have lived and breathed the life of a person with childhood and young adult-acquired chronic conditions. (See Figs. 1 and 2.)

### Editor

By Sneha Dave and Sydney Reed

Adolescent and young adult (AYA) patients are a growing demographic, with over 85% of children with congenital and chronic conditions surviving beyond adolescence (Yeo & Sawyer, 2005). While more of us are entering adulthood with lifelong conditions, current discussions surrounding the transition and transfer of care have not been appropriately holistic. Critical aspects that mark this transitional period in our lives are routinely overlooked and many systems have not evolved to provide the necessary accommodations this demographic needs to thrive. In order for equal opportunities and success in adulthood, various institutions must proactively address the increasing number of young people with chronic conditions who are coming of age and in dire need of tools, resources, and most of all, support.

Generation Patient, formerly known as the Health Advocacy Summit, is a nonprofit organization - created and led entirely by young adult patients - focused on empowering adolescents and young adults with chronic and rare conditions (chronic medical disabilities). Our organization facilitates events and programs that concentrate on the unique needs of this age group while simultaneously providing resources, connection, and community. We are utilizing our lived experiences as AYA patients to strategically address the most concerning obstacles that pose a threat to our quality of life and hinder us from reaching our full potential. As our name reflects, we are an entire generation of patients, who will likely continue to live the rest of our lives as such. For this reason, we believe it is important that society, and healthcare professionals in particular, expand their understanding of what it is to be a patient, not solely within the confines of the healthcare system, but throughout all the systems we encounter as we transition into adulthood and beyond.

### Our events and evolution

Peer relationships are crucial components to disease acceptance as well as establishing and maintaining a sense of self. Limitations that

Abbreviations: AYA, adolescents and young adults.

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result from serious chronic conditions can impede psychosocial development during young adulthood by inhibiting a person's ability to interact and engage with their peers. Since its inception, our organization has focused on creating peer support spaces that give young adult patients the opportunity to connect and build critical interpersonal relationships.

While the Health Advocacy Summit was originally the name of our organization, it now functions as the name for both our in-person and virtual events. Our first Summit in Indiana was created out of this need for peer support as well as a desire to connect with others navigating similar societal challenges, *even with different diagnoses*. Within one year we were facilitating additional Summits in South Texas and North Carolina. As we continued to grow in recognition during the year that followed, we expanded to San Francisco, after which we had plans to facilitate events across six different states in 2020. Although the initial pandemic did result in the cancelation of these in-person events, it also led to our decision to host our first International Virtual Health Advocacy Summit in the fall of 2020, which brought together over 300 young adults with chronic and rare conditions from around the world. In 2021, we held our second International Virtual Health Advocacy Summit and have opted to make this an annual event as it allows for the global community of young adult patients to come together and grants access to those unable to travel.

Our Summits are typically composed of sessions dedicated to the issues that impact our demographic most. Examples include mental health, vocational rehabilitation, intersecting identities, health policy, navigating the healthcare system, higher education, and more. While our Virtual Summit primarily caters to an international audience, the topics of our in-person Summits have primarily been region-specific to meet the needs and information gaps of young adult patients in differing locations. Speakers participating in our Summits are often young adult patients themselves, along with healthcare professionals, psychiatrists, social workers, and established activists who provide grounded information as well.

As our organization shifted its focus from solely in-person events and our reach grew on an international scale, it has become clear that continuous yearlong support and additional advocacy avenues were needed to bring about systemic change. In response, our organization has incorporated a variety of virtual meetings each month to support our community; Meanwhile also expanding our online programming to foster greater understanding and accessibility within society for those living with chronic conditions.

### Virtual community meetings

Peer support is an incredibly empowering, yet undervalued intervention for AYA patients. Over the course of two years, Generation

