Adolescent & Young Adult Cancer Newsletter

HIAYA
CANCER CARE PROGRAM

2023 Spring Newsletter

A Special AYA Awareness Edition

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

- AYA Awareness Week and a message from your HIAYA team!
- AYA Happenings
- Cancer Apps
- AYA Resources
- HIAYA Patient Spotlight
- HIAYA Caregiver Spotlight
- AYA Poem
- Research Study Opportunities
- Huntsman's and Intermountain's HIAYA websites

To subscribe to the HIAYA Newsletter CLICK HERE

Warm Hellos from HIAYA Leadership

In this special AYA Awareness newsletter, we wanted you to know that there are many people working to improve the care of AYA patients. There are many on your HIAYA team, working with you and sometimes behind the scenes, and are striving to improve the lives of AYA cancer patients, survivors and caregivers. We wanted you to meet them!

Our team – Dr. Anne Kirchhoff, Karely van Thiel Berghuijs, Heydon Kaddas, Perla Vaca Lopez, Austin Waters, Amy Chevrier, Monique Stefanou & Katie Rogers – are focused on understanding the health care needs of young cancer patients like you or your loved one! We are located at Huntsman Cancer Institute and involve young cancer patients (and their caregivers) from both the University of Utah and Intermountain clinics in our research. We also work on national studies that include patients from all over the country, including Kaiser Permanente in California, University of North Carolina, St. Jude Children's Research Hospital, and Wayne State University, among others. Some of our health care needs research includes understanding how health care costs during and after treatment affect patients, how to improve patient knowledge of health insurance, and what sort of health problems – known as late effects – patients experience after cancer treatment, with the goal of identifying solutions to these needs. Lately we've tested a new health insurance education program created specifically for young people going through cancer treatment. We are so grateful for all the support we have gotten from participants in our studies!

Intermountain Health oncology team: Dr. Mark Lewis, Rachel Montague, Zach Butterfield, Chelsey Winegar- specialize in the treatment and care for young patients and their families. We are located at Intermountain Medical Center but participate in the care of patients from all corners of the state. The Intermountain team will be utilizing the most up to date treatment options as well as identifying any barriers the patient may face during their treatment. Some of these needs may include but not limited to treatment planning, management of treatment side effects, addressing mental health concerns and psychosocial needs, and optimizing individual wellness. These experts address the patient as a whole, instead of only focusing on medical treatment. As part of this program, we have had the pleasure of Rachel and Chelsey leading several of our AYA connection groups discussing self-worth, emotional regulation, and ambiguous loss. Zach helps provide resources to cancer patients, and help with the HIAYA Young Adult Connections events. The Intermountain team is excited to continue the work with the AYA community and build upon the relationship to better serve this

population.

Hi AYAs!
PCH LOVES AYAs!
Pictured is (part of) our Childhood and AYA Cancer Survivorship Team- showing our support and love for AYAs.
At Primary Children's Hospital we have a Survivorship Clinic dedicated to the care of survivors of childhood and AYA cancer.
We see patients from 1 year old up to 39 years old (partly because we know the transition from pediatric providers to adult providers is tough!)
At Primary Children's Hospital we also have a AYA team that helps address all of the major issues of being diagnosed with cancer as an AYA: best treatment protocols/ clinical trials, psychosocial/ educational, oncofertility, cancer genetics, and survivorship!
Thanks for being an inspiration and trusting us with your care!
- PCH Childhood and AYA Cancer Survivorship Team
Stephanie, Taumoha, Kasey, Sam, Ashley, Doug (pictured from left to right); Kameron and Kellee (not pictured)

