



HAS

HEALTH ADVOCACY SUMMIT

*EMPOWERING THE NEXT GENERATION OF PATIENTS
LIVING WITH CHRONIC AND RARE ILLNESSES*

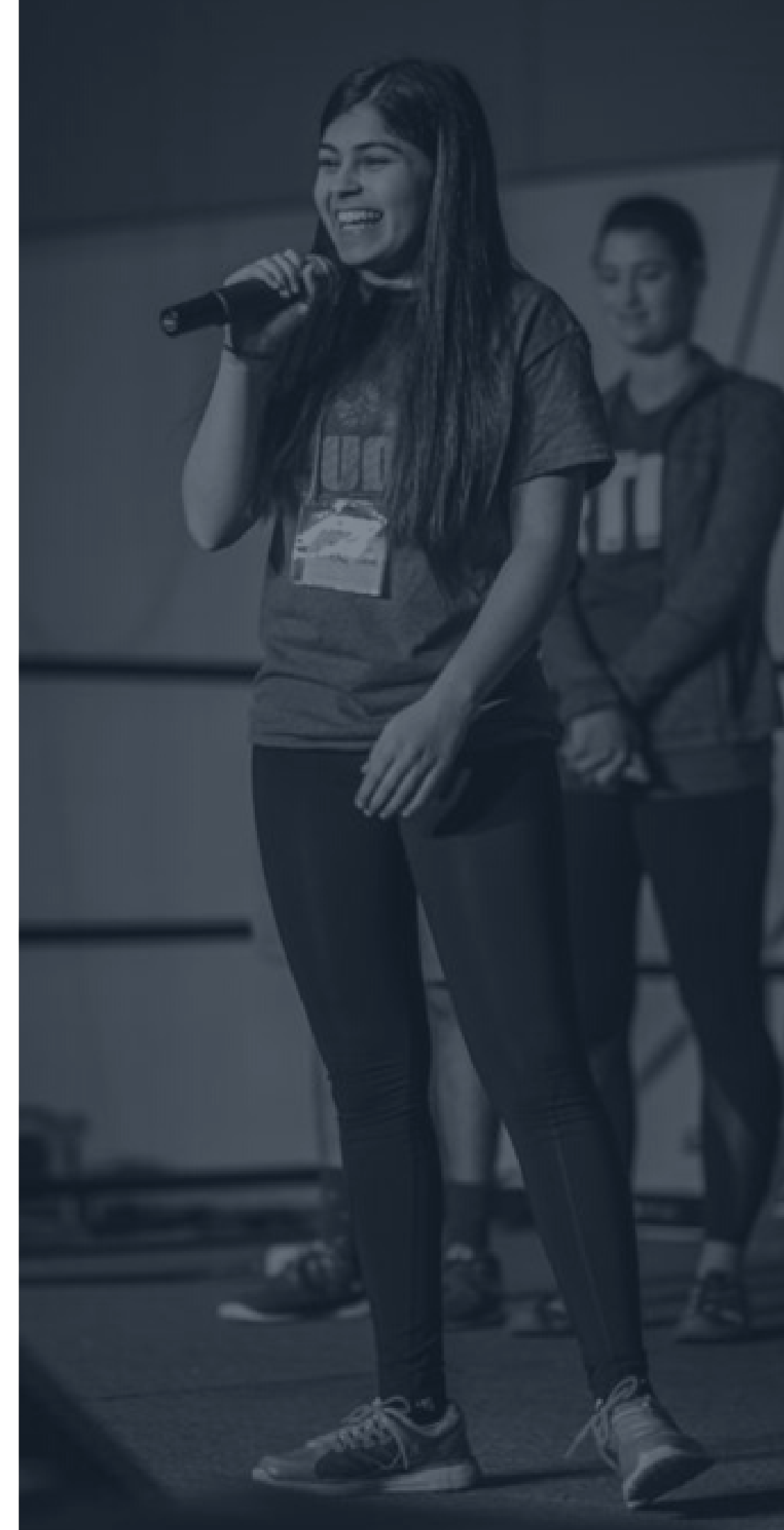
BACKGROUND

Young people with chronic conditions face an unprecedented period of instability which comes with many changes:

- They gain autonomy when managing their illness
- Undergo somatic and mental upheavals
- They leave pediatric care to move to adult care

Breaks in medical follow-up, non-adherence to treatment, and unhappiness are more frequent during this period.

