



Adolescent and Young Adult Cancer

Newsletter

2021 Spring Newsletter

The Spring Adolescent and Young Adult (AYA) Newsletter covers lots of topics including:

- AYA awareness week
- AYA book review and list of other AYA books
- AYA cancer podcasts
- Resources for AYAs during COVID-19
- Wellness and cancer
- HIAYA patient and family advisory board spotlight
- Young Adult Connections information
- Links to:
 - Give feedback on this newsletter, suggest future topics, and/or get more involved
 - HIAYA social media pages
 - Huntsman and Intermountain HIAYA websites

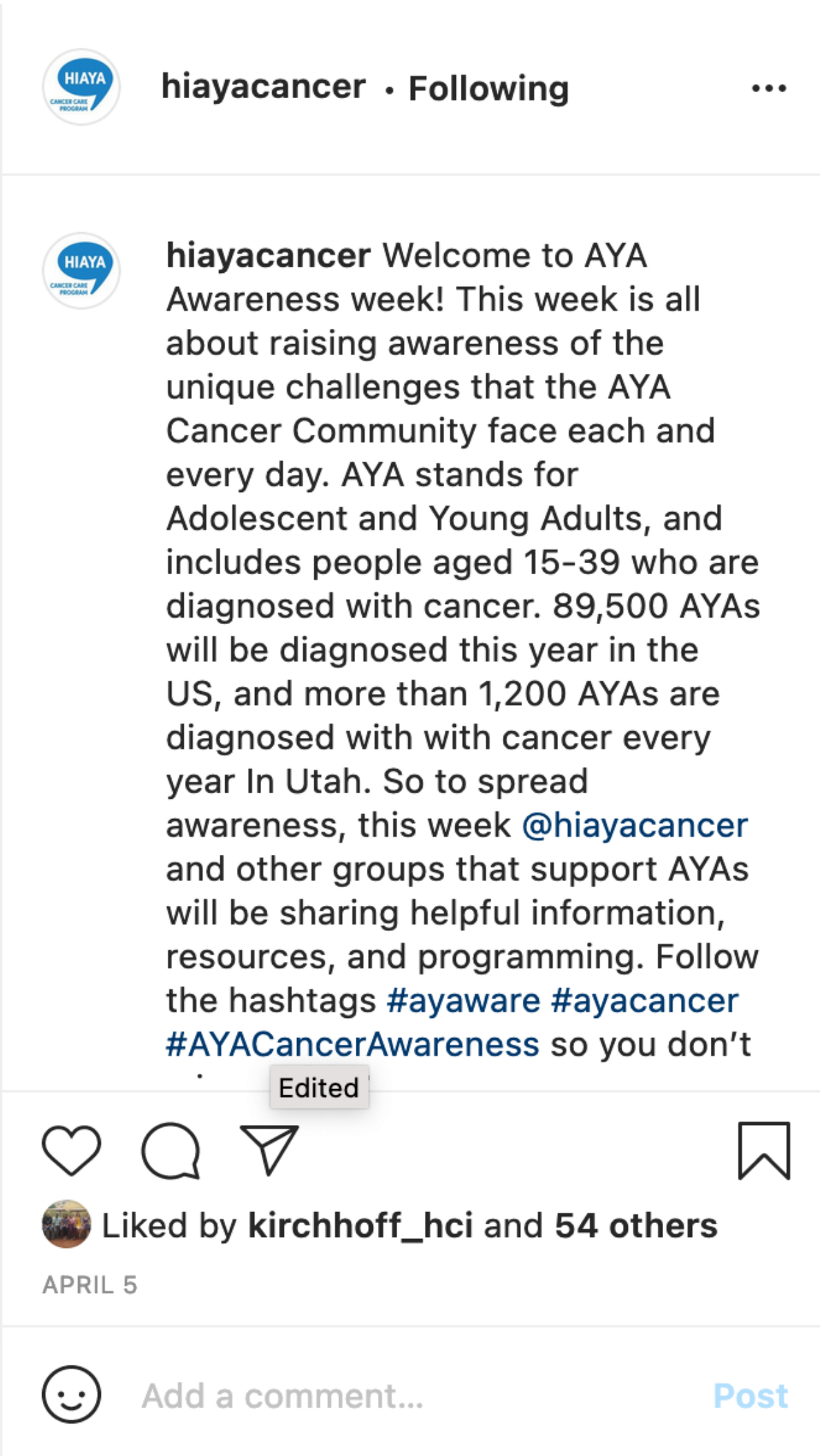
To subscribe to the HIAYA Newsletter [CLICK HERE](#)