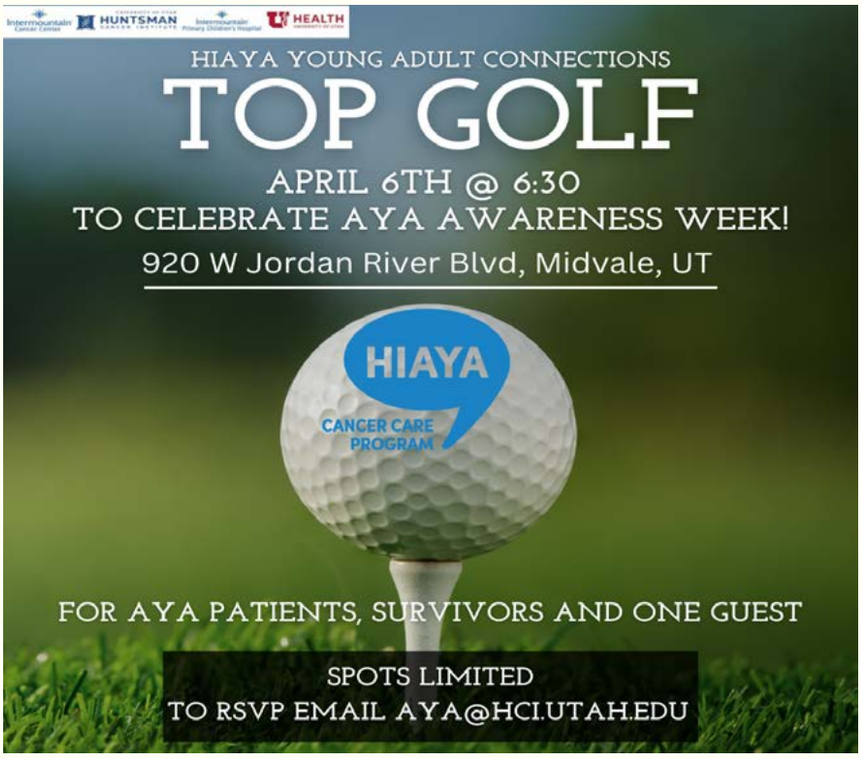
We are the some of the Patient and Public Education Department at Huntsman. We are a team of community outreach members, cancer learning specialists and patient navigators. We all work with the AYA population in some way and work with patients and behind the scenes to improve care of AYA patients, whether it is raising awareness, promoting screenings, answering cancer and cancer care questions, or helping patients navigate the health care system and the cancer experience, making TikToks to provide further education, or planning young adult connection events, we are here to provide support to the AYA cancer community!

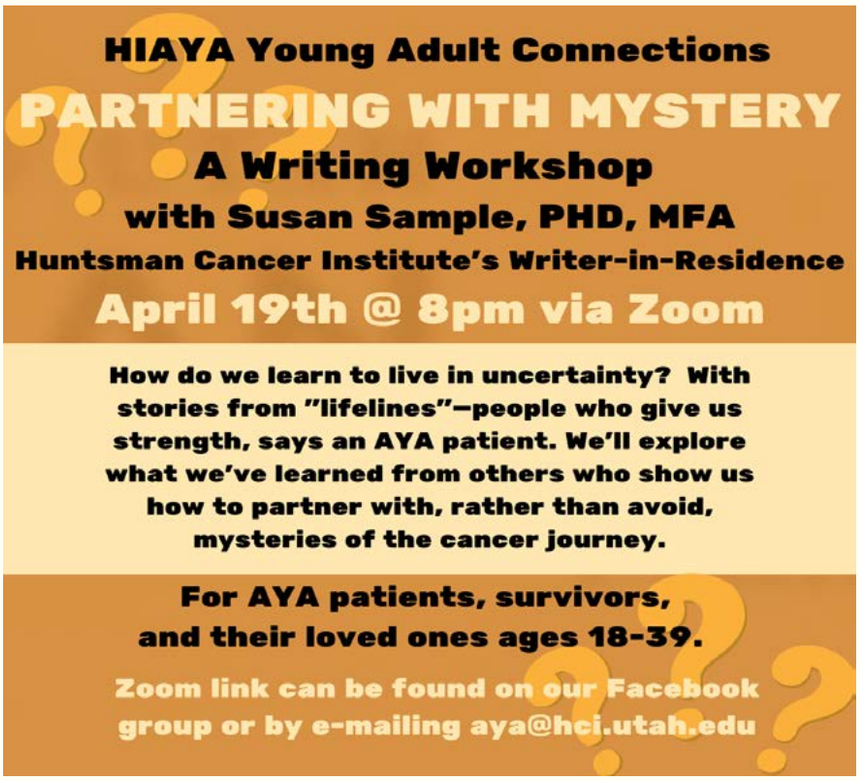
AYA Happenings

HIAYA Young Adult Connections

Our Young Adult Connections events are for AYA patients and their loved ones between the ages of 18-39. We have been having a great time the past few months! Check out the HIAYA Instagram and Facebook for information about the events. We hope you all will join us in the future!