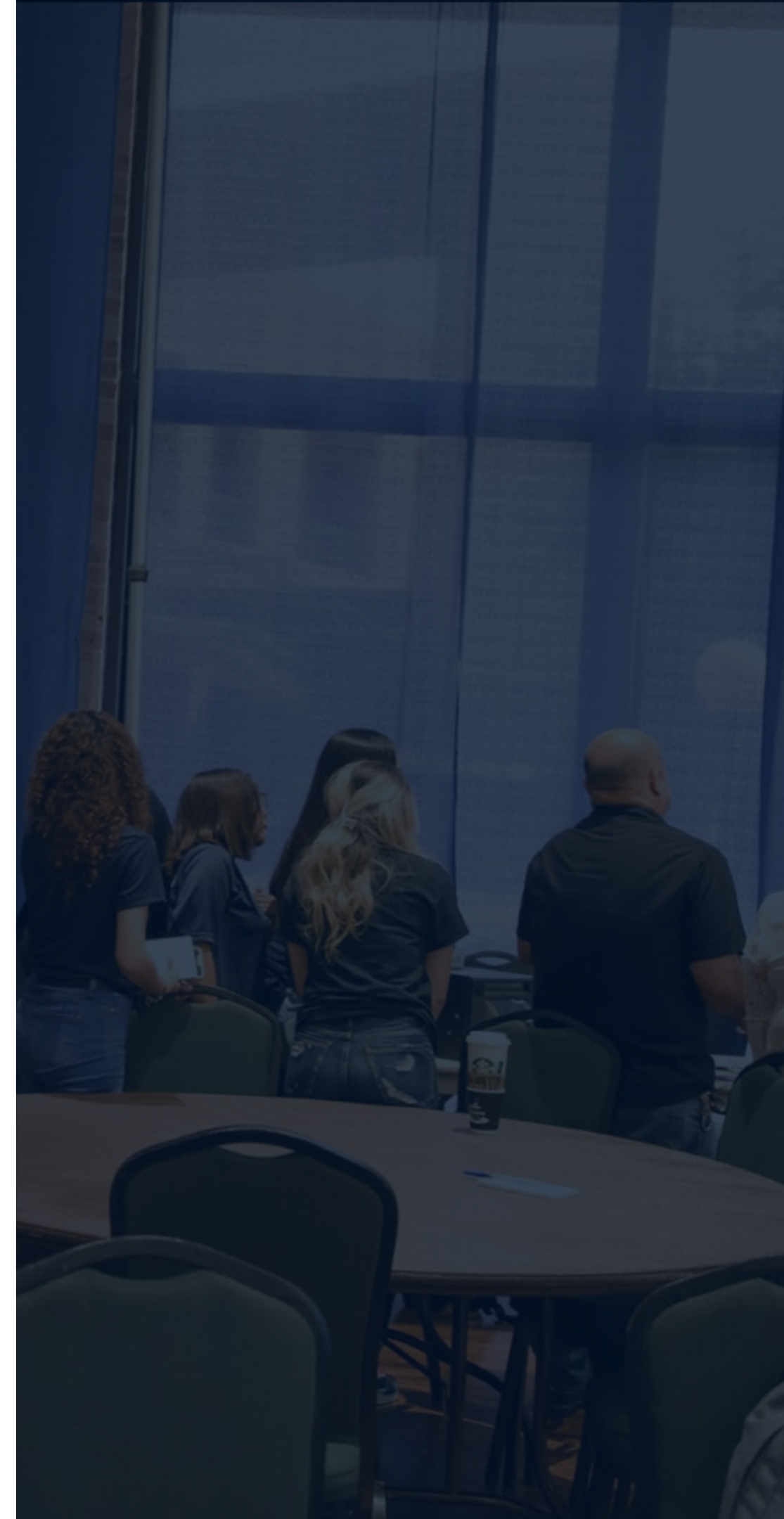
Young people find support in peers who have lived through similar experiences and who can share self-care strategies or tips on adapting, all of which are perceived as useful and effective.



TRANSITION

Transition is a period of global change:

- pubertal
- psychological
- social
- academic/professional
- health care services





