



# Adolescent and Young Adult Cancer

## Newsletter

# 2021 Winter Newsletter

Congratulations, we have made it through the longest year that ever existed!

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

- Life after treatment
- AYA book review and list of other AYA books
- HIAYA staff spotlights
- Update on the HIAYA COVID-19 and Cancer survey
- Resources for AYAs during COVID-19
- Studies currently recruiting AYAs
- 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](#)



# LIFE AFTER TREATMENT

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Going through treatment is an intense experience that impacts every aspect of patients' lives. Entering the survivorship phase of an individual's cancer journey can be just as intense but in very different ways. While everyone's journey is different, often thinking about going back to "normal" is scary; it is common for patients to feel lost and alone after their treatment ends. After spending so much time fighting their cancer many patients have a feeling of "now what?" after their treatment ends. This may feel counterintuitive as many people in the lives of patients will want them to feel happy and joyful after treatment. It is okay to not feel as happy as others expect you to. Returning to the routines and relationships you occupied before treatment can be hard and will take time. Just because treatment has ended doesn't mean that patients should stop seeking counseling or other services that helped them emotionally through treatment. Mental health is just as important after treatment as it is during treatment.

While patients work on understanding their feelings after treatment ends, they may begin to feel quite uncertain about the future. The fear of recurrence or relapse can at times be all consuming for some. Others may cope with this fear by staying busy or avoiding further medical care as not to remind themselves of the possibility of relapse. Dealing with these feelings of uncertainty can be hard.

Here are some things that other patients have done that may help you feel more in control:

- Take time to reflect on your cancer journey and the obstacles that you have overcome. Think about how the experience has changed you and what needs to change or doesn't in your life to align with who you are now.
  - How have your life goals changed?
  - Do you need to find new ways of feeling fulfilled?
- Discuss how you are feeling with trusted people in your life. Trusted people don't have to be your family, though they can be. They can also be friends, chosen family, counselors, or even other patients.
  - Beyond the people who are already in your life there are many organizations that hold support groups for young cancer patients. It may provide a sense of peace hearing and talking to other young people who have shared experiences.
- Acknowledge and accept what you do and do not have control over. While you may not be able to control if a relapse occurs there are other aspects about your health you can control.
  - You can ask your oncologist about a Survivorship Care Plan in order to not miss any scans or checkups needed to monitor for side effects of your cancer treatment.
  - Make a conscious effort to eat healthy foods. There might even be a dietician available to you at your cancer center who can help you plan your shopping trips and meals.
  - Find ways that you enjoy being active, while being kind to yourself knowing that treatment is tough on the body. Find activities that are accessible to the physical limitations you may have.

Entering a new stage of life – life after cancer – can be a difficult experience, especially for young patients. Young people already have so many competing responsibilities from school to finding a career to starting a family, survivorship concerns is just another layer. Hopefully the websites, books, and resources we have here in the newsletter provide you with reputable and new information about survivorship whether you're looking forward to the end of your treatment or you're years into survivorship. No matter what stage of your cancer journey you find yourself, remember that the adolescent and young adult patient navigator at your institution (contact information at the bottom of the newsletter) is always available to help.

Content was adapted by the HIAYA Team from these sources:

[NCI Facing Forward: Life After Cancer Treatment](#)

[CancerCare.org Post-Treatment Survivorship](#)

[ACS Life After Cancer](#)

# the BOOK review



*Invisible: How Young Women with Serious Health Issues Navigate Work, Relationships and the Pressure to Seem Just Fine* by Michele Lent Hirsch

Hirsch compiles interviews with dozens of women to represent perspectives of those whose health concerns collide with relationships, the workplace, and the health care setting itself. This book shares perspectives of women with a variety of chronic conditions including cancer, representing a variety of racial and ethnic groups, younger ages, and sexual and gender identities. A thyroid cancer survivor herself, Hirsch blends in her own experience and current research into psychosocial concerns in disease management.

Although this book doesn't provide tips for navigating life circumstances, it offers a glimpse into lives complicated by disease and disability. For someone who feels alone or isolated in their own experience, this book may offer stories they can relate to, ideas for preparing for awkward or difficult conversations, and hope that friends, families, employers, and medical providers can partner in finding happiness and fulfillment when facing chronic disease.

## More books for AYAs

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

By Kris Carr

*This Should Not Be Happening: Young adults with cancer*

By Anne Katz

*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](mailto:cancerinfo@hci.utah.edu), or visit [www.huntsmancancer.org/clc](http://www.huntsmancancer.org/clc).



# HIAYA Staff Spotlight

## Karlie Allen

HIAYA Patient Navigator and Program Coordinator

Meet the newest addition to the HIAYA team, Karlie Allen. Karlie just moved back to Utah from Orange County, California where she was a Child Life Specialist and the AYA Program Coordinator at a local children's hospital. While Karlie previously worked with a wide age range of patients, she loved her time with the older patients (18-26 years old) being treated at the children's hospital. Karlie shared with us that she admired the incredible insights, perspectives, and often humorous nature of the AYAs she worked with saying, *"Not to mention those patients always kept me laughing."* Karlie is really focused on hearing the voices of the patients she works with and making sure that the HIAYA program aligns with their needs. Read on to learn a little bit more about Karlie, her position in HIAYA, and what has been keeping her busy during the pandemic.



**Could you tell us a little bit more about what you do in your new position with HIAYA?** I am the AYA program coordinator and Huntsman patient navigator. As far as individually for patients, I am here to support them through their cancer journey. That includes connecting them to resources, listening to their problems, helping them find community, and navigate the healthcare system during and after their cancer. As the program coordinator I work on upkeep of existing programs like Young Adult Connections and our HIAYA social media as well as listening to the voices of our AYAs to create new programs to address their needs.

**What made you want to work for the HIAYA program?** I loved the time that I spent with my AYA patients. They were so real and taught me so much. It is exciting to me to help AYAs connect with each other and find solutions to their needs. I always tell people that there are no words to describe the strength and power that I have seen when AYA patients connect with each other and support each other. There are no words, it is one of the most beautiful connections I've ever seen. Seeing patients from very different backgrounds and ways of thinking connect and support each other is amazing. Which has drawn me to continue my work with the AYA population. As far as HIAYA goes, I had heard so many good things and am excited that the program is always looking to grow and be better. They also have a focus on the individual patients as well as the group and program which is really important to me.