Upcoming Events





AYA National Events

ELEPHANTS AND TEA

Check out Elephants and Tea's website to see what fun, supportive, and informational events you can join in your AYA community nationwide!

Click here to access the website

DIGITAL CANCERCON

FOR ADOLESCENTS & YOUNG ADULTS

Presented by stupidcancer

April 16 - 30, 2023

Digital CancerCon this year kicks off on Sunday, April 16th, but it will look a little different. Instead of being just one action-packed weekend of fun, education, and networking with your AYA friends and peers, join us on YOUR schedule over two weeks. There will be a mix of recorded presentations and live discussions, so you can meet and learn from your AYA cancer community on your own terms during those two weeks.

Click here to register

Cancer and Supportive Apps

BELONG Beating Cancer Together

- Interactive community
- Treatment navigation tools and tips
- Digital medical binder that can be shared with friends and family
- Clinical trial matching services
- Reminders and calendars
- Message boards where you can discuss topics with other cancer survivors anonymously

Caring Bridge

- Offers a safe secure place for patients and caregivers to share health updates, and for family and friends to respond with messages of support
- Can connect to GoFundMe
- Has 3 privacy settings

LivingWith Cancer Support

- Share how you are feeling. Track mood, pain, sleep, and steps
- Integrates with health apps and weareables
- Data to share with doctor
- Stay connected with loved ones
- Take notes and questions for doctor
- Stay organized, keep results, list of meds, and insurance

ChemoWave: Cancer Health Diary

- Helps track symptoms, medications, nausea, fatigue, anxiety, and constipation
- Track sleep, water consumption, how much you walk, and mood
- Helps you manage tasks so you can take control of ups and downs during treatment

CancerBuddy

- A social network for people facing cancer
- Find people who share your diagnosis, location and interest
- Resources, support groups led by medical professionals and counselors

Abridge for Patients

- Record your doctors visits
- Get transcribed summaries
- Confirm changes to your medications
- Find definitions, savings and more

Spring/Summer Outdoor Adventures

This is the time to continue living your life to the fullest beyond cancer. Get outdoors with other young adult cancer patients and survivors, talk about your experiences and build a community. It's time to get out of your comfort zone and try new things! Here are some resources to get you outdoors and explore different places, along with some other resources to help you thrive beyond cancer.

The Cassie Hines Shoes Cancer Foundation Base 2 Summit - A weeklong adventure in northern Michigan for AYAs 18-39 years old. Outdoor opportunities include hiking, kayaking, and biking. Free survivorship program that encompasses airfare, transportation, food, and more.

Project Koru - Connect with fellow survivors during a weeklong adventure camp. Survivors have the option to choose between an adventure by the ocean or in the mountains. Everything is included except airfare.

Dear Jack Foundation - The Breathe Now Wellness Retreat helps harness the transformational powers of yoga. Helps couples renew, learn and grow post-cancer. Available to AYAs 21-39 years old and their partners.

First Descents - A life-changing opportunity for young adults. Different opportunities are offered across the U.S for AYAs between 18-39 years old available to caregivers and other individuals with serious health condition and their partners.

Send It Outdoor Activities - Northern California adventures for AYAs 21-40 years old. Enjoy skiing, surfing, backpacking, rock climbing and more. Free activities and organization can help subsidize travel cost.

True North Trek - Go on a trek with other AYAs between the ages of 18-39! Some treks have the opportunity to bring a caregiver. Opportunities are all free to join.