AYA Awareness Week RECAP

AYA Awareness Week took place April 5-9th, 2021. Below we recap some of HIAYA's involvement in the #AYAAware campaign. The campaign highlighted the importance of being aware of AYA cancer and the specific needs of AYA patients.



#AYAAware on social media



The HIAYA program participated in AYA Awareness Week and posted all kind of posts about AYA's and their cancer journeys. Including spotlights of your fellow HIAYA patients and survivors. Check out the HIAYA Instagram by clicking the images below to read more.



#AYAAware in the news

Hope for adolescents and young adults diagnosed with cancer
Published by ABC 4 Local News
[Read here](#)



Roger Daltrey
Why I'm worried about the teenage cancer generation

Why I'm worried about the teenage cancer generation
Written by Roger Daltrey for the Spectator
[Read here](#)

CANCER CON 2021



A Message from Stupid Cancer

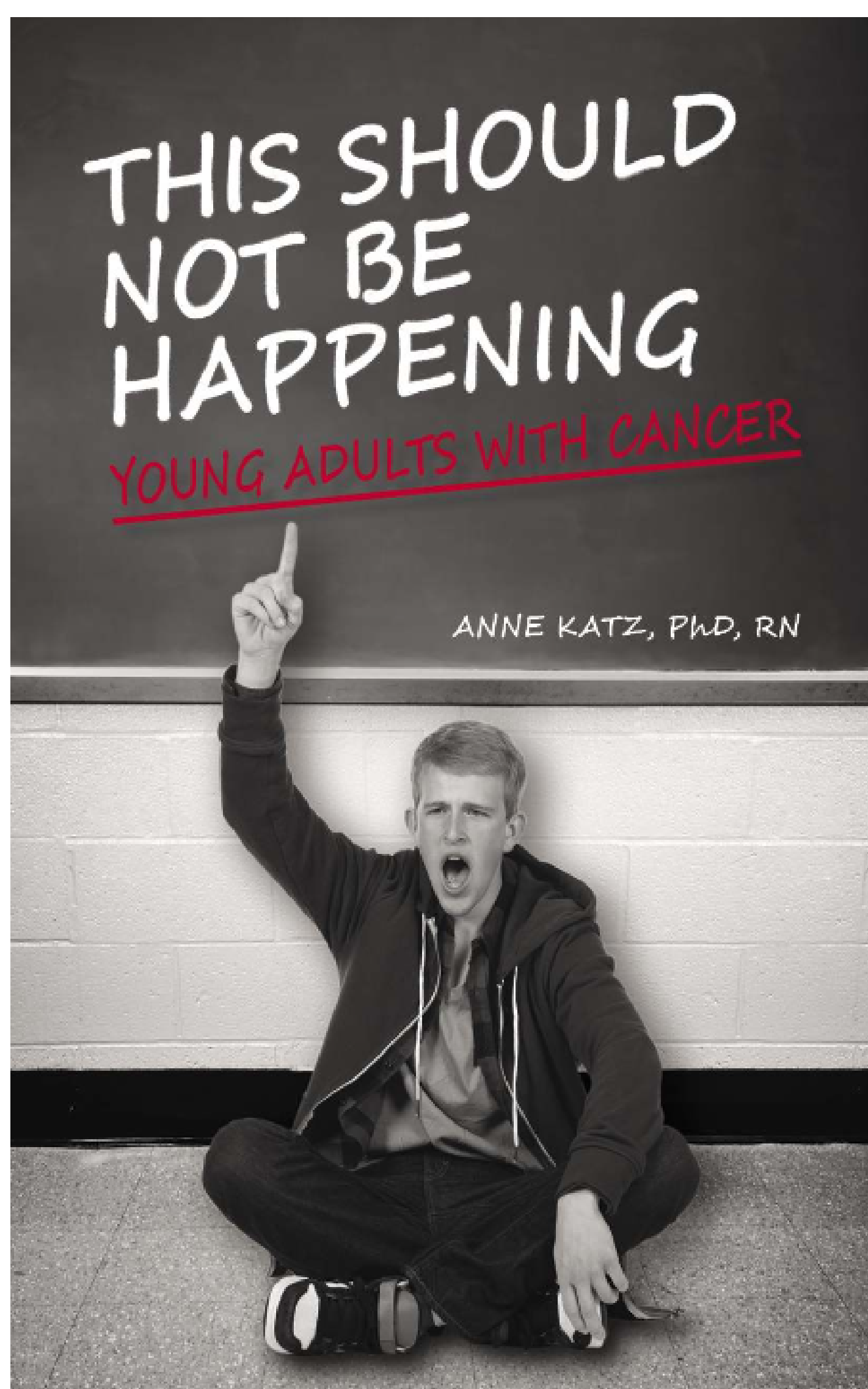
Since 2007, **CancerCon®** has ended isolation, built community, provided education, and redefined quality-of-life for those impacted by adolescent and young adult cancer. Each year, CancerCon® brings together hundreds of patients, survivors, caregivers, advocates, and health professionals to build community and connect adolescents and young adults to critical resources. As the COVID-19 pandemic continues, we are excited to gather our community for our second Digital CancerCon on **June 11 - 13, 2021.**