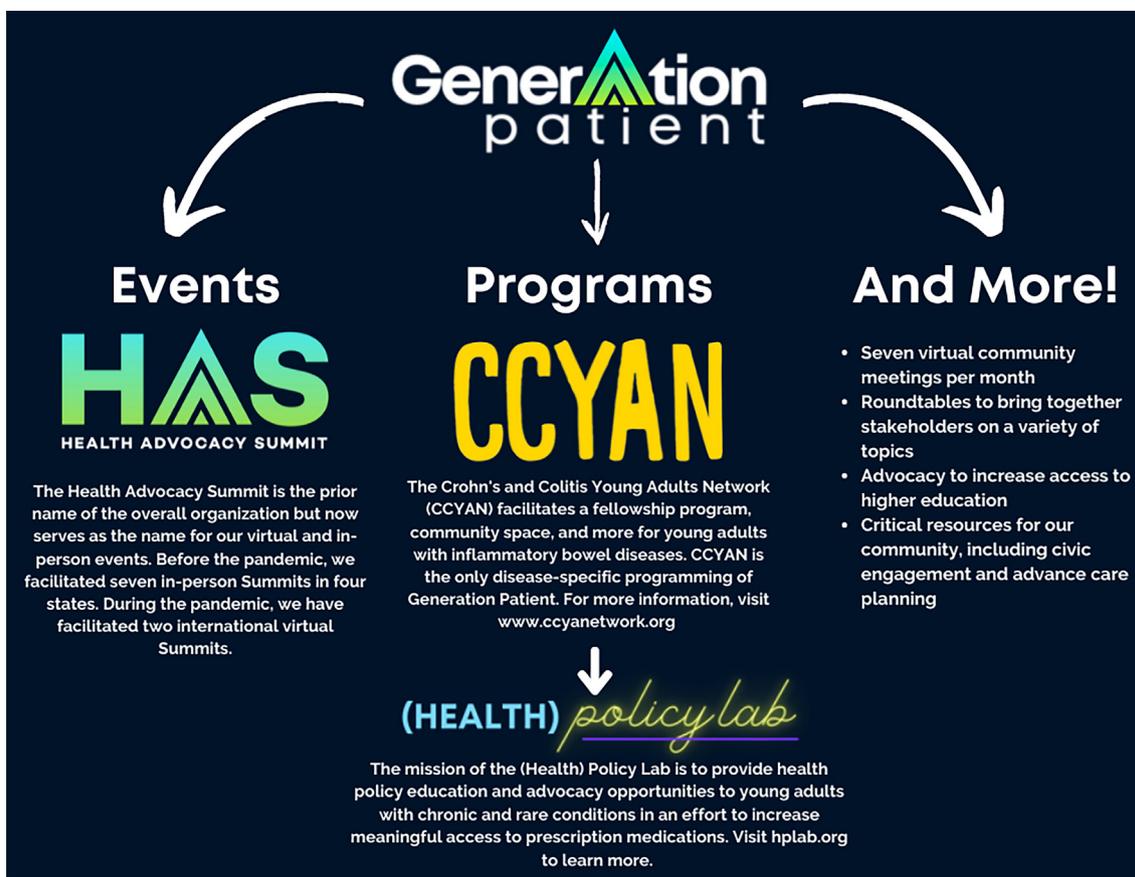


Fig. 1. Graphic of Generation Patient's Organizational Structure.

Patient has held over 250 virtual meetings to connect young adult patients in our community. What we have always known but what has been re-emphasized is that peer support should never be an afterthought, rather it must be a core part of our healthcare care as we transition into adulthood.

The majority of young adults that attend our community meetings live with complex, rare, or undiagnosed conditions. Across many disease groups, younger age at diagnosis often correlates with increased disease severity (Ashton et al., 2017; Webb et al., 2011). These cases are often compounded by the development of overlapping and

2021	2020
<ul style="list-style-type: none"> <li>• Global Health Policy: Pharmaceutical Patents</li> <li>• Advocating for Your Future: Higher Education and the workplace</li> <li>• Adaptive Ballet Class</li> <li>• Digital Activism: Grassroots Patient Advocacy</li> <li>• Exploring Intersecting Identities</li> <li>• Financial Resources</li> <li>• Emotional Wellbeing</li> <li>• International Perspectives: Malaysia, Uganda, and India</li> <li>• Exploring Art Therapy: An Interactive Session</li> <li>• Media Representation of Chronic Illness</li> <li>• Confidence, Body Image, and Chronic Illness</li> </ul>	<ul style="list-style-type: none"> <li>• Global Health Policy: Drug Pricing</li> <li>• ADA and Accommodations in Healthcare: Self-advocacy tips for transitioning from pediatric to adult primary care</li> <li>• International Perspectives: Chronic Illness Advocacy in India</li> <li>• Mental Health: Coping With the Emotional Dimensions of Chronic Illness</li> <li>• Navigating Insurance in the U.S.</li> <li>• Intersecting Identities and Minority Health</li> <li>• Mindfulness and Movement Exercise</li> <li>• Navigating Higher Education</li> <li>• Telling Your Story: Communicating With Peers, Loved Ones, Medical Professionals and More</li> <li>• Chronic Illness and Entrepreneurship</li> </ul>

Fig. 2. Table of topics from Generation Patient's Virtual Health Advocacy Summits in 2020 and 2021.

secondary conditions, as well as therapeutic complications. Furthermore, it can take immeasurable amounts of time and energy to get such complications properly diagnosed and treated, if at all. AYA patients face a barrage of distinct socioemotional challenges as a result, the most apparent of which is social isolation, which is what makes the peer support provided through our meetings so valuable.

During our 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 and culture as well. We continue to facilitate a number of virtual community meetings per month which all emphasize connection. Some of our meetings are topic-focused with discussions centered around themes such as medical disclosure, nutrition and diet, and anti-racism, while other meetings consist of more informal discussions that act as an opportunity to connect on a deeper level with people who inherently understand the challenges of chronic illness without explicitly having to discuss it.