**How does your work compare here versus in California?** There are definitely differences. I worked at a children's hospital for one, so the AYA population I worked with was much smaller than HIAYAs. Patients were also much more centrally located than here, where patients often cross state borders. I am actually really excited to learn how to best serve the older AYA population and how to help people connect across state boundaries. Interestingly, it is overall a lot of the same concerns, fears, wishes, and triumphs for the patients. Which to me really highlights the needs of AYAs and how common they are.

**What have you been doing to have safe and responsible fun during the pandemic?** Like so many others, I have become even more of an outdoorsy person. I was before as well, but I love hiking, finding cool waterfalls, exploring, being on the water, paddle boarding and stuff like that. For most of the pandemic I was in California, so it was easy for me to escape to a body of water. Also Zoom hangouts, which has been nice to connect with people in a new way. A lot of my family lives in Utah so we have been meeting up for socially distant, bring your own food, meals outside. I also love reading and have been trying to stay active by finding online workout videos.

**What is your favorite vacation you have ever been on and why?** This question was such a struggle for me because I love to travel. But I think the one that stood out to me the most was my trip to Scotland and Ireland. It was so beautiful. The towns I went to were so quaint and magical. I even kissed the Blarney Stone! I was actually there during the winter. The lights and Christmas markets they had were really cool. I hope to make it back some day.

# HIAYA COVID-19 and Cancer Research Update!

First and foremost,

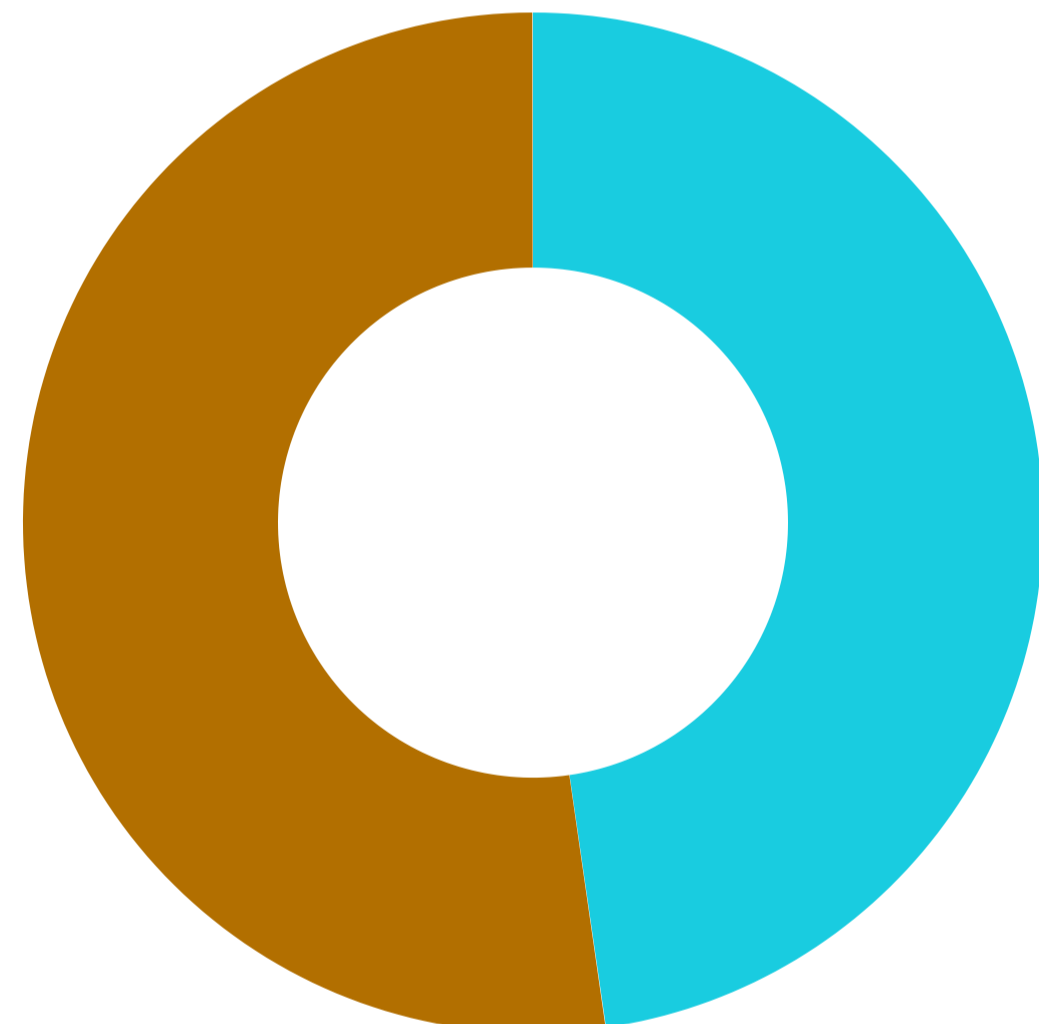
*Thank you!*

Thank you to everyone who completed our survey. We wouldn't be able to understand the unique needs of AYA patients and survivors and improve the HIAYA program without your participation. We will use the information from the survey to make sure our patients have the support they need during the COVID-19 pandemic.

Over 300 of you participated in the survey - below we show some of the results!