VALUES

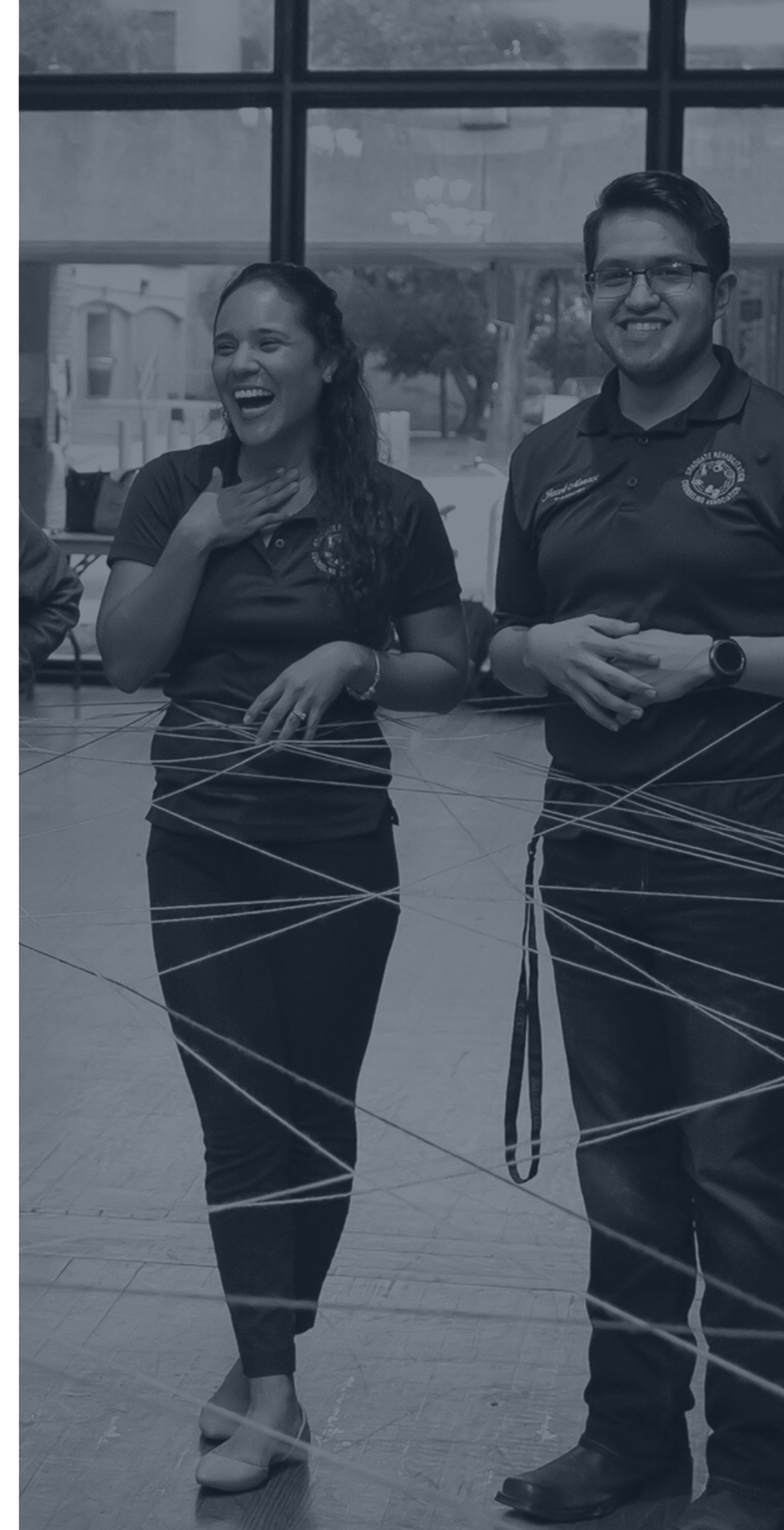
Our organization focuses on **peer connection, advocacy, and access to educational information and resources** as fundamental pathways to empowerment.

WE ARE LED ENTIRELY BY YOUNG ADULTS WITH CHRONIC AND RARE DISEASES

A 2017 study from the University of Lübeck assessed the experiences and needs of adolescents with chronic conditions and identified the unmet needs of patients transitioning from pediatric to adult care.

This study found that adolescents with chronic conditions "often lack **peer support** and **benefit from sharing experience and everyday strategies with others with similar health issues.**"

The HAS was founded on this need to come together and connect and we believe that fostering peer connection is fundamental to improving the quality of life for young adult patients.