WHO SHOULD ATTEND?

- Adolescent and young adult cancer patients and survivors 15-39 years old
- Adolescent and young adult cancer caregivers and family members
- Nonprofit patient advocate professionals
- Academic researchers studying adolescent and young adult oncology
- Pediatric, adolescent and young adult oncology nurses and social workers
- Industry executives working on patients' reported outcomes, patient-centered care, and digital health.

[CLICK HERE TO REGISTER!](#)

the BOOK review



This Should Not Be Happening: Young adults with cancer
by Anne Katz

Combining voices of a group of young adult cancer patients with patient experience research, Dr. Katz compiled an accessible and inclusive volume of tips, tricks, resources, and perspectives that can be useful to AYA cancer patients and their loved ones. The book is organized into three sections: 1) being sick, 2) being a person, and 3) being an adult.

The first section provides information about dealing with medical professionals and making treatment decisions, navigating emotional effects, and preparing for fertility, changes in health, and circumstances related to the

diagnosis of a serious disease. The second section focuses on helping patients be themselves during treatment while navigating relationships with family and friends, dating and sexuality, managing nutrition and other health behaviors, and seeking other forms of support. The third section outlines issues related to reentering the workplace and continuing with education.

In each of these sections, Dr. Katz provides clear information while highlighting summarized tips for easy access. Each section includes quotes from other AYA cancer patients that share their experience and perspective on the topic. A short biography of each of the AYA patients interviewed is included as an appendix at the end.

More books for AYAs

Crazy Sexy Cancer Survivor: More rebellion and fire for your healing journey.