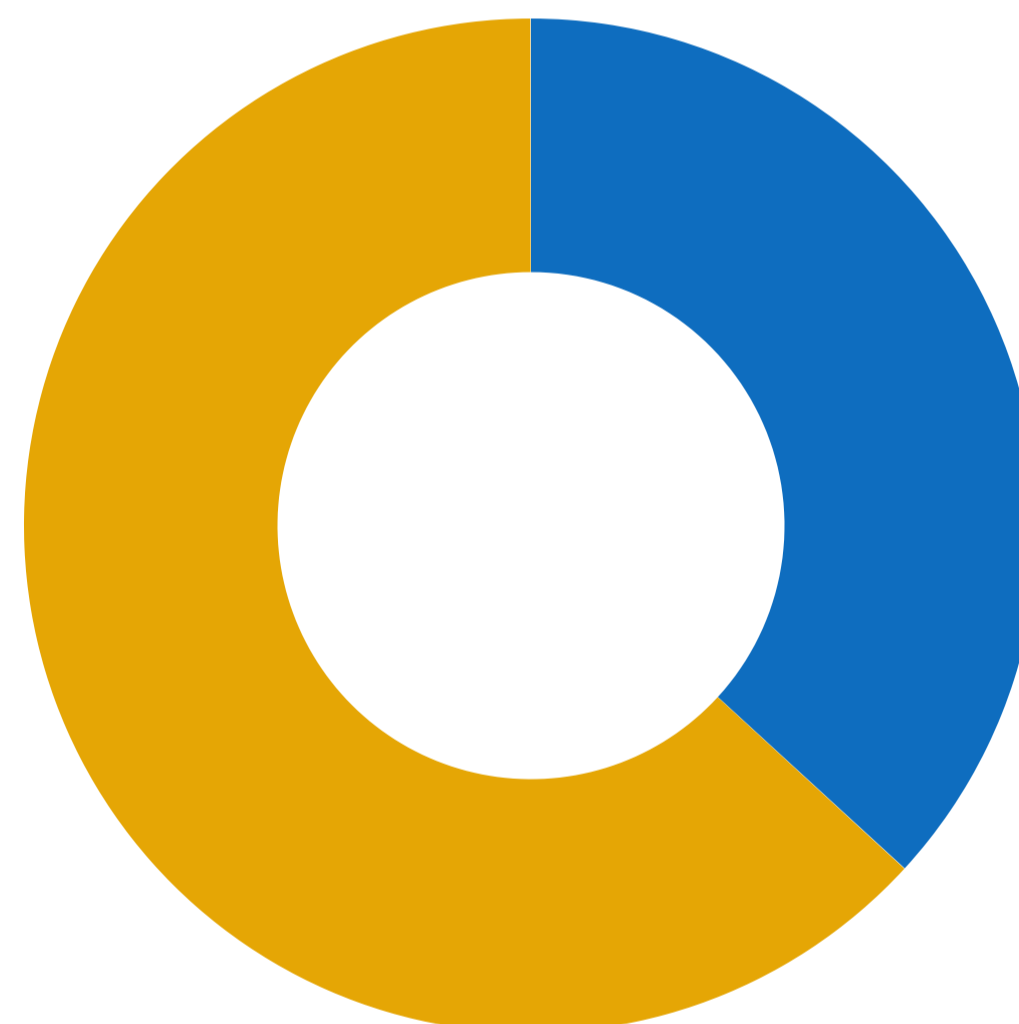
## AYA Demographics

Treatment Status



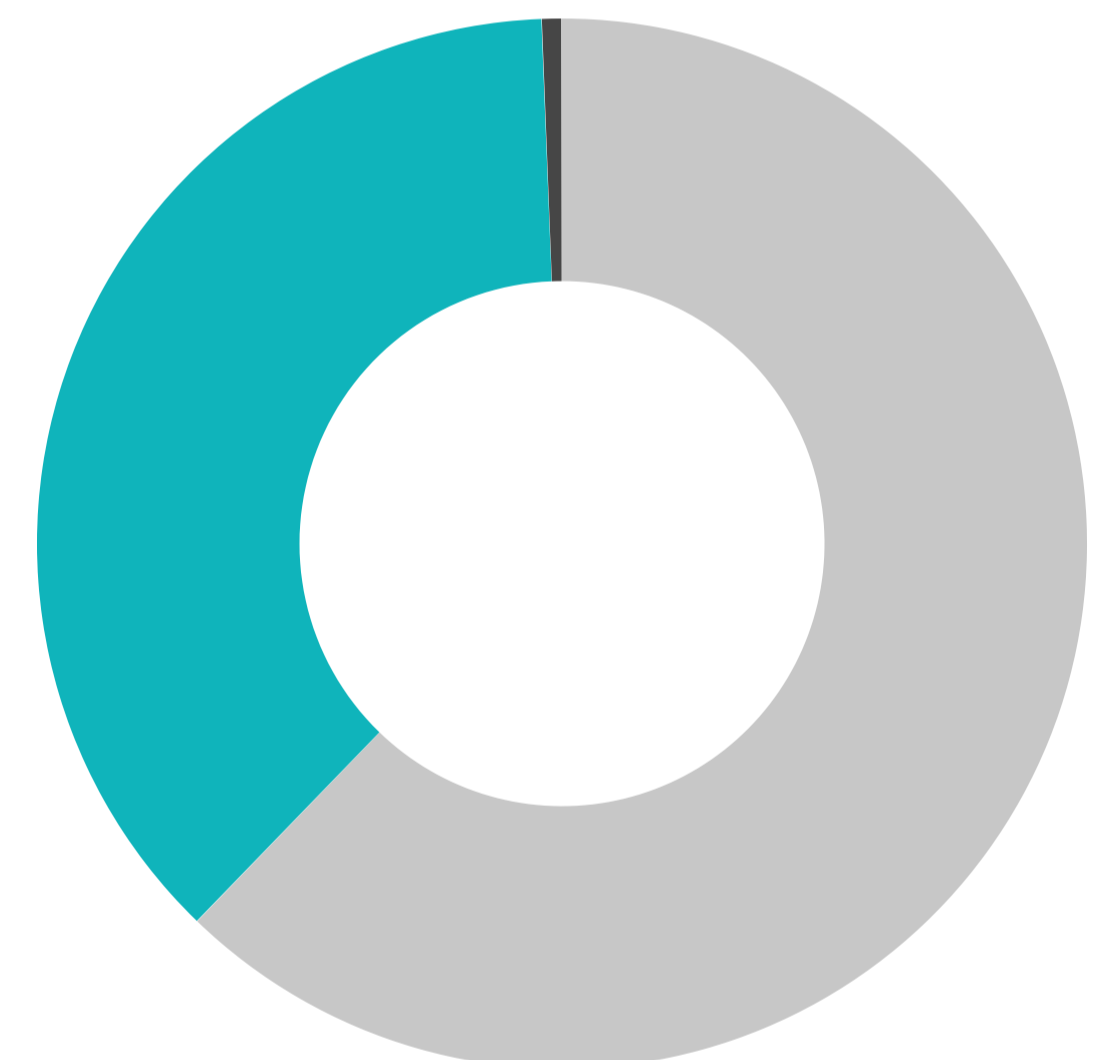
■ On Treatment (47.73%)  
■ Off Treatment (52.27%)

