



Global
Resource for
Advancing
Cancer
Education

SAYING YES

**Courage, resilience, and unwavering
determination in the face of a cancer
diagnosis**

Chaundra Bishop

C A N C E R G R A C E . O R G



SAYING YES

Chaundra's story is shared by the Global Resource for Advancing Cancer Education (cancerGRACE.org) as part of the Patient Perspectives - Clinical Trials Experiences Storytelling Program. This program aims to give those diagnosed with cancer a voice to share their experiences participating in clinical trials and help others understand the importance of participating in clinical trials.



CHAUNDRA BISHOP

is an 8-year cancer survivor. At the age of 29, she was diagnosed in June 2016 with Stage IV Intrahepatic Cholangiocarcinoma, non-resectable. Traditional chemotherapy worked to reduce the 13mm tumor discovered in her liver making her eligible for a resection in May 2017.

Unfortunately, after 8 months, Chaundra experienced a reoccurrence that she continues to battle. She is currently undergoing treatment for lung metastasis at the University of Chicago.

Since her diagnosis, Chaundra has not stopped living. She has maintained a full-time job since her diagnosis. Her work has focused on creating strategies to increase visibility, participation, and the well-being of underserved communities through health education and promotion. In her current role as a Champaign Regional Health Officer for the Illinois Department of Public Health, she consults with County Boards of Health and Local Health Department Administrators in interpreting public health rules and regulations and assists with planning and implementing policies and procedures in accordance with the Director's Office.

Additionally, Chaundra was elected to the Urbana City Council in 2021, serves on the Planned Parenthood Illinois Action Board of Directors, and is the president of the Urbana-Champaign chapter of Sigma Gamma Rho Sorority, Inc.

Chaundra holds a Bachelor's Degree in Biological Sciences and a minor in Chemistry from Quincy University, along with a Master's in Public Health Science from Western Illinois University. When she isn't working or volunteering in the Urbana area, you can find Chaundra traveling or reading a mystery novel!

C A N C E R G R A C E . O R G

CONTENTS

1
WHERE IT BEGAN

2
LIFE CHANGING RESULTS

3
UNKNOWN PRIMARY

4
BOOP

5
MEANWHILE

CONTENTS

6
UNDERREPRESENTATION IN CLINICAL TRIALS

7
STICKING WITH IT

8
BOLD DECISIONS

9
PERSONAL TRIUMPH

10
THE UNPREDICTABLE NATURE OF THE
DISEASE

1 WHERE IT BEGAN

In the tapestry of life, some threads are woven with unexpected challenges that test the very fabric of our being. Yet, it's often in the face of adversity that the most beautiful stories emerge, tales of courage, resilience, and unwavering determination. I am one with such a story. A story of a journey with Cholangiocarcinoma, which has become a testament to the power of resilience and the beauty of saying yes to life's myriad opportunities. From the moment I received my diagnosis, I have made a conscious decision not to let cancer define my existence. Instead, I saw this life-altering diagnosis as an invitation to explore the unknown, to venture beyond the boundaries of my comfort zone, and to seize each moment with unwavering determination.

My journey with cancer began in the summer of 2016 in June when I went for my annual checkup with my primary care physician. I had no complaints when I went in for my appointment, so everything proceeded as normal. My labs came back and I got a call from the doctor's nurse who told me that my liver enzymes were a bit high, but that could be due to various things and that the doctor wanted me to come in a few weeks to get the labs redrawn.

I went back and the enzymes were even higher and then a THIRD time I went and they were higher still, again!

She apparently didn't like what she saw and sent me to get an ultrasound of my liver. A mass in my liver was seen on the ultrasound but she told me not to panic, that sometimes masses are benign and because I was experiencing no symptoms, she couldn't imagine it being anything else.

2 LIFE CHANGING RESULTS

I prepared for a liver biopsy, with that in mind, feeling optimistic that it wouldn't come back as cancerous. The next thing I knew, I was getting a call from an oncologist's office to talk about the results of the biopsy.

