DDF Advocate Stories 2025

ALABAMA

Kermit Farmer – Auburn It was a twist of fate, a cruel end to a life dedicated to service. Kermit Farmer, founder and Chief Ethos Officer of Paths, embarked on a mission to make the world better for others, driven by the personal pain of his late wife's battle with stomach cancer.In an emotional interview, Kermit shared the profound experience of walking with his wife, Dr. Linda Farmer, through her excruciating medical journey. Linda, an oncologist herself, faced the very disease she dedicated her career to fighting. Kermit vividly recounted the challenges, from Linda's diagnosis to her last days in hospice care at home."I needed a path to help me through that. But there was none. I needed more timely information. It's not lost on me that millions of caregivers and patients go through a very similar experience every single day," Kermit explained, emphasizing the lack of resources for caregivers facing similar situations.The catalyst for Paths was a letter Linda wrote to her 700 patients, revealing her own battle with cancer. Linda imparted wisdom and hope in her selfless act, leaving a lasting impact on those she cared for. Kermit reflected, "That's who she was." Kermit's background in logistics and his firsthand experience with Linda's frustrations as an oncologist fueled his determination to bridge the communication gap between doctors and patients. The vision for Paths emerged – an online platform facilitating education and communication for healthcare providers and patients.The journey wasn't about entrepreneurship for Kermit; it was personal. "I need a reason to get out of bed – a reason to live," he expressed. To honor Linda's legacy, Kermit contacted experts, including Ryan Troll, Head of Experimentation at Capital One, to bring his vision to life.Paths officially launched at a Stomach Cancer Symposium at Duke University, marking the beginning of a transformative relationship company. Kermit emphasized the importance of rebuilding the doctor-patient relationship and providing timely, proactive information to alleviate patient concerns.The interview delved into the challenges of compliance and the journey to become fully HIPAA and SOC 2 compliant. Kermit's investment in Paths, both emotionally and financially, showcased his dedication to the cause.As the conversation turned to funding, Kermit revealed his fearless approach, likening himself to a Viking burning his boats – no turning back. However, he acknowledged the need for external financing and emphasized the importance of aligning with partners who share the vision and bring industry expertise.In closing, Kermit offered advice to aspiring entrepreneurs, stressing the value of seeking guidance and acknowledging the pivotal role played by the New Venture Accelerator in Paths' journey. The story of Kermit Farmer and Paths is a testament to love, resilience, and the power of transforming personal pain into a force for positive change.

ARIZONA

Lissett McKee – Tucson My name is Lissett McKee. I am 62 years old and have been married to my best friend for 34 years. I don't want to use the cliché saying he is my soul mate, but he is my perfect partner. He has helped me through two cancer battles. The first was in 2018, when I was diagnosed with breast cancer. I underwent a lumpectomy, radiation, reconstruction, and several revisions. For as long as I can remember, I have experienced gastric problems, but I never paid much attention to them. In 2021, I visited my primary care physician, who initially suspected I might have kidney stones. He ordered a CT scan, and that's when the radiologist found a mass in my stomach. I was sent for an endoscopy, which confirmed the mass. However, the practice where I had the procedure could not perform a biopsy. So, off I went to the university hospital for a biopsy. Next thing I knew, I was in the hospital having half of my stomach removed. One week later, I was discharged and attempted to eat my first meal. Unfortunately, I could not keep any food down, and I was rushed back to the ER. Hours later, I was readmitted. This time, I spent over three weeks in the hospital and was NPO (nothing by mouth) the entire time. I had to be fed through a central line, which kept getting clogged. I have lost about 45 pounds, which is great in some ways, but nothing fits me anymore—haha! This journey has been incredibly tough, filled with many ups and downs, both physically and emotionally. After my breast cancer surgery, I felt a sense of relief because I was prescribed a medication to help prevent recurrence. However, this time around, I was told that I do not have a specific gene mutation that would allow me to take preventive medication for my stomach cancer. If my cancer returns, I will qualify for Imatinib (Gleevec), but it is a very toxic medication that I would have to take for the rest of my life. Reading between the lines, this means my time would be limited. You can imagine how important research is to me and for future patients facing my dilemma. Instead of having a preventive treatment, I must undergo CT scans of my stomach, chest, and abdomen every three months for the first three years. Thank God, as of my last oncologist visit, I am now down to twice a year! While frequent scans are not ideal, I had little choice. I know that medicine has evolved tremendously, but it still does not reassure me that my cancer will not return. I have a unique perspective on cancer because I worked for oncologists for 5 1/2 years. I am not afraid of death, and hearing "you have cancer" does not scare me, but that does not mean I want my life to be cut short. I am grateful to be alive. I have lived a wonderful life. I was lucky—purely by accident, a wonderful radiologist caught something he wasn't even looking for. I was diagnosed at stage 2. Most are not so fortunate and are diagnosed when the disease has already progressed much further. I wish for others—especially younger people—to never have to go through what I did. Hopefully, with more research and funding, we can improve early detection methods and maybe, one day, eradicate stomach cancer altogether.