Epic Experience Beyond Cancer - Weeklong outdoor an in Colorado for AYAs 18+. Activities for the winter and summer months such as skiing, snow shoeing, hiking, water rafting, and more! Activities are free to join.

HIAYA Patient Spotlight

Mark

Meet Mark, a member of the HIAYA fam. We are so grateful that Mark would share his story and experience with his HIAYA community!

Can you tell us about yourself?

Hello fellow AYA patients! My name is Mark Seguin. I have three sisters and a brother and stellar parents. I'm 37 years old. My wife, Michelle (who is an absolute legend, btw) and I have two boys, 10 and 7 years old. As a family, we enjoy the outdoors and traveling quite a bit. Usually, we stick to road tripping and don't stray too far from home; places like southern Utah, Moab, and various lakes and reservoirs to go boating and enjoy the "beaches". Beyond that we have family in Florida that we visit occasionally and have even been lucky enough to visit extended family in Ireland a few years ago.

Some hobbies I have personally are snowboarding, basketball, general fitness, mountain biking (the mellow kind) hiking, and really anything outdoors. I try not to take living minutes away from the Wasatch mountains for granted. Having a family is something I have always wanted and sharing my hobbies with my children is an absolute privilege! For example, I never thought that snowboarding could be more enjoyable than I had experienced for myself, and now seeing my boys learn and being able to ride with them at Brighton makes the experience special almost beyond description.

What is your cancer story?

My cancer story really starts in April 2020. That's not when I was diagnosed but with pandemic hitting full force I committed to a structured at-home fitness plan. I stayed committed and was slowly building a home gym. I was making really great progress physically and was kind of re-learning how to be "in tune" with my body.

In September that year I had, what I would come to find out later, my first symptom of colon cancer. I got a cramp in my gut that was bad enough to keep me in bed for half a day and I missed work. Next day? Felt much better, assumed I had eaten something that disagreed with me. Life went on. In October, my family and I were on a road trip to Southern Utah and about a quarter of the way into the drive, I got another cramp. Wow, that's weird, I must have eaten the same food or something that caused this last time. "Luckily" it wasn't as bad as the one from the month before and we continued our trip unencumbered.

December 2020. The month my life changed forever. The cramping returned. It was worse this time. Eventually it started to "localize" to my lower right abdomen and my wife took me to the ER. I honestly felt kind of dumb going to the ER for "cramping" but I knew something wasn't right. They took scans which came back showing "inflammation" in my gut. The ER doctor asked me about my family cancer history, which scared me a bit. Upon discharge I was referred to a gastroenterologist, whom I saw on December 9th. I asked him about the ER doctor's comment about cancer history and he said based on my demographics and health status he didn't think it was cancer (womp wah). Regardless, we proceeded with a colonoscopy.

My first colonoscopy was done on December 16, 2020. I was 35 years old; TEN YEARS younger than the recommended screening age. All because of cramping which the gastroenterologist was pretty sure wasn't cancer. Turns out it was cancer. I'll never forget the look on his face when he had to tell me they found a mass that "looks like cancer". Maybe it was the propofol, but my first reaction was "What do we do next?". Honestly, that has been my outlook throughout this whole thing. Don't get me wrong, I have certainly had my fair share of breakdowns, doubts and nightmarish fears, but I have tried to keep the focus on relentlessly moving forward.

From that point, I had a successful colon resection which eliminated 18-24 inches of my guts, along with the tumor. Unfortunately, it had spread to lymph nodes, so I was diagnosed with Stage III colon cancer at the age of 35. From there I did chemo (oxaliplatin and capecitabine) for a few months. Side effects messed me up pretty bad. I lost almost 40lbs. That cold sensitivity and general malaise is no joke. However, with a TON of support, I made it through. Ringing that bell was incredible!

I know that's a lot, but it helps to give context so you know what I mean when I say you absolutely MUST listen to your body when it is whispering so that you don't have to deal with it when it is screaming. Multiple doctors have told me if I had blown off the colonoscopy, even for a couple months, my outcome would have been "a totally different story".