Essential Worker



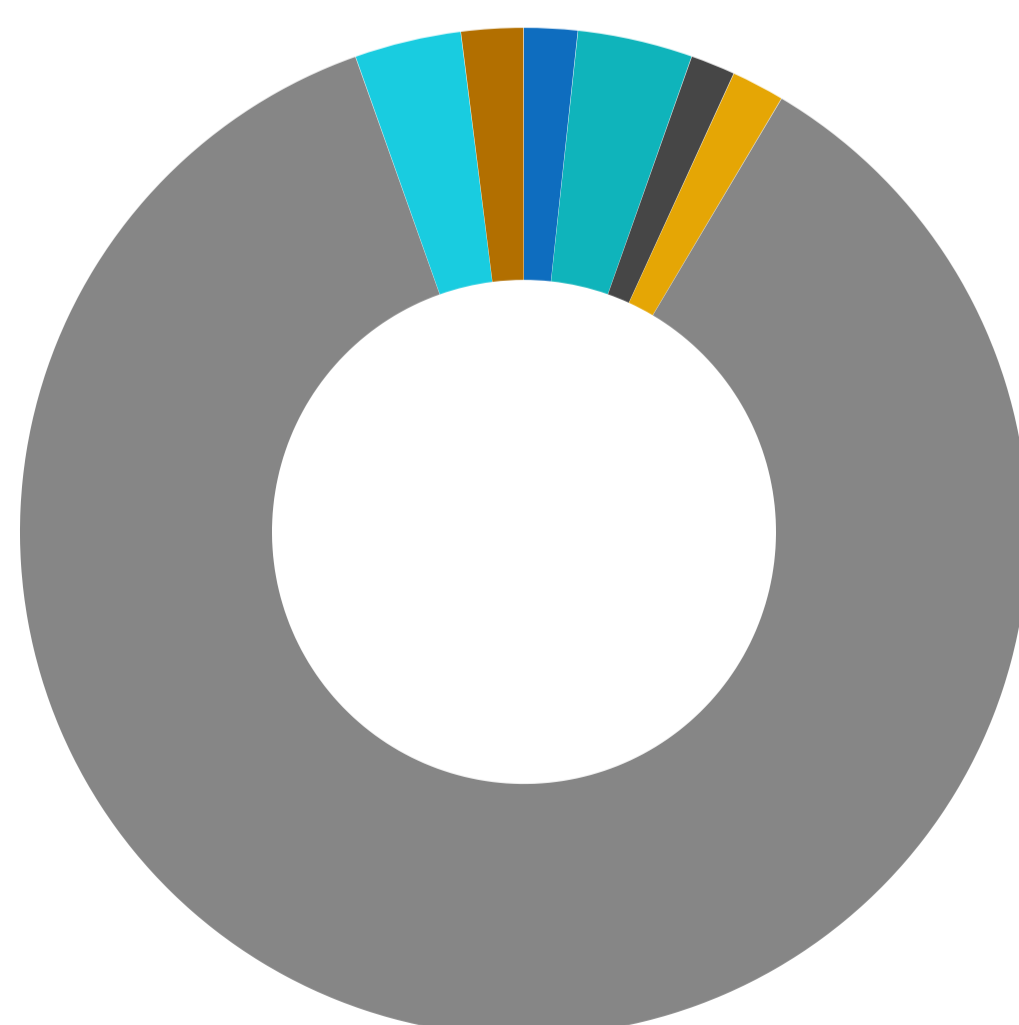
■ Yes (36.83%) ■ No (63.17%)

Gender



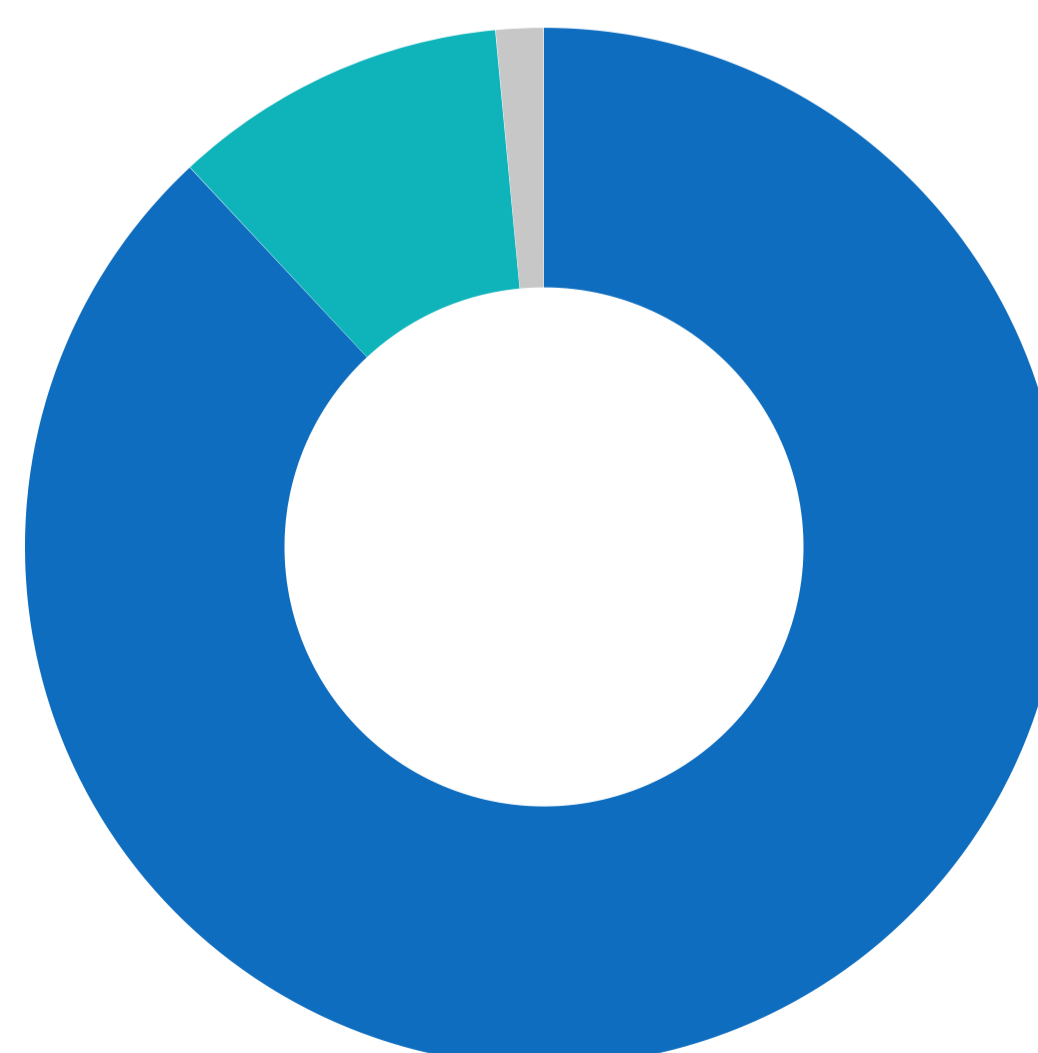
■ Female (62.24%) ■ Male (37.16%)  
■ Transgender or Nonbinary (0.6%)