Niccole Branson – Chandler At the beginning of 2021, I was a healthy 37-year-old woman, or so I thought. I never needed to or went to the doctor for anything. In April, I started to have some minor stomach issues. I wasn't eating as much as I usually would, and things that I usually ate or drank began to make me sick and bloated. I had been having some stressful situations with work, so I chalked it up to nerves and stress getting the best of me. By the beginning of May, I started getting some mild acid reflux. By the end of the month, I had gotten so sick to my stomach that I threw up a couple of times. At the beginning of June, the acid reflux was so bad that I couldn't sleep in my bed because I couldn't lay down comfortably or sleep soundly without being woken up by throwing up in my mouth. I took some over-the-counter medications to try and rid myself of the reflux. The medicine helped, but I had no appetite by the beginning of July; if I ate, I felt like vomiting and got very bloated, and I could barely get myself off the couch. I searched the internet for available primary care doctors and gastroenterologists. Because I never went to the doctor, I didn't have a PCP, and it was like pulling teeth to get in to see someone. Luckily, I found a great gastro place that could get me in the second week of July. I also went a few days later to a PCP. She ordered an ultrasound of my belly, where they found my stomach was bloated and full of liquid. She wanted me to go to the ER; instead, I had her send my reports to the gastroenterologist place I had gone to, and I went back in to see them. I had my first endoscopy on July 26, the day before my 38th birthday. CT scan on Wednesday, July 28, and was diagnosed on Monday August 2, 2021 with adenocarcinoma in the antrum of my stomach. The tumor was covering my pyloric sphincter, not allowing anything to pass into my intestine. That is why I had terrible acid reflux, bloating, vomiting, and no desire to eat or drink. My team of doctors had me scheduled for my port placement and diagnostic laparoscopy the same week as my diagnosis. The tumor was found to be localized to my stomach with only one tiny nodule they found on the exterior that came back benign. My first chemo was on August 10. My partial gastrectomy, where they removed approximately 80% of my stomach and my gallbladder, happened on November 4, 2021. After my surgery, they restaged me to stage 3 when pathology came back, finding cancer in some of my lymph nodes surrounding my stomach. Welcome to 2022! I just completed 25 rounds of radiation along with oral chemotherapy. I have a few weeks off to recover before I start four more rounds of chemo. My oncologist did a gene test and found I have the BRCA-1 mutation, which caused my stomach cancer. I knew breast cancer ran in my family, but I didn't know it could cause me stomach cancer. I am halfway through fighting this beast, and I am here to tell everyone my story in hopes I can make a difference in someone else's life to catch this before it is too late. I was young and healthy; never did I think I would be diagnosed with stomach cancer.

