A Kidney Cancer Diary

Chase Griffith, 46, lives in Dallas with his wife and two sons. He has metastatic chromophobe renal cell carcinoma.

March 13, 2023 As Told To Bob Barnett

I was born in Oklahoma. I met Meghan in college, but we only started dating seriously in 2007, when we both wound up in Dallas. We got married in 2008, had Fletcher in 2011, Harrison in 2013. I was a lawyer for 10 years but quit to work for a friend's financial start-up. I was happy. Things were going as well as you could script in a movie.

December 2018

I had had mild abdominal pain on my left side. My PCP does a physical exam and scans for kidney stones. It was diverticulosis on the left side, but he found a 6 centimeter mass on my right kidney. He calls that night to tell me he thinks it's kidney cancer.

My wife found Solomon Woldu, a urologist who specializes in malignancies, at UT Southwestern Medical Center. I get an MRI. He tells me it looks like kidney cancer but can't confirm without a biopsy, which is scheduled for the day after Christmas; a nephrectomy (surgical removal of a kidney) is scheduled for January if the biopsy is positive.

January 2019

Biopsy results are mixed. I consider canceling surgery, but my friend, a retired pediatric oncologist, urges me to move forward, as did Dr. Woldu. Pathology results reveal it's a rare form of kidney cancer—chromophobe renal cell carcinoma. It was Stage III—the tumor had extended into kidney fat. Nephrectomy is a success. I am declared cancer-free, with scans ordered for every three months. We didn't tell the kids it was cancer. They were 5 and 7.

Chase Griffith and his family Courtesy of Chase Griffith

April 2019–March 2021

Scans show no signs of cancer for two years. It's an odd feeling. I know I'd had cancer, but it was just surgery, like knee surgery. One day in 2020, driving in the car, a story about cancer came on the radio. Meghan gives me a look that meant: "If you're going to tell the kids, now is a good time." So I say, "Remember when I had that kidney removed? That was actually cancer. We were told it was cured."

April 2021

Abdominal MRI results show a small liver lesion. Dr. Woldu calls that evening. He mentions a variety of treatment options if it is metastasis. We schedule a biopsy. Phone calls to the family that evening are excruciating. We try to keep things normal over Easter weekend. We tell Dr. Woldu that if it's metastatic, we want to get Hans Hammers, a renowned kidney cancer oncologist at UT Southwestern. He says we can have whoever we want. We also set up next-generation genetic sequencing—a close family friend works for the company that does it. [Editor's note: This technology allows for DNA to be tested quickly and inexpensively to see whether there are tumor mutations that might be drug targets.]

We get a brain MRI, which fortunately shows no metastasis. A couple of weeks later, I wake up

with severe abdominal pain. The CT scan shows no appendicitis but new nodules that hadn't shown up on the MRI. Biopsy results were benign. But Dr. Woldu said, "Don't start popping champagne yet." He thinks it's a false negative.

July–September 2021

Scan shows growth. A new biopsy shows it is metastatic chromophobe renal cell carcinoma. Now, I really feel like a cancer patient. We really started researching. It was heartbreaking: no treatments, no research. I continue to work. We told the kids that the cancer was back. I don't want them to be scared but also don't want to hide anything from them.

Dr. Hammers recommends we wait for a three-drug clinical trial opening in the fall—two immunotherapy meds and a targeted therapy. One day in spring, in the car, getting a Slurpee, my youngest asks, "Hey, Dad, are you going to die from your cancer?" I'm not going to say everything will be fine. I tell him that we are getting the best treatment possible with the best doctors possible. I remind them that I am doing well today, and no one can truly know what the future holds. Our focus should be on giving thanks for today.

During this time, we learn that the Kidney Cancer Research Alliance (KCCure) has a patient-driven Chromophobe Research Grant Award of $50,000. We make our first donation.

October–December 2021

The first infusion in late October goes fine, as does the second one on November 10. But by Thanksgiving, I start feeling bad, cold all the time, can't sleep, heart racing. Lab work shows my liver enzymes are off the charts. My doctors tell me that my immune system is attacking my liver—a side effect of immunotherapy. They stop all treatment, prescribe steroids, suggest hospital admission.

Our youngest son's birthday is the next day. Dr. Hammers says, "Go home and spend his birthday with him." I start 200 milligrams of prednisone the next day. He warns me that steroids are very altering, not to make any decisions. I can't sleep, am hungry like a 13-year-old.

Liver enzymes start to come down. Since steroids make me immunocompromised, given COVID, we decide to take our boys out of in-person school until it's less dangerous.

I taper steroids, restart the targeted therapy. But when I go down to 10 mg of steroids, my liver inflammation comes back, requiring hospitalization, high steroid doses and a new immunosuppressant. I am days away from liver failure, likely death.

While I'm in the hospital, my wife reaches out to KCCure's Dena Battle, who puts us in touch with Lisa Henske, an oncologist at Brigham and Women's Hospital, who spends an hour with us on a Zoom call. She sends us a very small study out of Europe with nine chromophobe patients who have good results with two targeted therapies. She suggests we see Dr. Toni Choueiri, an oncologist at the Dana-Farber Cancer Center in Boston. Within hours, we receive a text from Dr. Henske that Dr. Choueiri will see me in February.

February–April 2022

We start the first drug of new treatment on March 3. We send our children back to in-person school. We decide to have a fundraiser for the KCCure Chromophobe Research Grant Award. Our goal is $25,000 over three weeks. We raise $20K in 24 hours, nearly $60K overall. Donations of $100 and $200 came from all over the country. We are blown away. In April, I add the second drug to my treatment.

June 2022

Tumors have shrunk 20% across the board, no new tumors. I tolerate treatment well and taper off all immune suppressants. We take a family vacation.

August–December 2022

Tumors are stable. I feel great physically. I have a few lingering side effects, such as high blood pressure and cholesterol, so I have medicine for that. I continue to work. I’m coaching football.

My faith has strengthened through this journey. Through the guidance of a dear friend, I have discovered much hope and understanding through the teachings of Jesus Christ.

The only way to get through something like this is to have faith and focus on making the days with my family and friends count. Whether those days are in the hundreds, thousands or tens of thousands, doesn’t matter. Enjoy today. It’s the only one any of us have.