OUR LOCATIONS

*Boston, Massachusetts

*New York City, New York

*Chicago, Illinois

*South Florida

Indianapolis, Indiana

San Francisco, California

McAllen, Texas

ENDS 15.03.19

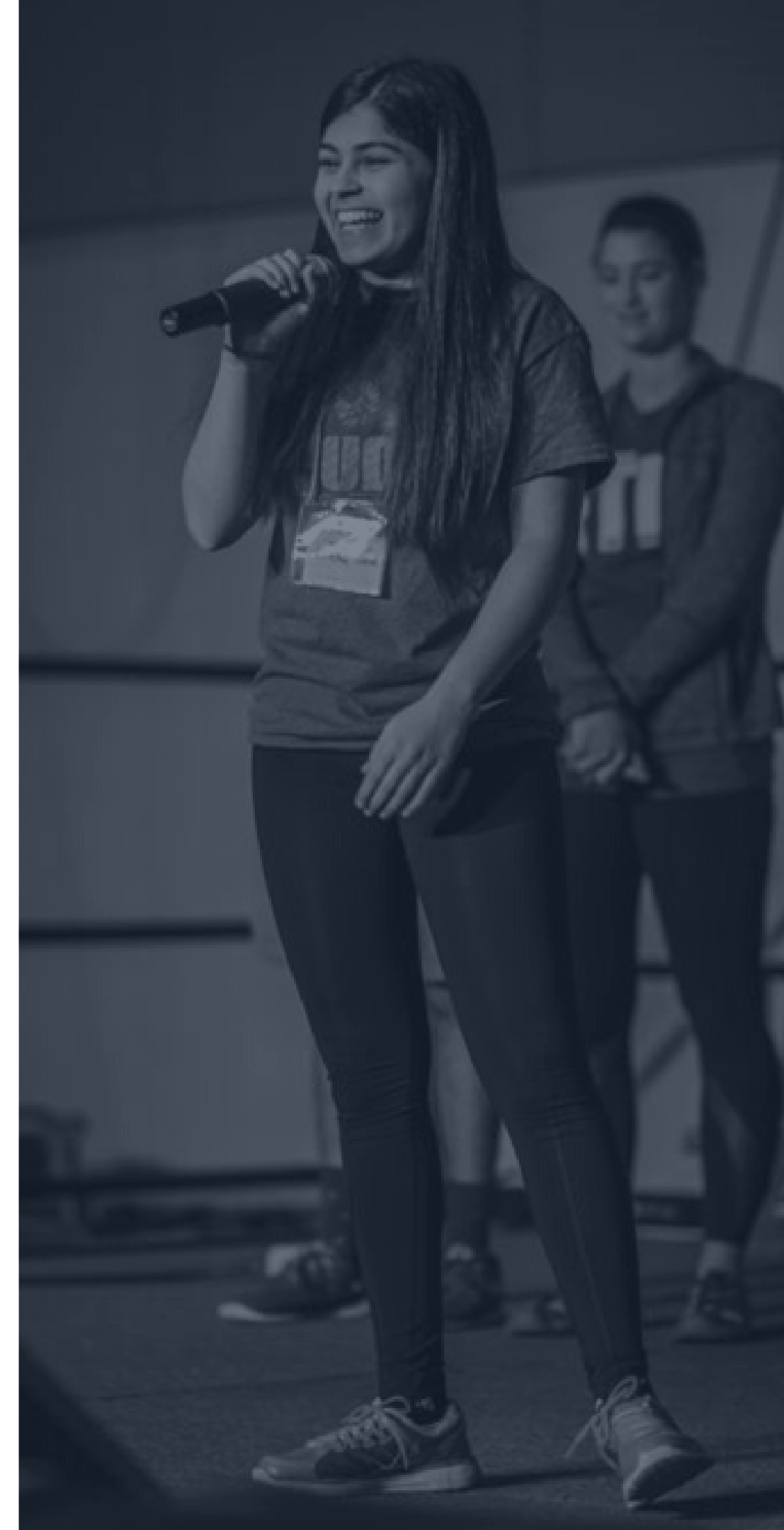
14 RUSTON PLACE, ROSEBERY

Durham, North Carolina

ADVOCACY

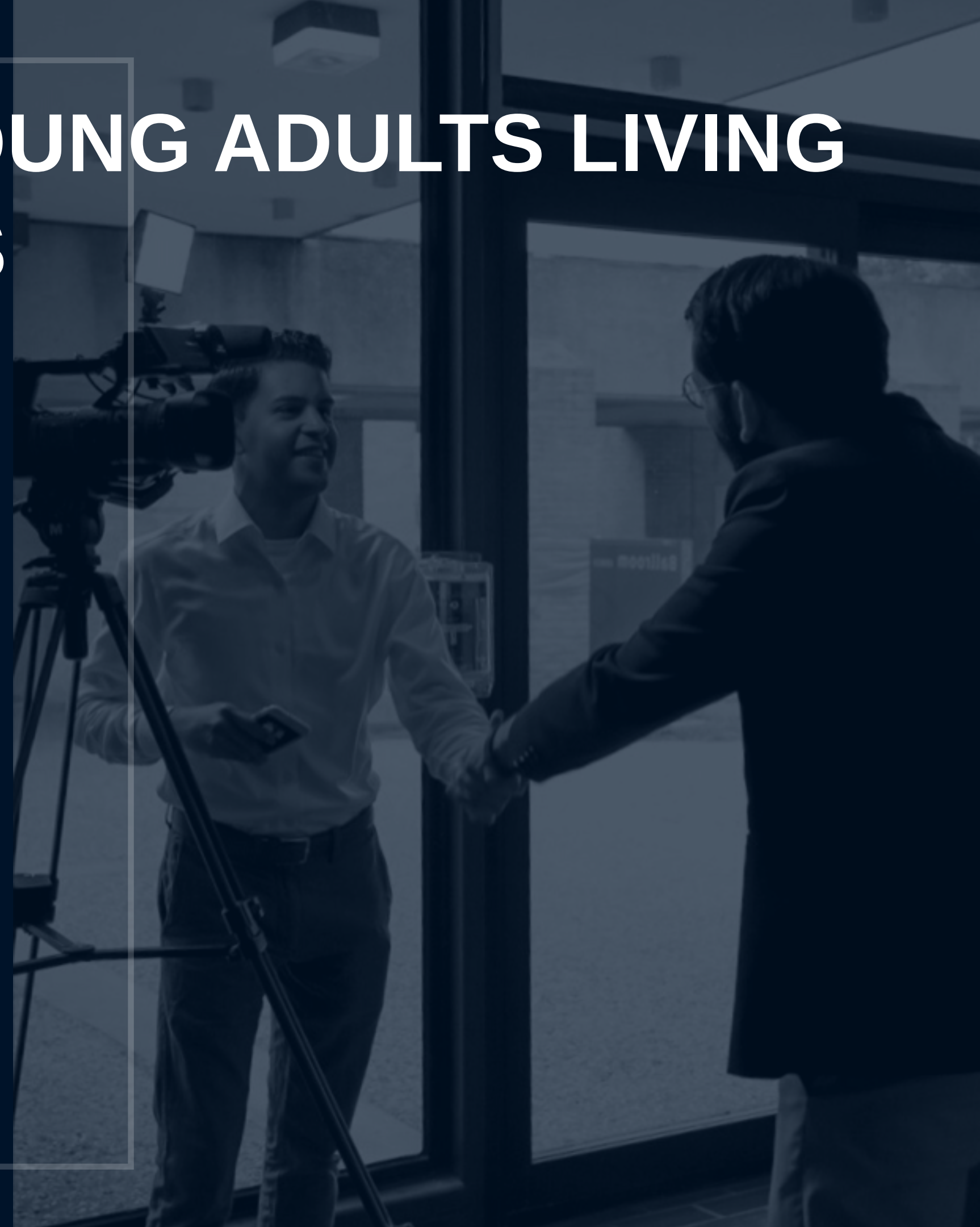
Being able to effectively advocate for yourself is a skill that no patient can afford to be without, which is why advocacy is a major part of the events and programs produced by the HAS. Topics of focus include:

- healthcare policy and legislative initiatives
- vocational rehabilitation and counseling
- mental health
- health insurance and financial resources
- pain management
- communication strategies
- prevention and wellness
- peer-led discussions
- relationships
- recreational therapy
- imposter syndrome with a chronic illness