By Kris Carr

Everything Changes: The Insider's Guide to Cancer in Your 20's and 30's

By Kairol Rosenthal

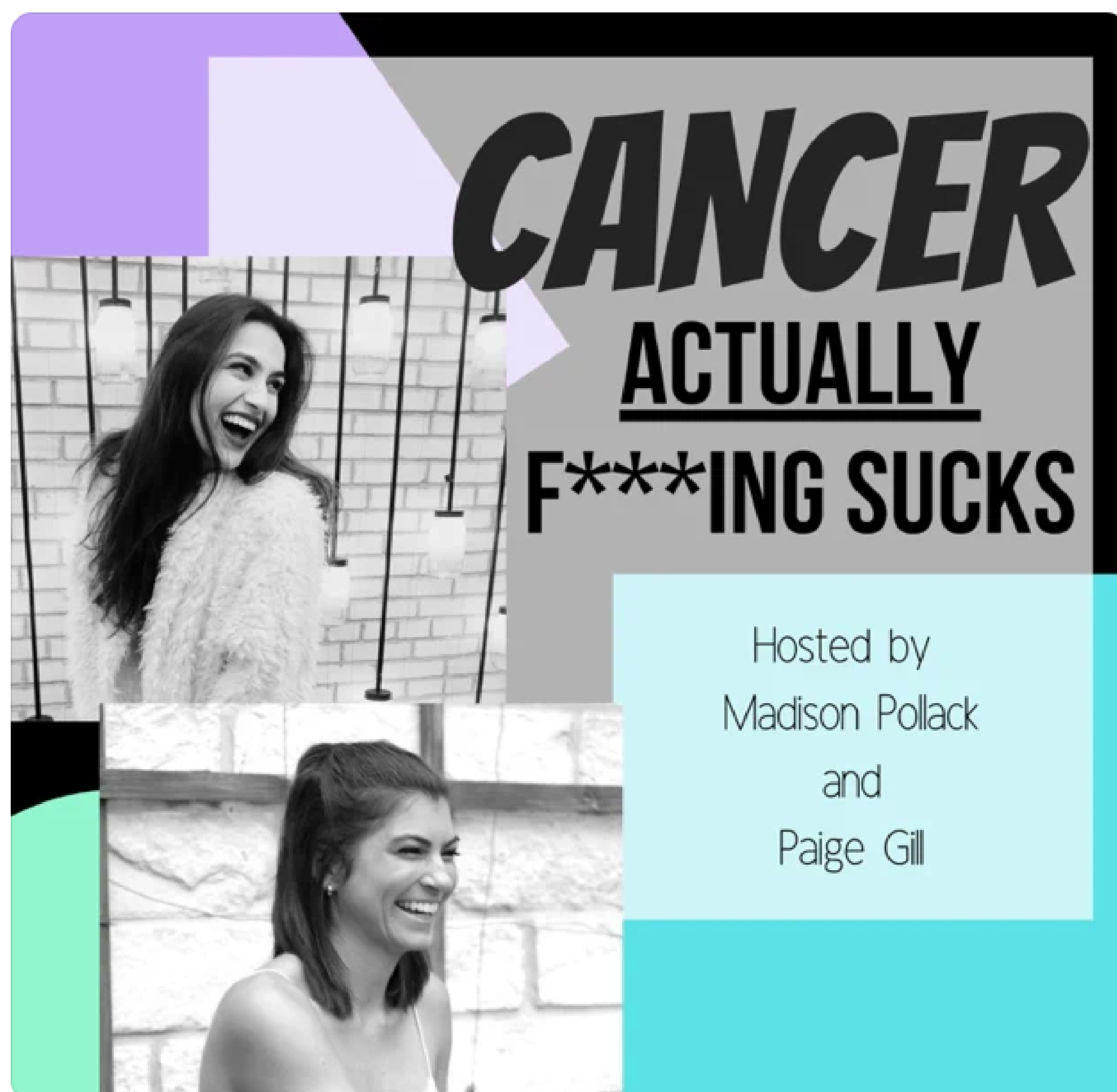
This is Cancer: Everything you need to know, from the waiting room to the bedroom.

By Laura Holmes Haddad



These books and others are available for check out from the Cancer Learning Center at Huntsman Cancer Institute. A free, public resource, the Cancer Learning Center provides a lending library, printed and electronic information related to all aspects of cancer, and empathetic health educators who can talk with you and your loved ones about your concerns. For more information call 1-888-424-2100, email cancerinfo@hci.utah.edu, or visit www.huntsmancancer.org/clc.

AYA CANCER PODCASTS



37 episodes

Cancer Actually F***ing Sucks

Hosted by Madison Pollack and Paige Gill

This 37 episode podcast is hosted by two young cancer survivors, Madison and Paige, who set out to let you know you are not alone in your cancer journey. Each episode Madison and Paige are joined by a guest including other young survivors, caregivers of young survivors, and professionals. Paige and Maddy dive deep with each of their guests discussing the trauma of getting a cancer diagnosis and how folks cope.