I don't think there is another day in my life that I remember so vividly than the one when I heard the words, "It's cancer".

There I sat in the exam room across from the doctor whose words just changed my entire life. As he began explaining everything, he reached over to grab the tissue box and handed it to me; I declined the tissue with dry eyes and a racing mind.

I don't remember all the exact words he said, but when he finished, I simply said, *what do we do next?*



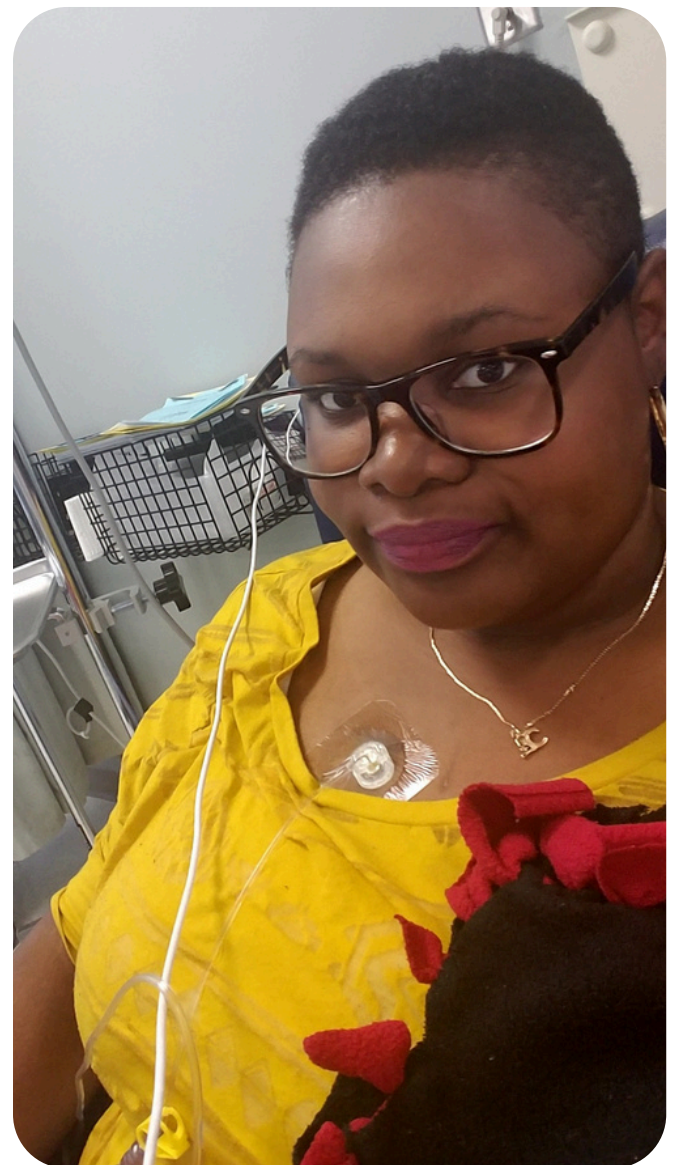
3

UNKNOWN PRIMARY

At that time, my oncologist had called my cancer one of unknown primary which meant they didn't know where the cancer had come from; I have found to be very common among those eventually diagnosed with Cholangiocarcinoma. I'm grateful to have found a doctor who didn't hesitate to research and consult with other doctors to find as many answers as I wanted.

I was finally diagnosed with Stage IV Bile Duct Cancer or Cholangiocarcinoma. I remember being devastated when they told me that I wasn't eligible for surgery -- That my tumor was too big to remove from my body, and I couldn't even fathom how that could even be possible!

With that news, I began chemotherapy, carboplatin, and gemcitabine, and was on that from August 2016 until May 2017 when my scans showed the tumor in my liver had responded incredibly well to the chemo and shrunk to an operable size.



Surgery, a liver resection, was scheduled for May 22, 2017. The liver resection which removed the tumor, my gallbladder, & about 60% of my liver was considered a success with clear margins. It took about 6 weeks to recover from the resection. Soon after I began an adjuvant treatment of capecitabine and gemzar and after about six months, my scans continued to show no evidence of disease. I was starting to get excited, I thought that after a little more than a year, my fight with cancer was going to be over!