### Higher education and chronic medical disabilities

Adolescents and young adults living with chronic medical disabilities are at a critical and potentially arduous point in their lives. Financial independence looms and their future autonomy, security, and quality of life hang in the balance. Higher education is often an opportunity for competitive integrated employment, but while young people with chronic conditions have equal numbers of high school graduation rates compared to their healthy peers, they are only half as likely to graduate from college (Maslow et al., 2011).

Students with chronic medical disabilities face unique challenges that create barriers to the higher education opportunities they desperately need. Such barriers include but are not limited to having an invisible or nonapparent condition, the unpredictability and fluctuating severity of many chronic medical conditions (dynamic disabilities), and an inherent lack of education and understanding of chronic medical disabilities by university staff and administrators.

There is a substantial lack of awareness, research, and resources at the intersection of higher education and chronic medical conditions that must be addressed which is why we facilitated our Roundtable on Higher Education and Chronic Medical Disabilities as an initial effort to help bridge this gap. This Roundtable brought together both students and higher education professionals to recognize the unique learning and socioemotional needs of college students with chronic medical disabilities, as well as identify the current barriers within the higher education system. Topics discussed include the current gaps in research and resources, existing structures and opportunities for change, accessibility and inclusion within student life, and promoting a campus culture that embraces students with chronic medical disabilities.

### Health policy lab

The future can be a fearful concept for young adults facing a lifetime of illness, the impact of which has not received adequate attention. The financial burden of a chronic illness alone can be massive. Twenty-three percent of chronically ill patients interviewed by the Harvard T. Chan School of Medicine reported being unable to pay for basic necessities like food and housing (Being Seriously Ill in America Today, 2018). Through our own experiences and those of our community members, it is clear that oftentimes the greatest barrier to realizing our full potential and thriving into adulthood is inevitably financial.

Many of us are on numerous prescription medications, some of which have exorbitant costs. The Health Policy Lab is a program under Generation Patient in which we aim to provide education and advocacy

opportunities with regard to health policy and prescription drug pricing. Issues of health policy and health economics are complex and can greatly affect the lives of young adult patients. Yet, as patients, it is urgent that we have a foundational understanding of these systems and that our perspectives are heard as policy decisions in can impact our lives for decades to come. Currently, our work through the Health Policy Lab focuses on several areas such as promoting greater inclusion of AYA patients within clinical trials, policies related to the Food and Drug Administration, and addressing the pharmaceutical industry's direct-to-consumer advertising on social media.

It should also be noted that due to the combined impact of high-cost medications and the devastating expense of lifelong medical care, Generation Patient has decided to protect both our organization's independence and the integrity of our work by declining all funding from the medical-industrial complex, including pharmaceutical and insurance companies until there is greater widespread affordability and access to lifesaving medications and treatment. This position makes us one of the very few independent patient advocacy groups.

### The Crohn's and colitis young adults network

The Crohn's and Colitis Young Adults Network is the only disease-specific programming at Generation Patient, focused on young adults with Inflammatory Bowel Diseases. The CCYAN originally began as a newsletter created by Sneha Dave and her late friend Cory Lane, both of whom were living with extremely severe conditions, as a way to connect with other teenagers. Over time, the CCYAN transformed into an international platform and fellowship program for young adults with IBD. The fellowship program is aimed at providing opportunities to a select group of young adult IBD patients, many of whom have gone on to create advocacy movements of their own. Fellows come from all over the world, including Ethiopia, Dubai, India, Greece, Malaysia, Canada, and the U.S. Our fellows produce monthly website content for our community, receive a stipend for their participation, and are also given the opportunity to engage with monthly speakers as well as attend a U.S.-based IBD conference.

### Final thoughts

As the number of young adults with chronic and rare conditions continues to grow, there must be more attention and research specifically focused on young adult patients. As an organization, we look forward to partnering with healthcare professionals so that research is done with, and not on our demographic. It is through dedicated research, by both patients and the healthcare community together, that we can foster greater understanding and dismantle current societal barriers faced by AYA patients.

Additionally, we want to encourage healthcare professionals to recognize the transformational effects of peer support on disease acceptance and management, and to incorporate peer support measures as an essential part of treatment plans for young adult patients. As of 2022, Generation Patient offers at least seven virtual meetings per month focused on providing peer support and we will continue these meetings an integral part of our organization. These are safe spaces that anyone from around the world is welcome to join and connect with others who have an inherent understanding of their experience.

Finally, concerning issue-specific advocacy in areas such as drug pricing and higher education, we would like to highlight the pivotal role that healthcare professionals can play in advocating alongside us. The support from healthcare professionals is valued and respected not only by patients but by society which puts healthcare professionals in a unique position to aid in the creation of systems that promote accessibility and improve the future quality of life for young patients everywhere.

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