Fast forward to March 2023, life is pretty normal for me now (other than the occasional bout of existential dread ;)). I have been getting scans every six months and I do blood work monitoring every three months and I am currently cancer free! I'm still in the midst of the highest risk period for recurrence, but am doing everything I can to prevent it; basically eating healthy, being as active as possible, working out daily, and taking baby aspirin every day.

What made you want to be a part of HIAYA and share your story?

I'm lucky to have a great support system. Even with that, it's really cool to know this group of people exists where we can go to be around peers with similar life experiences. Also, I want to take advantage of every opportunity to spread awareness and remind people that YOU must be your own biggest advocate, trust your instincts, get second opinions, and be generally in tune with your body.

What are some of your life goals?

My biggest goal is to continue to do my best to be a good husband and father. Beyond that, I want to stay active and fit so I can share in the hobbies that my kids pick up. A newer goal is to use my cancer story to raise awareness. Colon cancer in the AYA community is predicted to become more and more prevalent and people need to know what to look for and get screened as early as possible.

What is your favorite trip you have taken and why?

I mentioned it before, but our family trip to Ireland was an absolute dream. We went in January so it was cold, but that also made for less tourists. Some highlights: getting to spend time with my wife's extended family there, the Titanic Museum, a double decker green bus tour through Dublin, seeing the Northern Ireland coast with a fresh coat of snow, a clear afternoon and sunset at the Cliffs of Moher, and some delicious food.

HIAYA
Caregiver Spotlight

Carrie

Meet Carrie a member of the HIAYA fam and an AYA caregiver. We are so grateful that Carrie would share her story and experience with her HIAYA community!

Can you tell us about yourself?

I was born in Pocatello, Idaho and grew up in Lava Hot Springs. I currently live in Chubbuck, ID. My husband and I have been married almost eight years. We have a daughter who is 5 and a son who is almost 2. We also have a goldendoodle named Link.

What is your cancer caregiver story?

My husband is a police officer and started to have lots of hip pain in November 2021. We thought it was just from all his gear. He had an MRI to see what was going on. His MRI was abnormal so lots of testing was done. All his labs came back fine. They ran so many tests and scans and finally after almost two months of waiting and wondering, we found out on March 6, 2022, he had Acute Lymphoblastic Leukemia with extramedullary involvement. It was a relief to know his diagnosis after being told so many possible things. On March 8, we were told to head down to Utah. We left our two kids and didn't know when we would see them again. Our son was only 10 months old, and we had never left him at night. It was one of the hardest days of this whole journey. Kenny was admitted to Huntsman for about 3.5 weeks the first time. He was sent home and was to come back for weekly chemo. After only two weeks of being home, his pain returned but worse this time. Seeing Kenny in pain was the worst part. I had watched him be in pain the last five months and seeing the pain come back was heartbreaking. Kenny was told to head back to Huntsman where we learned that the chemo was not working and the disease was progressing. A new pet scan showed a seven-inch tumor in his hip that was beginning to affect his blood vessels. He was admitted again two days before our son's first birthday and Easter. This was just the beginning of all the holidays and events that Kenny would miss out on. No chemo was working on Kenny's cancer and even the doctors at Huntsman were having to reach out. At one point, they were honest with us and said they weren't sure they would be able to heal Kenny. Kenny did Car-T in July and was cancer free after it. It was truly a miracle because nothing else was working. He also had no pain which he hadn't had in so long. The next step was a bone marrow transplant. Nothing in our journey was easy. He had donors fall through, ended up getting a surgery and having Covid which delayed the transplant. On November 17, he was finally able to get his transplant. He spent 3.5 months in Utah including all the holidays. On February 27, he was finally able to come home, and he is officially cancer free. Kenny is planning on going back to work in April, and he is so excited!

No one knows how hard it is to be a caregiver until you actually are one. Kenny never really needed any physical help, but I was always emotionally and mentally drained. I was trying to work full time, be a single mom when Kenny was admitted, and trying to see Kenny as much as I could while being 2.5 hours away. Leaving Kenny to go back home to my kids and my job was the hardest thing to do. I am so grateful for the staff at Huntsman who took care of Kenny and was his friend when I couldn't be there. I had to learn to accept help and even ask for help because we couldn't have survived the last year without the help of so many people.