4

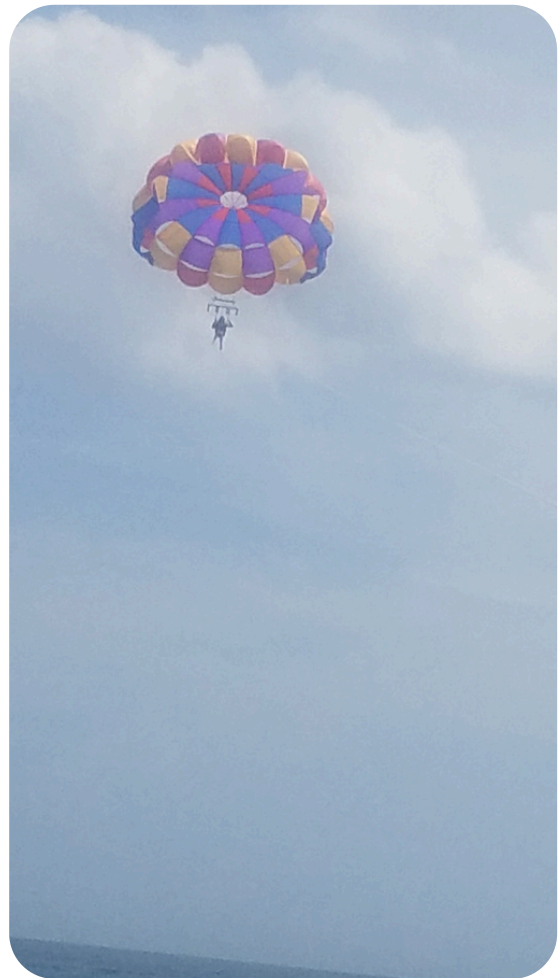
BOOP

My PET scan in January 2018 showed an enlarging mass on the lower left lobe of the lung which after biopsy showed bronchiolitis obliterans organizing pneumonia (BOOP). I remember saying, I don't know what that is, but it doesn't have the word cancer in it so I was relieved.



From parasailing in Jamaica

With the all-clear from cancer, I began taking the opportunity to really LIVE!



to ziplining in Costa Rica

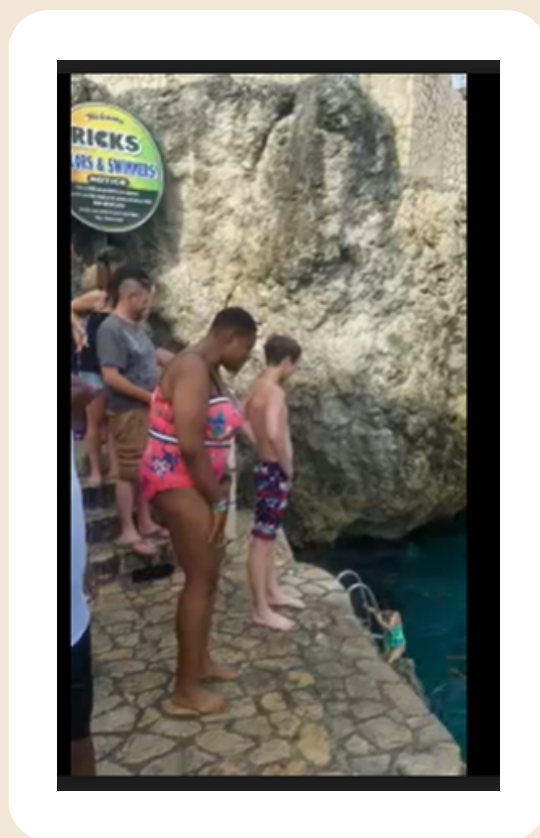


I fearlessly explored the world, refusing to let fear or doubt hold me back. Even the mishap of losing a pair of glasses in the waters of the Dominican Republic couldn't dampen my zest for life.