[Listen here](#)

Life on Pause

Hosted by a group of young survivors at Penn State Health

This podcast only started at the end of 2020 but already has 9 episodes and is a bit of a quicker listen than the previous podcast. Each episode the life on pause crew jumps into a topic based discussion. Topics include the experience of cancer as a young person, college and cancer, as well as taboo topics like developing a dark sense of humor, playing the cancer card, and survivor's guilt.

[Listen here](#)



9 episodes

Wellness and Cancer

Fitness and Exercise



Many exercises are safe and effective for individuals who are receiving treatment or are done with treatment. Some exercises can even help with cancer-related fatigue. Talk to your doctor about which exercises are right for you!

[Click here](#) to visit Intermountain's LiVe Well Center's page for more exercise videos!

Huntsman Cancer Institute's Wellness & Integrative Health Center offers virtual and in person fitness courses Monday through Friday!

[Click here](#) for more information.

Monday	Tuesday	Wednesday	Thursday	Friday
7-7am High Low	10-10:30am Tai	11:30am - 12pm	10:30am-11:25am	6:30-7am Core
12-12:30pm	Chi/Qigong	Cardio Intervals	Yoga	Yoga
Resistance training	11-11:30am Yoga	4:30-5pm	11:30am-12pm	10-11am Minding
4:30-5:30pm		Zumba	High Low	Motion
Zumba		5-5:30pm Yoga		11:30- 12pm
				Pilates

Nutrition - Cucumber Melon Feta Salad

- 1 tbsp. fresh lemon juice
- 2 tbsp. sunflower or safflower oil
- 1 tsp. honey
- 1/4 tsp. sea salt
- Black pepper
- 3 c. seeded, cubed honeydew melon or watermelon
- 1/2 Armenian or English cucumber, sliced 1/4" thick
- 2 tbsp. finely chopped red onion
- 2 tbsp. chopped fresh dill or mint
- 3 oz. feta cheese, crumbled



Find this recipe and more in the Huntsman cookbook - [click here](#)

1. Pour lemon juice in a large bowl. Whisk in oil in a steady stream until combined. Whisk in honey, salt, and pepper.
2. Add melon, cucumber, onion, and dill or mint. toss gently to combine
3. Top with feta cheese

COVID-19 Resources for AYAs

Educational

[Cancer and Careers COVID-19 Resources](#)

[Triage Cancer COVID-19](#)

[ULMAN Foundation](#)

Food

[Crossroads Urban Center - Emergency Food Pantry](#)

[Utah Community Action Food Pantry](#)

[Relief Pack Utah](#)

Mental Health

[United Way 2-1-1- Program](#)

[CDC: Coping with Stress](#)

Financial

[UCA HEAT Program](#)

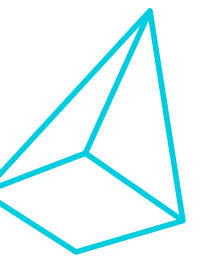
[Lymphoma Research Foundation](#)

[Colorectal Cancer Alliance](#)

AYA Cancer Community

[Elephant and Tea](#)

[Young Survival](#)



HIAYA Board Spotlight

Andrea Hoffman

HIAYA Patient and Family Advisory Board

Meet one of the wonderful HIAYA Patient and Family Advisory Board (PFAB) members. The HIAYA PFAB is a group of young survivors and caregivers that provide feedback on everything HIAYA related, from the services available to the research conducted. Andrea has been on the PFAB since the beginning of HIAYA in 2015 and even helped set up the program before the PFAB existed. Keep reading to learn all about the wonderful Andrea!



Andrea, could you tell us about yourself?

Hello! I am a 34 year old Salt Lake City native, who currently works as a pediatric nurse. I was diagnosed with Hodgkin's Lymphoma twice in my twenties. First, when I was 22, back in 2009. I went through three months of chemo over a summer, the treatment was fast and aggressive as lymphoma grows quickly, and by the fall I was in remission. This may be an odd perspective, but at that time cancer wasn't the worst thing I had been through as I struggled with mental illness a lot in my teens and early twenties.

Could you tell us more about that?