Race



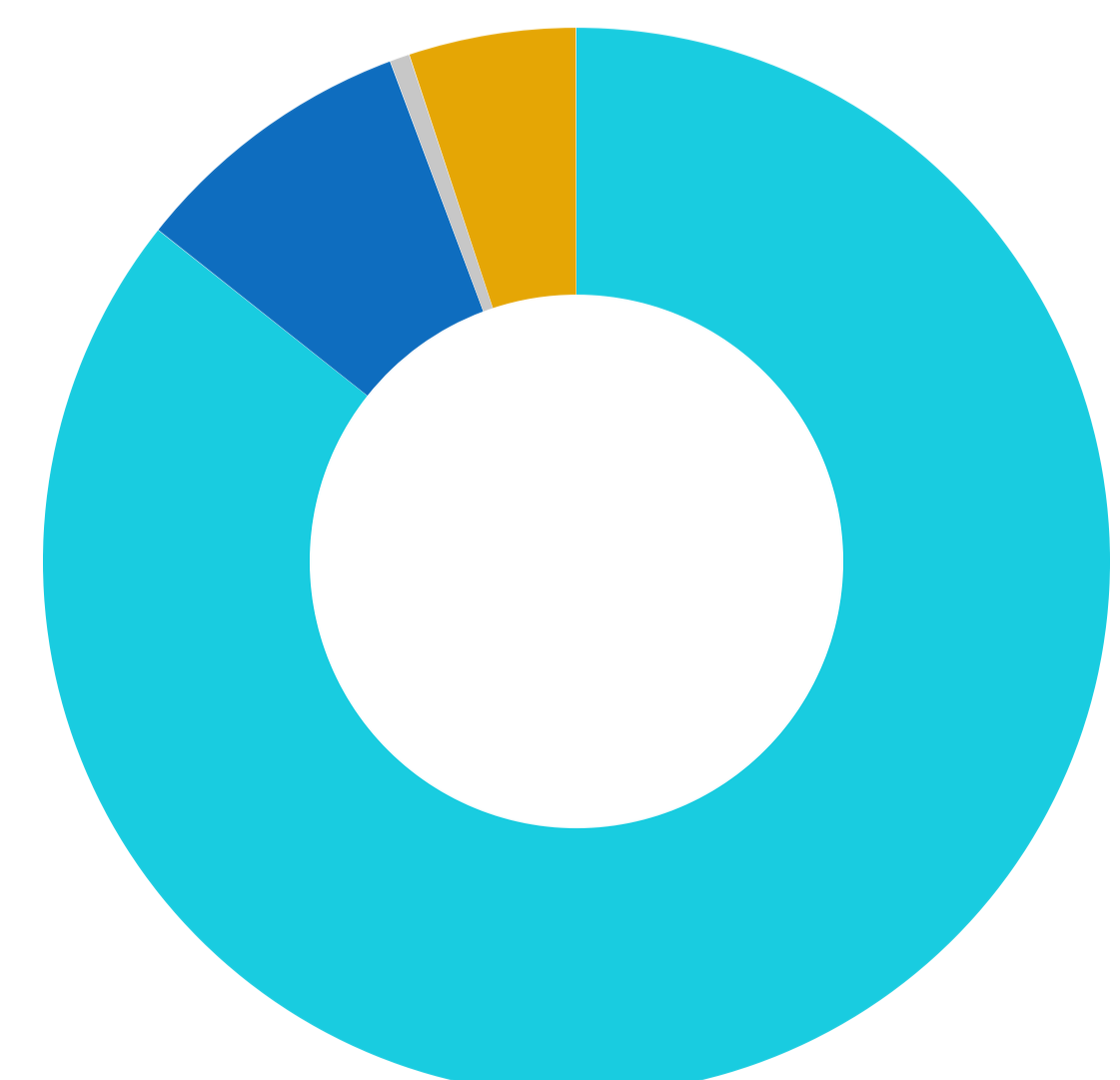
■ Native American (1.71%)  
■ Asian (3.7%) ■ Black (1.42%)  
■ Pacific Islander (1.71%)  
■ White (86.04%) ■ Other (3.42%)  
■ Prefer not to answer (1.99%)

Ethnicity



■ Non-Hispanic or Latino (88.06%)  
■ Hispanic or Latino (10.45%)  
■ Prefer not to answer (1.49%)

Sexual Orientation



■ Heterosexual (85.67%)  
■ Sexual minority (8.66%)  
■ I don't know (0.6%)  
■ Prefer not to answer (5.07%)

# COVID-19 & Health Care

## 45.7%

**Skipped or delayed health care**

The pandemic has had substantial impacts on the timing of AYAs' health care. Since the COVID-19 pandemic started in March 2020, nearly half (45.7%) of AYAs who took the survey reported either delaying or skipping a health care appointment.