HEALTH LITERACY FOR YOUNG ADULTS LIVING WITH CHRONIC ILLNESSES

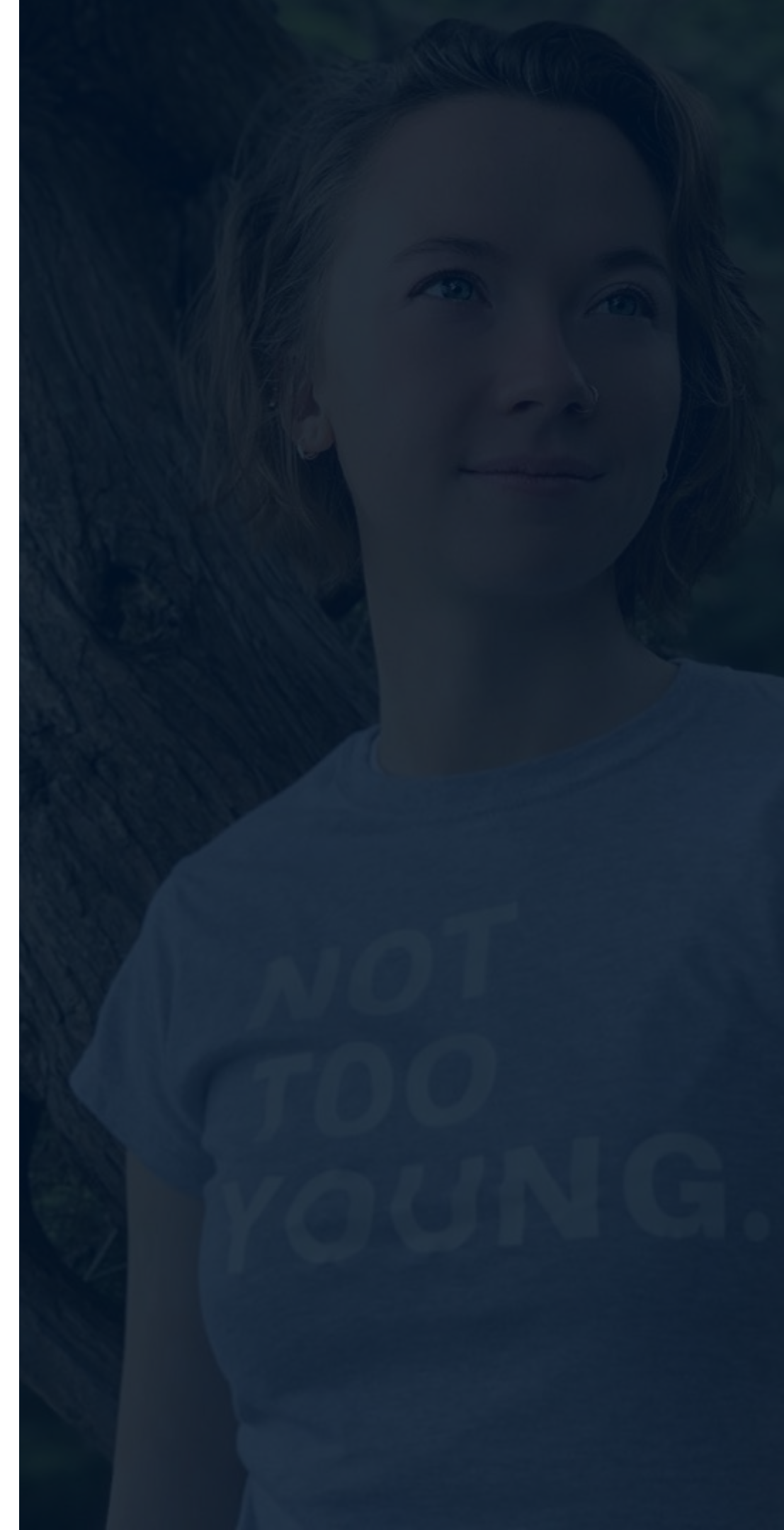
- What medications am I on? What is the dosage?
- How do I refill a prescription?
- How do I begin to talk with insurance on my own?
What happens when I turn 26?
- What accommodations can I receive in school? In the workplace?
- What types of questions should I ask my doctor?
How should I prepare for a doctors appointment?
- How should I be proactive about getting the psychosocial support I need?



KEY TAKEAWAYS

One of the first places they are able to connect with their peers exclusively. Many did not like the idea of health professionals watching and hearing what they said.

Need for more social and casual meetups to foster this connection and share support for empowerment.



HEALTH POLICY LITERACY AND TRANSPARENCY

•AbbVie, Bristol-Myers Squibb, Pfizer, Merck & Co., AstraZeneca and Johnson & Johnson together contributed more than **\$680 million** to hundreds of patient groups and other nonprofits last year, according to a Bloomberg examination of data the companies sent to the Finance Committee. Often, these are the patient advocacy groups testifying on Congress (and the slowest to speak up about pricing, one of the most important issues for patients).