Yeah, I went through my cancer, finished, but then continued to struggle for the next year with my mental illness. I ended up seeking help and going to a yearlong treatment facility in Texas. After I got back from Texas, I was able to put my life together and finally felt like I had a life worth fighting for.

During that process I recognized that I needed support to revisit the cancer diagnosis stuff. That is when I found the Cancer Wellness House. There was a young adult support group that met about once a month, but there were only 3 people, 2 survivors and 1 caregiver. We tried for years to pull something together because we knew people needed support, but nothing really got off the ground.

What about your second cancer diagnosis?

About 6 months after I returned from Texas, at my 2 year cancer follow up the doctors found another mass growing in my chest. It was in a very dangerous place to biopsy as it was between my heart and lungs. We watched that mass for a year not knowing whether it was cancerous or not. Living in that state of constant unknown was one of the toughest things I've ever gone through, and it taught me so much about patience.



I was finally able to get a biopsy right after I got into nursing school and transferred to Westminster College with a full ride scholarship. Unfortunately, I found out the cancer was back, and I had to drop out to complete treatment. This time around was much more intense, I needed radiation and chemo. They even prepped me for a stem cell transfer but decided not to do it. Hopefully, I'll never need those cells that are hanging out somewhere. My last

treatment was in the spring of 2013 and I have been cancer free since then!

After my treatment ended, I went back to nursing school. I never imagined that I would work in oncology but as I neared the end of my nursing degree, everything on my resume was perfect for pediatric oncology nursing. I actually ended up doing my nursing capstone on the Hematology/Oncology unit at Primary Children's with the doctors and nurses that treated me. I worked on the unit for about two years before it became too much for me emotionally. I decided I needed to move on and worked on the neonatal intensive care unit (NICU) for a couple years and am now a School Nurse for a small private school in the area.

What made you want to stay involved with HIAYA and be a part of the HIAYA Patient and Family Advisory Board?

I just love the idea that I can be there for other patients so that they don't have to go through what I did, and that they don't have to feel as alone as I did. I want them to know that there is always something to reach for, that keeps me going. The other thing, maybe selfishly, is that cancer never goes away, so being a part of the board is a way to keep my foot in the water. I always want to learn about the recent developments, but I also want to be a voice for young survivors in the program.

Join on of our AYA research studies!

All studies can be completed 100% online and have flexible scheduling. If any of the study opportunities below peak your interest reach out to the contact listed for more information and to see if you are eligible!



HIAYA CHAT Study

HIAYA CHAT is a study to help AYA's better understand their health insurance and costs during their first year of their cancer treatment.

- Everyone will receive two surveys
- Half of participants will also receive health insurance education sessions taught by an AYA patient navigator
- \$40-\$60 in gift cards for participating

Interested in participating? Contact Karely Mann at Karely.Mann@hci.utah.edu or call/text 801-970-3625

Telephone Symptom Management Study

This research study is designed to help you manage symptoms such as the fatigue, depression and anxiety often experienced during cancer treatment.

- We are recruiting AYAs who are currently receiving treatment and a study partner (friend or family member)
- The study involves participating in regular over the phone assessments of your symptoms and other topics
- Participants can receive up to \$190 in gift cards for participating in the study