In efforts to keep patients safe and distanced from others many health care appointments moved online. Since the COVID-19 pandemic started, 67.2% of AYAs who took the survey attended an appointment using telehealth.

## 67.2%

**Attended an appointment using telehealth**

## 35.1%

**Reported worse quality of care due to telehealth**

However, while telehealth may reduce exposure to COVID-19, quality of care may be at risk. Of those who switched to telehealth during the pandemic, over one third (35.1%) reported worse quality of care.

# COVID-19 & Employment/Finances

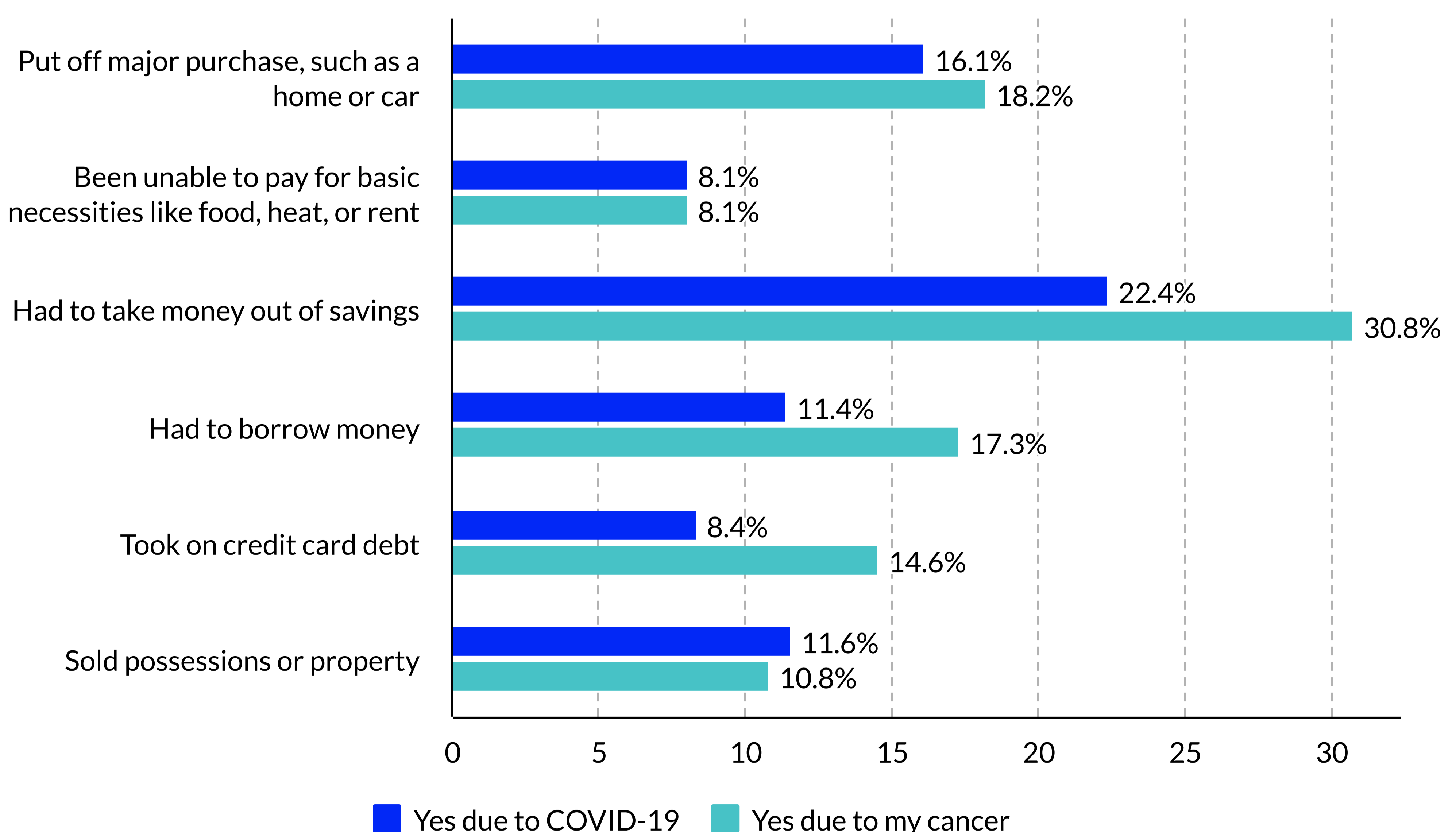
## 29.3%

**Report a reduction in their hours including furlough and being laid off**

Nearly a third of AYAs who were employed when they took the survey reported a reduction in their hours since the pandemic started. The reductions include being furloughed and laid off completely. The extent to which COVID-19 vs. cancer vs. other factors influenced this decrease warrants further research.

## COVID-19 and Cancer's Impact on AYA's Finances

While COVID-19 has affected the finances of AYAs, we also know that cancer treatment can affect finances. Participants indicated that both COVID-19 and cancer had negative effects on several financial aspects of their lives, including:



\*Percentages equal more than 100% as individuals could pick choose multiple options.

It has been a difficult year financially for many AYAs. As the pandemic continues, many AYAs may still face health care, financial, and employment challenges. We list some resources on the next page that could help. Also, please reach out to the HIAYA patient navigators if needed.