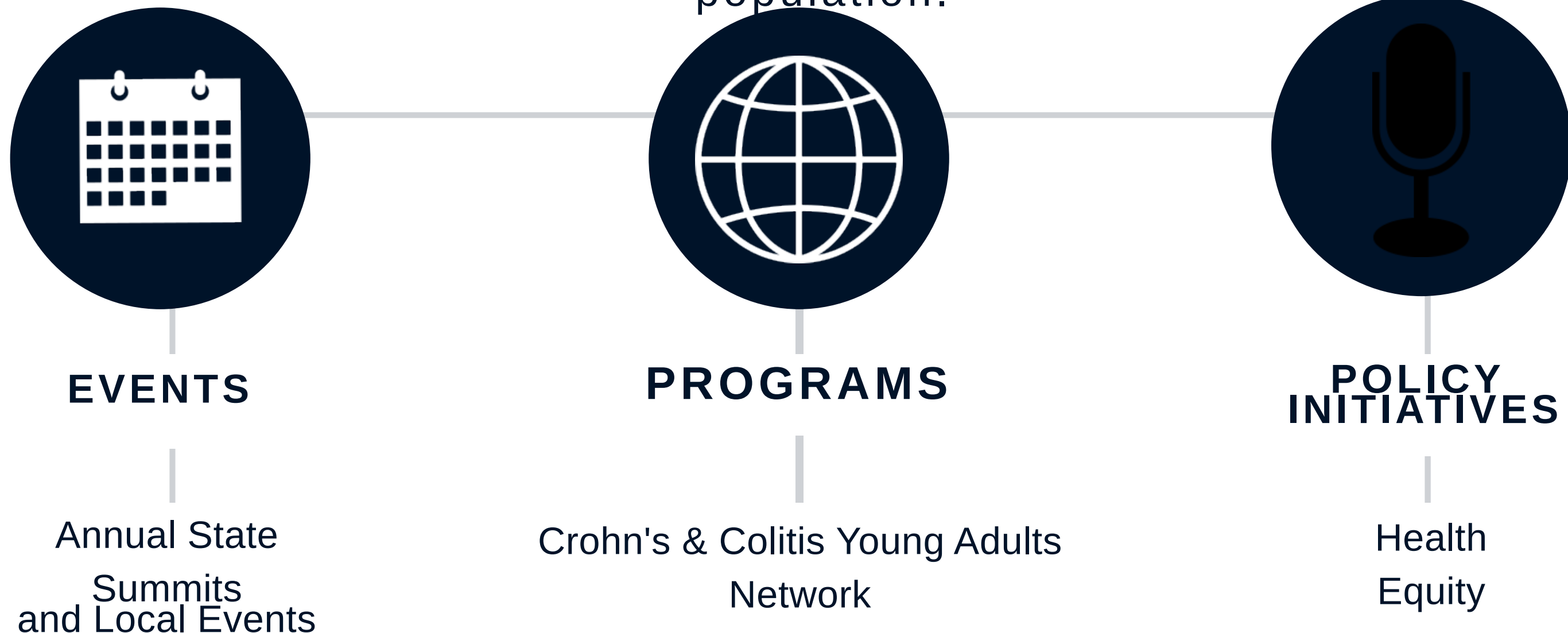
•The next generation of patients must be aware of their role of advocacy within health care.

We are proudly supported by the Cystic Fibrosis Foundation and The Leona M. and Harry B. Helmsley Charitable Trust.