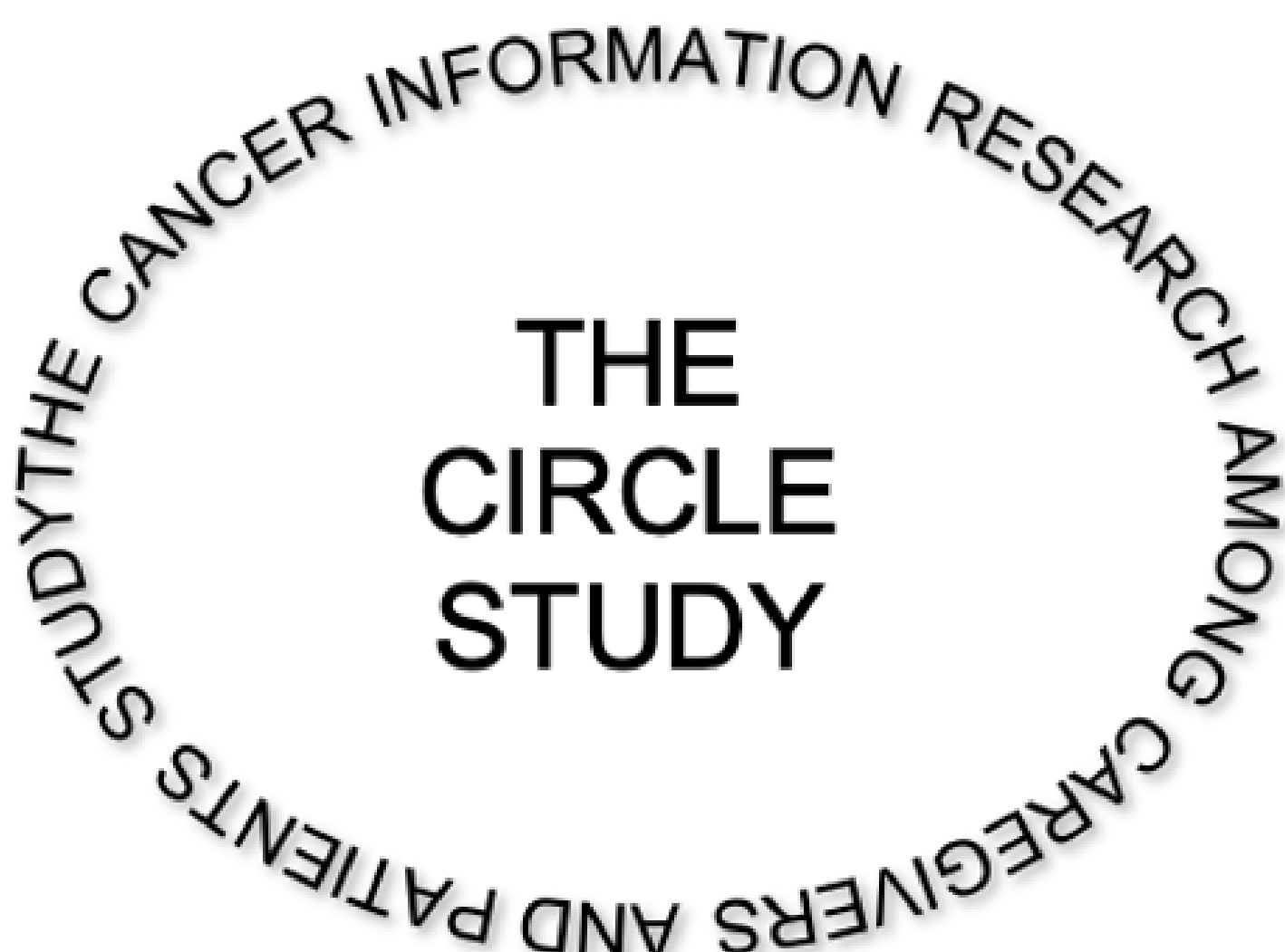
Interested in participating? Contact Bettina Hofacre at 520-235-9186 or bhofacre@email.arizona.edu (habla español) or Ana Acuña Morales at 520-235-9186 or aam1@arizona.edu (habla español)

CIRCLE Study

We want to learn more about your experiences with cancer information on social media. You are eligible for this study if you are currently receiving treatment for cancer and have a family member or friend who will participate with you.

- We will ask you and your family member or friend do an online survey and a telephone interview.
- It will take about 30-60 minutes total to be in the study
- Participants and family member or friend will each receive a \$40 gift card for participating.