5 MEANWHILE

The weight of a diagnosis like this, one where the survival rate after 5 years is only 20%, could have crushed my spirit of many, but instead, I took it as a clarion call to live life with a newfound fervor, to seize each moment with a tenacity unmatched by adversity.

Cancer gave me every reason to say no, but I have defiantly lived the past seven years saying yes—to new experiences, new challenges, and new opportunities. My refusal to be defined by this diagnosis is a testament to the strength of the human spirit, a reminder that even in the darkest of times, there is light to be found.



Meanwhile, while I was busy living, the cancer was creeping back in.

In September 2018, my PET scan revealed disease progression with increasing size and numbers of pulmonary nodules ranging from 2-10mm. With that devastating setback, I began chemotherapy again, this time Gemcitabine & Oxaliplatin in October 2018. Eventually, the oxaliplatin was becoming too toxic for me so it was time for me to pursue other treatment options.

I had Genomic testing done which showed I had the FGFR2 mutation, which helped to inform me which clinical drug trials to pursue. Clinical trials serve as the cornerstone of medical advancement and pave the way for new treatments, medications, and therapies.

6 UNDERREPRESENTATION IN CLINICAL TRIALS

Participating in a clinical trial allowed me to gain access to cutting-edge treatments that may not be available otherwise. This can offer hope and potentially improved outcomes for individuals who have exhausted standard treatment options.

Many clinical trials for all types of disease research face the persistent challenge of the underrepresentation of minority groups.



This underrepresentation hampers the accuracy and effectiveness of medical research. Minority communities often experience different health concerns or respond differently to treatments due to genetic, cultural, or environmental factors.

Without their representation in clinical trials, medical advancements may not accurately reflect how treatments work across diverse populations. This disparity perpetuates health inequities and hinders advancements.

My enrollment in my first clinical trial came when I started seeing an oncologist at Siteman Cancer Center at Barnes Jewish Hospital in St. Louis, three hours from my home. At that time, it was one of the toughest things I'd ever been through. The trial, which didn't have a name, and just went by a bunch of letters and numbers, was a Phase 1 trial that involved Toll-like Receptors that stimulated an immune response.

The drug was administered subcutaneously on Day 1, Day 8, and Day 15 in 28-day cycles. After each and every single injection, 6 hours later I would develop rigors, fever, and tachycardia – which is why in the beginning I would have to stay overnight at the hospital.

I said clinical trial participation is necessary, but not easy!

Amidst the rigors of treatment and the uncertainty that comes with living with a chronic illness, I continued to work full-time.

Despite the grueling treatment, I embarked on a remarkable journey of both personal and professional growth; continuing to pursue my passion for public health with unwavering dedication. My commitment to making a difference in the lives of others led me to three career advancements in five years, landing a dream role with the Illinois Department of Public Health a couple of years ago.

Cancer gave me every reason to say no, but I have defiantly lived the past seven years saying yes.



7 STICKING WITH IT

Even though there were times it was so difficult, I stuck with it because I kept asking myself, what if it works?! And with a cancer as rare as mine, my participation in trials was even more important.

Eventually, I washed out of the Phase 1 trial in St. Louis due to disease progression in June 2020. It was disappointing, to say the least. Each time I had this feeling of being blindsided by this unexpected outcome. It left me with a sense of frustration and dare I say, even anger, directed towards the disease itself or towards the perceived injustice of the situation.

Alongside these emotions, there was also a sense of grief—a mourning for the hopes and expectations that were tied to the treatment's success. Dreams of remission, of returning to a sense of normalcy, all suddenly felt out of reach, replaced by

the stark reality of continued uncertainty and fear. But my eternal optimism didn't let me dwell in that headspace for long—it was time to regroup for the continued fight.



In July 2020, my oncologist let me know of recent FDA approval for an FGFR2-specific drug Pemigatinib or Pemazyre (Pem). I started this drug at 13mg, and saw positive response after the first eight weeks-- but eventually had to dose reduce to 9mg in December 2020 due to some unbearable side effects.