What made you want to be a part of HIAYA and share your story?

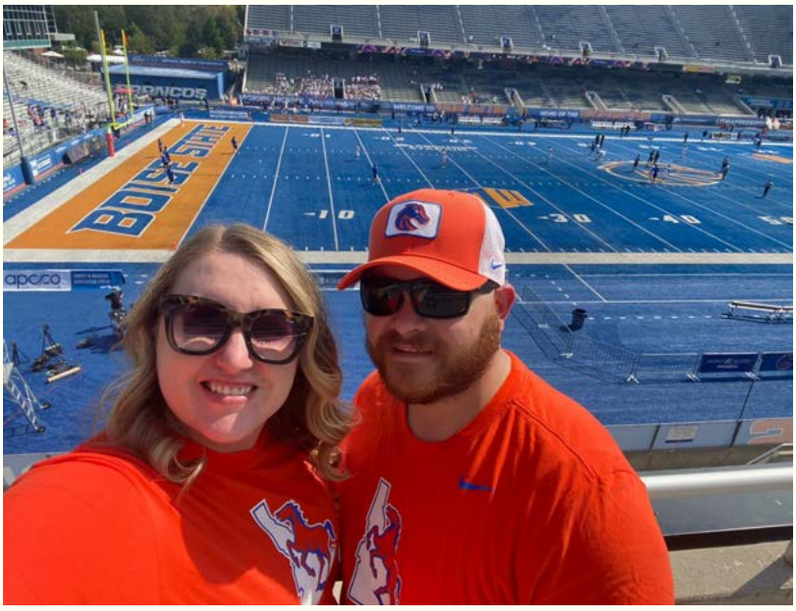
We wanted to be part of HIAYA so we could hear other peoples' stories who were going through the same things as we were.

What do you do for work?

I have been a Registered Nurse at Portneuf Medical Center for 11 years. I worked on medsurg, labor and delivery, and am currently a nurse informaticist. I help train and support providers on our EMR.

What is your favorite trip you have taken and why?

One of my favorite trips was going to the Oregon Coast with my husband on our first-year anniversary. We stayed in an ocean front condo and were able to hear the ocean every day. We saw lots of beaches, went on hikes, went to the zoo, deep sea fishing, and went on a private salmon fishing trip. We are going to take our kids to Disneyland in September so I am sure I will have a new favorite trip after seeing the Disney magic through their eyes for the first time. We were supposed to go in October of last year for my daughter's birthday, but instead we were prepping for transplant.



AYA Poem

This beautiful poem was written by Huntsman Cancer Institute's writer-in-residence by using words and insights provided by AYA patients at one of our young adult connections writing workshops. We wanted to share these touching words with you all.

Found in the Journal of Adolescent Health

NADIE TE QUITA LO BAILADO

(No one can take away what you have danced)

*Imagine a prom...*I say to the girls,
eyes without lashes, scalps sculpted by chemo.
They live at a crossroads of scars: fingertips
tracing tender ridges; palms spread wide
across wombs they call *Perhaps...*
To them, prom is a tradition meaningless
as *ever after. Happily* is right now.
So what will you wear?
On the screen, one young woman rises
from her couch: *Knee pads and combat boots*
so I can balance. Bright red lipstick

and oh, real fluttery lashes!
Another gestures, her hand seeming
to reach across the grid: *I'd twirl in a skirt*
of tie-dyed silk in all different colors, you know?
I'd wear a Grecian toga for camouflage, says the girl
who describes her chest *concave. Golden gladiator sandals*
'cause I've got bad neuropathy, and I'd wear a wig,
bejeweled with lots and lots of curls!
The oldest, dark hair falling out a second time,
raises her arms higher than her shoulders:
My skirt is red and black, a full circle
when I swirl. My blouse has spaghetti straps,
and I'm dancing with everyone, even my uncle who says he can't!
Even me, her hands inviting mine in and out, in and out
to the salsa beat. And then she breaks away to syncopated shouts--
Oh yeah! Oh yeah!—shining under a starless sky.