Interested in participating? Contact Echo Warner at 801-244-7040 (call or text) or echowarner@email.arizona.edu

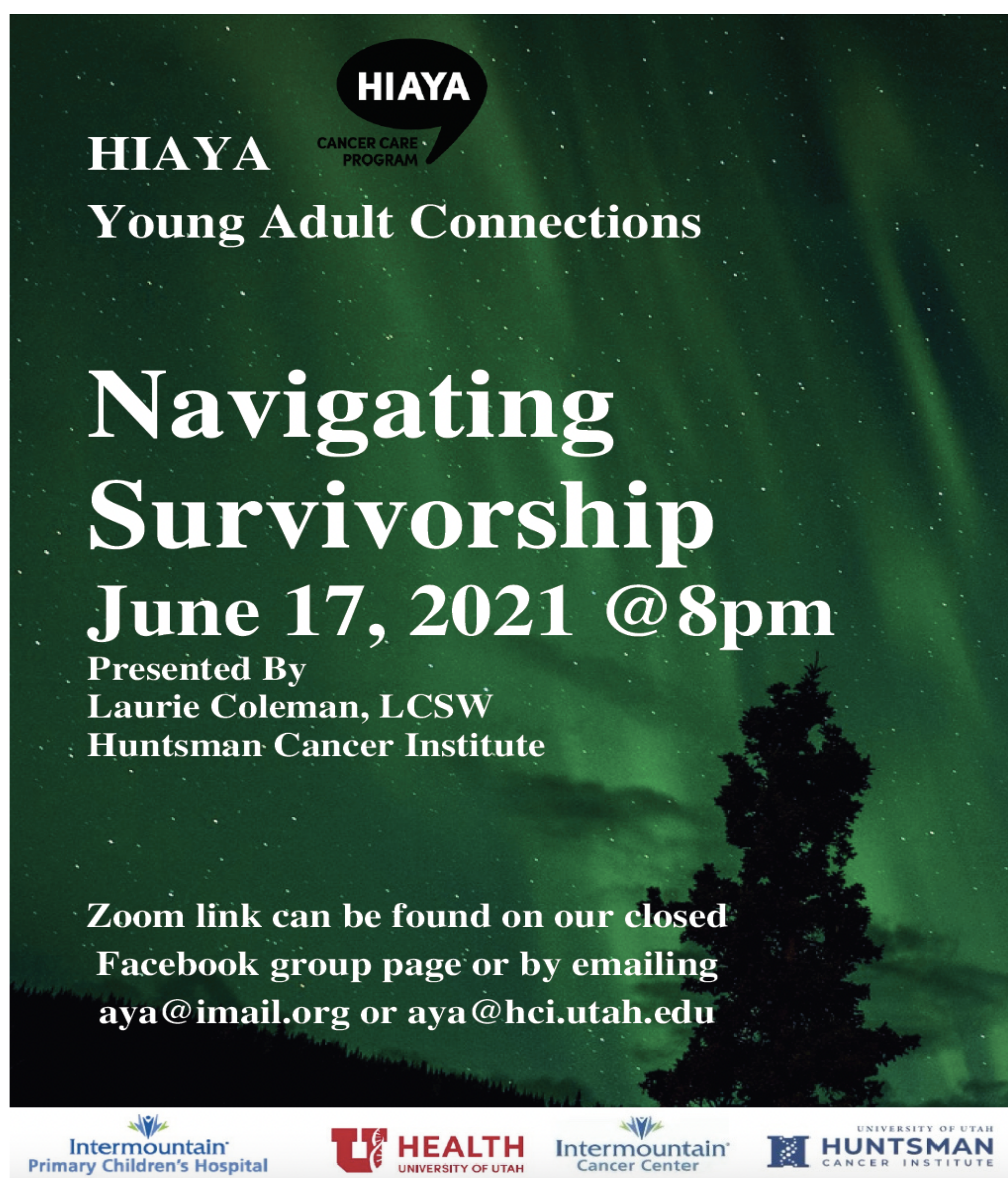


Young Adult Connections

7-8 pm

The first Wednesday of each month
AND
The third Thursday of each month

on Zoom!



Interested in Getting Involved?

Are there topics you wished we covered?

Would you be interested in helping come up with content or even writing the AYA newsletter?

Would you like to be featured as a patient/survivor spotlight?

If you said 'yes' to any of these questions, let us know below!

[Interest Form](#)

Stay Connected!

Join us on social media and stay connected with other AYA patients and caregivers!

Connect with an AYA Patient Navigator
aya@imail.org or 801-507-3889



@HIAYACANCER



@HIAYACANCER



HIAYA CANCER GROUP