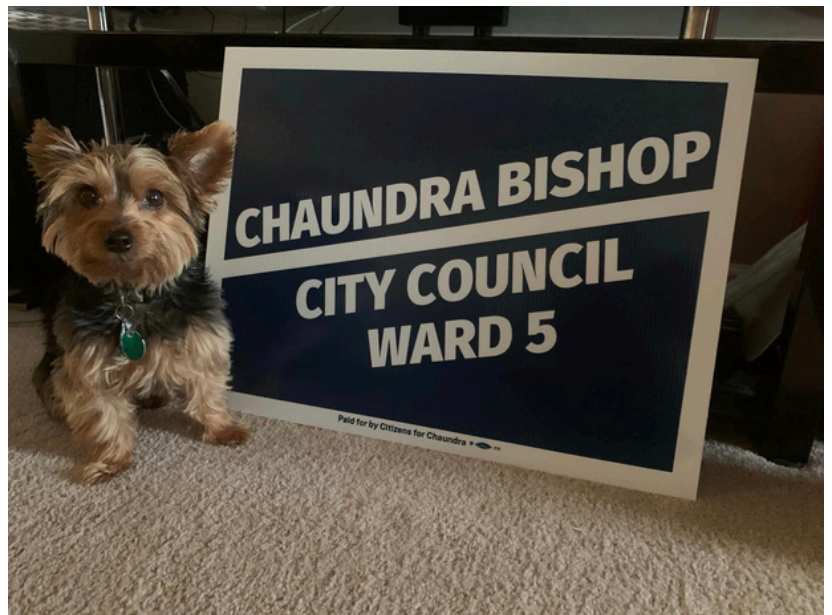
8 BOLD DECISIONS

I was on Pem until disease progression was spotted on a CT in December 2021. A realization I've had from this journey is that **I'm braver than I ever thought I was** and **I'm stronger than I ever believed.**

When you're diagnosed with cancer, a person is often thrust into a position of being brave. **Many times, we must be brave even when we don't necessarily want to be.** Additionally, cancer pushes you out of your comfort zone. It's WILD to think that if it weren't for cancer, I wouldn't have been brave enough to take the leaps I have.

In the same year, Pem stopped working, I was elected to the Urbana City Council.

Despite the challenges posed by cancer and the exhaustive side effects of treatments, I made a bold decision to run for city council, driven by a deep-seated desire to make a meaningful difference in my community.



This was the journey of getting out of my comfort zone and saying yes, after all.

6

PERSONAL TRIUMPH

When the votes were tallied, I had won overwhelmingly against my opponent. The victory was not just a personal triumph—it was a triumph for resilience, for perseverance, and for the unwavering belief that anything is possible, even in the face of the greatest of obstacles.

Also, that year, I had to again change oncologists, moving my care to the University of Chicago, which was two hours from my home. Under the care of Dr. Andy Liao, we quickly came to an understanding—if a beach or an adventure is calling, I must go!



I continued with the theme of saying yes and not letting cancer or its treatments allow me to miss out on life.

In December 2021, I began another clinical trial for the FGFR2 mutation, this one called RLY-4008. After the first 8 weeks, I had a positive response with shrinkage and eradication of some tumors in the lungs but had some very noticeable side effects including nail changes, mouth sores, fatigue, and dry eyes.

By June of 2022, disease progression was once again confirmed with CT, and RLY-4008 was discontinued. With RLY-4008 out of my system, I started another trial with Futibatinib, now called Lytgobi since it's FDA approval. Two weeks into futibatinib cycle, my symptoms became intolerable which called for a brief pause. I stopped taking the drug for a week until the symptoms resolved and restarted at a lower dose:

16mg instead of 20mg to alleviate the intensity of the side effects. I stayed at the lower dose until April 2023.

Following that unsuccessful trial, I approached Dr. Liao with the idea of pursuing Tumor Infiltrating Leukocytes (TIL) therapy as my next course of treatment. I was enrolled in the trial at the University of Pittsburg Medical Center.