Research Study Opportunities

We are exploring ways to curb the influence of online cancer misinformation on cancer patients. A major roadblock to stopping cancer misinformation is that scientists do not have a good way of measuring how much online misinformation

cancer patients are exposed to. Fortunately, there are new technologies that are commonly used in the workplace that have the potential to solve this problem and help us to stop the spread of harmful cancer misinformation.

For more information reach out to Echo Warner at Echo.warner@nurs.utah.edu

MEASUREMENT AMONG CANCER PATIENTS

The COMET Study is looking for participants.

FOR MORE INFORMATION, CONTACT US:

ECHO.WARNER@NURS.UTAH.EDU

Learn more about clinical trials at Huntsman Cancer Institute

WHO CAN PARTICIPATE?

- Are you 18 years old or older?
- Were you diagnosed with cancer in the last 5 years?
- Do you use a smartphone, tablet, or computer to search for cancer information?

WHAT IS REQUIRED?

- Baseline survey
- One month of web monitoring
- Follow-up survery

Each participant who completes the study will receive a $40 gift card at the end of the study.

Study Opportunity for Patients and Caregivers who Identify as LGBTQ+

Purpose:
We want to listen to the voices of LGBTQ (lesbian, gay, bisexual, transgender, queer, questioning) patients and families with the goal of assessing the current state of LGBTQ-inclusivity at Primary Children's Hospital (PCH), with emphasis on LGBTQ-inclusivity for patients and caregivers of patients with life-limiting or life-threatening illnesses.

Eligibility:

- 10 years old and older
- Received (or has a child who received) inpatient or outpatient medical care at PCH in the last two years, including bereaved parents
- Self identify as LGBTQ (lesbian, gay, bisexual, transgender, queer, or questioning) or is the caregiver of an LGBTQ patient
- English speaking

Patients and caregivers who enroll will complete a 45 min to 1 hour interview where they will be asked about their experiences at Primary Children's Hospital and their thoughts about LGBTQ inclusivity.

Participants will be given a $20 gift card for their time and contribution to the study.

CONTACT:
Bridget Dorsey
Email:
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Phone:
801.829.8579

Scan this QR code to take the screening survey and

Contact a Navigator

aya@hci.utah.edu

aya@imail.org

Huntsman Cancer Institute - HIAYA Website

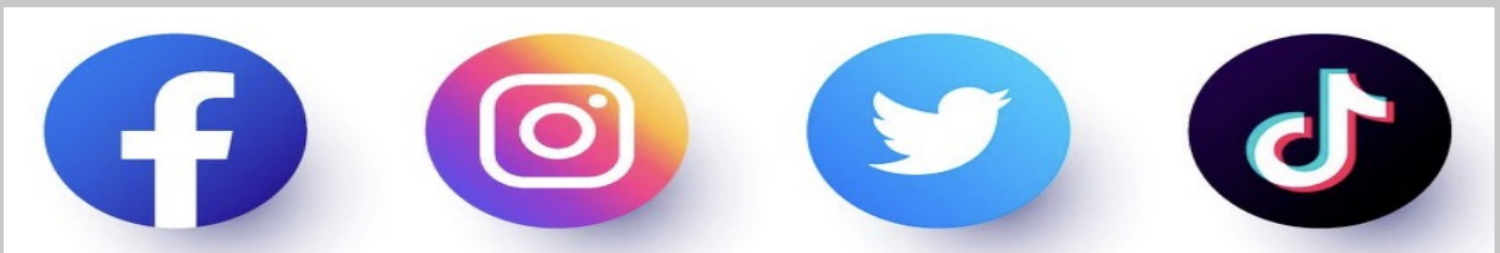
Intermountain Healthcare - HIAYA Website

Reach out today if you or a loved one would like more assistance with any of these:

- Community resources
- Education
- Employment
- Fertility
- Financial services
- Support and connection
- Wellness resources
- Insurance questions
- Survivorship
- Other concerns

Stay Connected!

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



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