# 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 Staff Spotlight

## Mark Lewis

HIAYA Co-Medical Director and Oncologist

Meet one of the wonderful leaders of the HIAYA program, Dr. Mark Lewis. Mark joined HIAYA in 2016 at the same time as the original patient navigator, Sara Salmon. He is an oncologist at Intermountain Healthcare. Mark is a fierce advocate for meeting the needs of AYA cancer patients and survivors. He is a frequent guest on AYA-specific platforms including our own Young Adult Connections as well as events like *YA Cancer Gabfest*, hosted by Elephants and Tea and Lacuna Loft. If you haven't had the pleasure of meeting Mark, check out his Twitter where he is guaranteed to make you laugh and maybe learn something new (twitter handle: @marklewismd)!



**Could you tell us a little bit more about what you do in your position with HIAYA?** AYA cancer has always been an interest of mine, especially – selfishly! – since I myself had cancer; I have a genetic predisposition to cancer that I have passed on to my son. Accordingly I am very interested in young-onset malignancy, specifically in the genetic context. What I try to do for HIAYA is provide guidance on what I perceive to be the needs of the AYA population from the patient-physician perspective.

**Why are you passionate about working with AYA cancer patients and survivors?** I diagnosed myself with my tumor syndrome when I was 30, when I was an AYA myself! I saw how it changed my professional development and family life, including having children. I have always been very lucky working in the medical field that my employers have been understanding and encouraged me to be vocal about being an AYA patient. Having been given that privilege, I have been very deliberate about being an exhibitionist when it comes to my experience as I know that many young people cannot, for fear of losing their confidentiality, being discriminated against, or because of the stigma that still exists for young people with cancer. As far as working with patients after treatment, oncologists are almost victims of our own success. As medicine progresses and we cure more and more young people, we now have to deal with the darker side of long-term survival, including late effects and second cancers. We as oncologists cannot ignore how the treatment we use now may impact later quality of life.



*(Dr. Lewis as his medical school rapper persona: Slim Pasty)*

**What is the hardest thing about treating AYAs?** One problem that we have in the United States is that our definition of AYA is very broad – 15-39 years of age. This definition is great because it is inclusive, but also challenging because it really spans two disciplines: pediatric and adult oncology. Some adult oncologists get quite uncomfortable treating young patients, younger than 21, as most patients in oncology are much older. So there comes a time when patients who were diagnosed younger must transition their care from pediatric to adult oncology. This proves difficult both for the patient and providers to ensure continuity of care and trust. Often AYAs may feel to an uncomfortable extent like they have to be in charge of their own care when bridging the gap between the two disciplines.

**How do you have time to be Twitter famous and a doctor?** My wife always says that I am addicted to dopamine, which is probably fair! Honestly it is a

wonderful outlet for me, it is like a mini-escape from the gravity of patient care. On the more serious side I use Twitter to curate new medical information that is constantly coming out. I started my Twitter account in 2012 when it was almost seen as unprofessional or frivolous, whereas now it seems almost mandatory for oncologists to use it to keep up with advancements in the field and new research. Another benefit of Twitter is that lots of my AYA patients follow me and are digital natives, so in a way my Twitter humanizes me to them. Oncologists are just people too and hopefully my Twitter helps soften the image of the oncologists and potentially lead to more trust and shared decision making.

**What have you been doing to have safe, responsible fun during the pandemic?** I have been able to reconnect with my high school friends through text and Zoom happy hours. It is pretty common for doctors during med school and training to lose touch with friends outside of healthcare, so it has been really great to reconnect to lighten the seriousness of this year.

**What was your favorite vacation and why?** I am Scottish and half of my family comes from an island off the coast of Scotland called Islay. We have had some really wonderful times there on vacation. We took a trip a couple of years ago where I got to show my kids the house that their great-great-great-great-grandmother grew up in. That was my favorite vacation because it had so much familial meaning.



# Join an AYA research study!

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



## 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](mailto:Karely.Mann@hci.utah.edu).

## SNaSI Study

COVID-19 is making it harder for a lot of AYAs to get the social support they may be used to or need. Are you getting the social support you need within your support system? We'd like to hear how you are doing during the pandemic.

- We are recruiting AYAs who were diagnosed with cancer in the last 5 years and one of their support persons
  - AYA and support person must sign up together
- Participants receive up to \$150 in gift cards for participating in the study

Interested in participating? Contact Kelly Mansfield at 801-548-8840 (text or call) or at [SNaSI-Study@utah.edu](mailto:SNaSI-Study@utah.edu).



## 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](mailto:bhofacre@email.arizona.edu) (habla español) or Ana Acuña Morales at 520-235-9186 or [aam1@arizona.edu](mailto:aam1@arizona.edu) (habla español)