MOVING FORWARD

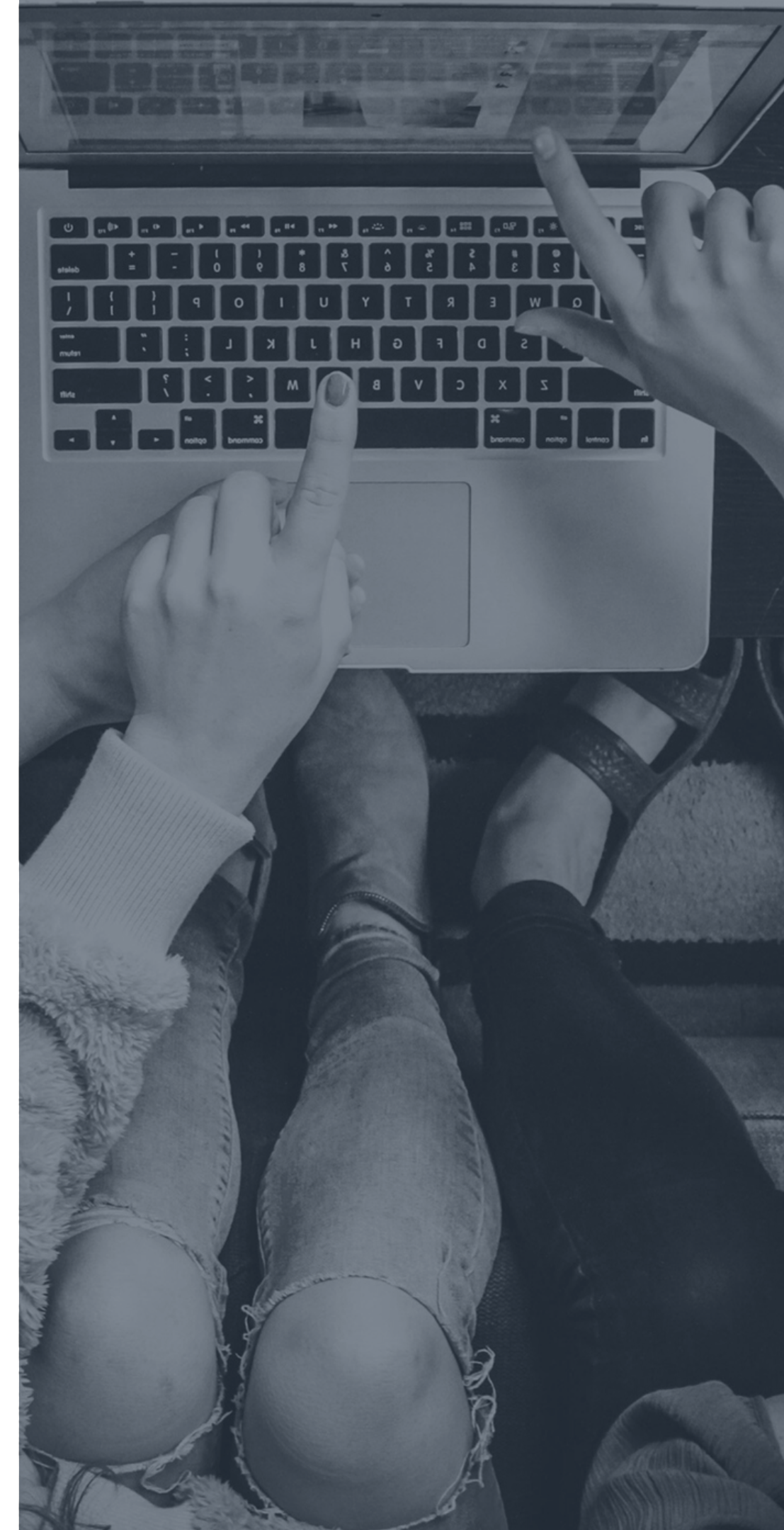
Originally, the HAS focused solely on the creation of our annual summits, but we have realized that these events alone are not enough to adequately support the community of younger patients who suffer from chronic conditions. We must create greater support infrastructure to accommodate the growing needs of the young adult patient population.



ONLINE PROGRAMMING

Due to the dire need of support networks for young adult patients, the HAS is in the process of creating online programs that can provide year-round support to patients across the globe.

We are interested in developing individual programs that focus on specific issues and conditions affecting young adults within the broader chronic illness community.



CROHN'S AND COLITIS YOUNG ADULTS NETWORK

- One of our yearlong programs is the Crohn's and Colitis Young Adults Network (CCYAN):
 - An **international, yearlong fellowship** that produces videos, articles, and stories by young adults with inflammatory bowel disease. *Fellows are required to attend a fully-paid trip to a national IBD conference.*
 - The fellows are selected based upon having a diagnosis of IBD, writing skills and a desire to get involved in advocacy work.
 - Fellows convene virtually to hear from prominent activists such as Ally Bain of Ally's Law and Samantha Reid, from Patients For Affordable



ONLINE ATTENDANCE

Some attendees are unable to attend the Summits in person (e.g. patients with Cystic Fibrosis).

MEDICAL SCHOOL FELLOWSHIP

- Many of our attendees have expressed interest in teaching medical students about using proper language and the importance of proper transition:
 - We will select fellows for each Summit from medical school to shadow the event.
 - Fellows will have the opportunity to reflect on their experiences to share with their peers in medical school.



HEALTH EQUITY

Through our work with young patients living in rural communities in Texas and Indiana, we were confronted with the systemic disparities of disadvantaged populations in our country's healthcare system.

For this reason, we are investing time and resources to help build a *culture of health equity through health literacy*.

- *South Texas*
- *Indiana*



PARTNERSHIPS & COLLABORATIONS

- American College Health Association
- National Scleroderma Foundation
- Chronic Disease Coalition
- Inspire
- ReelAbilities Film Festival
- Invisible Disabilities Association
- Patients for Affordable Drugs
- College Diabetes Network
- Because of its innovative services and impact on rural communities, the HAS was recognized by the **Rural Health Information Hub** as one of their influential rural health organizations.



PRESENTATIONS

- Stanford Medicine X
- Harvard T.H. Chan School of Public Health
- Harvard Boston Children's CME Course
- Digital Health Summit
- Healthcare Transition Research Consortium
- National Scleroderma Foundation
- Marian University Meaningful Medicine
- Others including Governor's Council for People with Disabilities, Childhood Conditions Summit, etc.



CONTACT



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