7 THE UNPREDICTABLE NATURE OF THE DISEASE

Beginning July 2023, I was flying back and forth regularly to Pittsburg, while working full time, sitting on the city council, while sitting on a board of directors, and while being president of my Sorority chapter. This TIL trial was the most personalized or targeted therapies that I had ever enrolled in as it aims to treat cancer based on an individual's specific genetic makeup or other biomarkers.

This approach allows for more precise and tailored treatment. The process began with the removal of a tumor, then identifying the fighter T cells within that tumor, growing them in a lab, and then infusing them back into the patient to fight the cancer.

Before receiving the T cells, I had to go through a chemotherapy regimen, which I tolerated pretty well. The chemotherapy temporarily wiped out my existing immune system to make it more likely for the new T cells to work. I was thrilled and excited to receive 46 billion cells on September 20th last year, but nothing prepared me for the side effects.

It was about as bad as my St. Louis experience, maybe even a little worse. I was in the hospital for four weeks reminding myself that what I was enduring was worth it, maybe not for me, **but for the next person diagnosed with Cholangiocarcinoma.**

Turns out, the results weren't quite what the trial team nor I were anticipating. There was no reduction in the number of tumors in my lungs, but since May 2023 there hasn't been any growth of any tumors either. Each treatment regimen represents not only hope but also an investment of time, energy, and emotional resilience.

When those treatments do not yield the desired results, it can feel like a devastating setback. But I often remind myself, that with every trial participant something new is learned,

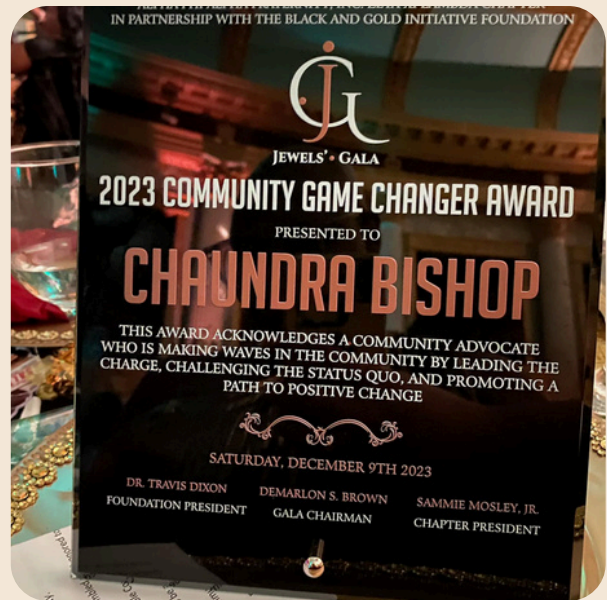


something is improved, and the results are better for the next. Ultimately, experiencing disappointments when treatments fail is an integral part of the cancer journey—one that underscores the unpredictable nature of the disease.

While it may feel overwhelming at the moment, it's important to remember that setbacks are not synonymous with defeat. Each new challenge presents an opportunity for growth, resilience, and renewed determination to continue fighting for a brighter tomorrow.

IN THE END, I SHARE MY JOURNEY

with Cholangiocarcinoma to give others hope, to show that there's no typical cancer patient, and to help others survive.



BY SAYING YES

to more things, I have not only had the opportunity to transform my own life but have also had the opportunity to make an impact on the lives of countless others.

THIS JOURNEY IS A REMINDER

that even in the face of life's greatest challenges, there is beauty to be found, strength to be discovered, and joy to be embraced. A reminder that in the face of adversity, we have the power to rise above— to live and to thrive.



Setbacks are not
synonymous with
defeat

Chaundra Bishop



C A N C E R G R A C E . O R G



Global
Resource for
Advancing
Cancer
Education



FOR MORE INFORMATION

about Cholangiocarcinoma, please visit our friends
at the Cholangiocarcinoma Foundation,
<https://cholangiocarcinoma.org>.



Cholangiocarcinoma
Foundation®

A H U G E T H A N K Y O U T O O U R
S P O N S O R S



Chaundra Bishop