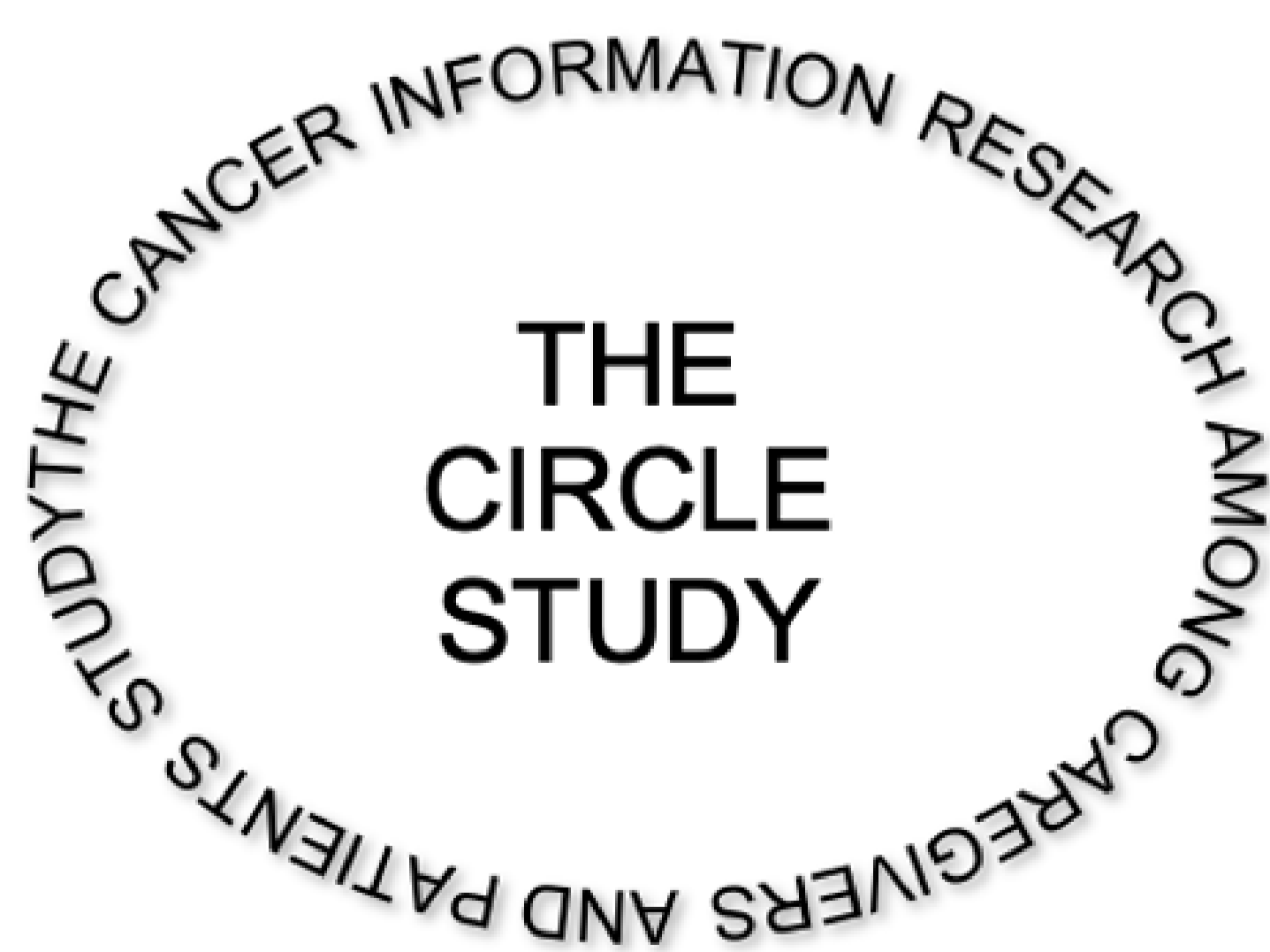


## CIRCLE Study

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.

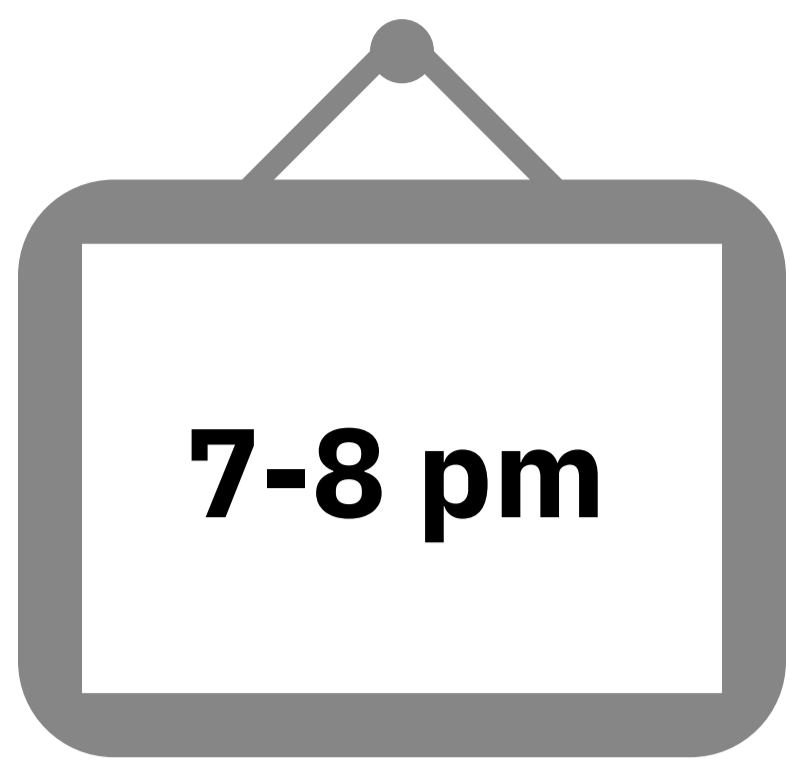
- We will ask you and your family member or friend do an online survey and a telephone interview.
- It will take about 30-60 minutes total to be in the study
- Participants and family member or friend will each receive a \$40 gift card for participating.

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



# Young Adult Connections

**Young Adult Connections will now be held twice a month!**



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



**YOUNG ADULT CONNECTIONS**  
FOR CANCER PATIENTS, SURVIVORS, AND CAREGIVERS  
AGES 18-39

**HAVE YOU EXPERIENCED CHEMO BRAIN?**

**Special Guest**  
**Cecily Huff Smith RN**  
Cancer Survivor and Oncology Nurse Navigator  
Intermountain Healthcare

**FEBRUARY 3 (WEDNESDAY) AT 7PM**  
Please find Zoom Meeting Link and Meeting ID on our closed Facebook group page or send a request to [aya@imail.org](mailto:aya@imail.org)

**HUNTSMAN** UNIVERSITY OF UTAH **HEALTH** **Intermountain** Cancer Center **Intermountain** Primary Children's Hospital

**YOUNG ADULT CONNECTIONS**  
CANCER PATIENTS, SURVIVORS, AND CAREGIVERS  
AGES 18 - 39

**GAME NIGHT**

**HIAYA**  
CANCER CARE PROGRAM

**FEBRUARY 18, 2021 @7 PM**

PLEASE FIND ZOOM MEETING LINK AND MEETING ID ON OUR CLOSED FACEBOOK GROUP PAGE OR SEND A REQUEST TO [AYA@HCL.UTAH.EDU](mailto:AYA@HCL.UTAH.EDU)

**HUNTSMAN** UNIVERSITY OF UTAH **HEALTH** **Intermountain** Cancer Center **Intermountain** Primary Children's Hospital

## 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](mailto:aya@imail.org) or 801-507-3889



@HIAYACANCER



@HIAYACANCER



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