Nicole Rimza – Glendale I sit here today looking healthy, Im active person with a little appetite for food but a great appetite for life and the memories we make along the way. To look at me you'd never know what this body and spirit of mine has gone through. For those who don't know me I'm a mother, wife, daughter, and friend to many. Im about to turn 44 and Im very proud to say that as just a few years ago I didn't know if I'd make it to the next day. At the young age of 32 I was diagnosed with stomach cancer. Those are the words you never want to hear and the words you will remember the very location, sound, smell of the room and your heart beating through your chest. Unfortunately, there are too many who know this exact feeling which is why I'm here today to advocate and spread awareness for stomach cancer. My story, I was diagnosed with stomach cancer in March of 2012. Not only was I told I had cancer, but I was also told I had one of the most aggressive forms of cancer as it grows like carpet and I have about a 6% chance to make it to 5 years. The cancer had already grown outside my stomach wall and made it to my lymph nodes which lowers my chances of survival. I was determined to beat the statistics. Leading up to my diagnosis I had been having continuous abdominal issues. I would have very dark stool, diarrhea, and stomach pains which my Doctors misdiagnosed as Chrones Disease and the treatment left me unhealed. My GYN thought the pain could be due to my uterine lining and we made the hard decision to complete a hysterectomy at a young age. It took several trips to the doctor and a variety of different procedures until an EDG was done to locate the tumor. I found a Doctor who was not okay with my symptoms and performed the EDG which led to my diagnosis of diffuse-type gastric adenocarcinoma. Dr Singer had lined up my next appointments with an Oncologist prior to giving me the news, I still thank him til this very day! I started chemo immediately, I took Xeloda, Epirubicin & cisplatin for eight weeks until I had my stomach removed on June 24'th 2012. The surgery was smooth, but a wound infection kept me in the hospital for nearly three weeks. Having never eaten without a stomach before really took some adjusting. It was a constant battle trying to figure out what my body liked. I finally started adjusting to the dietary restrictions and then it was time for another round of chemotherapy. This second round of chemotherapy was terrible. I started docetaxel and oxaliplatin. The nausea and vomiting were much more intense without my stomach. I had several severe reactions to this chemo which ultimately led to me stopping the chemo all together and I leaned on diet and natural paths to heal my body. I couldn't have done this with my faith in God, my family by my side and my children to keep me pushing through! My husband was my rock, I never felt alone as he made every single appointment, chemo treatment and multiple hospital stays. January 24th this year marked 10 years since I heard the all clear! 10 years ago, I dreamed of making it to this day… I feel like the luckiest woman alive and I pray that everyone here today gets to feel the way I do today. I'm here with Debbie's Dream Foundation to raise awareness and increase funding to save more lives.

ARKANSAS

Roger Engnell - Fort Smith My journey into the CDH1 mutation world started on Thanksgiving Day, November 28, 1980. My grandparents were up to celebrate the holidays with us when my grandfather became ill. He was taken to a local hospital and never returned. He died nine days later, and an autopsy showed that he died of stomach cancer—the following spring, my mother was diagnosed with breast cancer and would need a mastectomy. Back to back, cancer had infiltrated our family. There were no warning signs. Cancer just showed up. Then, in October 2014, I was driving home from work when I received a call from my little sister. She had been diagnosed with breast cancer and would need a double mastectomy, chemo, and radiation treatments. Genetic testing was done, and the CDH1 genetic mutation was found. My CDH1 Mutation date was February 9, 2015. Testing done at the University of Minnesota genetics lab found the mutation. From there, I met with the University of Minnesota medical staff and the staff at the Mayo Clinic in Rochester, Minnesota. My options were to ignore it and get on with my life, test yearly, hoping they never find stomach cancer, or I could proceed with a total gastrectomy, eliminate the chances, and get on with my life. In all of those options, I had to trust, hope, and pray cancer never showed up. I chose the latter—several reasons played into the decision. First, I had just finished a battle with a brain tumor, so to go through that and not fight now made no sense to me. Second, was my family history of cancer. Two of my grandparents died of cancer. My father died of cancer, and my mom battled cancer, my sister and two of my brothers have battled cancer. Third, and most importantly, My family. My dad died of cancer at the age of 62. He never got a chance to know my kids, his grandkids. He missed out on so much. The final decision was that I was NOT going to miss out on my kids' lives, so on August 4, 2015, a total gastrectomy was performed by Dr. Micheal Kendrick. The team was highly knowledgeable about the CDH1 mutation and took great care of me. Fast forward to today, I am now 61 and still standing strong with my wife of 36 years. I get to have game nights with my children, partners, and friends. But the real cherries on top are three young grandsons who know me and call me "Papa"! Did I make the right decision? ABSOLUTELY! Despite the challenging surgery, dozens of follow-ups, and almost as many strictures, I would do it again. Life is worth it.

CALIFORNIA

Lorraine Bacon – Ramona

I was diagnosed with invasive lobular breast cancer in 2017. My husband is active duty Navy and was in the first part of a six month deployment. I went through chemotherapy, surgery, radiation, and finally thought the journey was over. The doctors decided to run a genetic panel due to the lack of details on my father's side of the family (he was not in my life at the time). After nearly a year of beating cancer, we found out I had the CDH-1 gene mutation. We found out my father's mother died at the age of 50 from stomach cancer and there was a lot of stomach cancer in her family. My father and his two brothers were tested and found that all three of them also tested positive for CDH-1. My adult children tested, and my daughter came back negative while my son tested positive. My daughter has two sons, so it was a blessing she tested negative, but we knew our son would have some important decisions to make. Additionally, my cousins were tested and most of them also tested positive for CDH-1. The doctors recommended a total gastrectomy (who knew you could live without a stomach?!) and I had my surgery the day before Thanksgiving in 2018. This changed my life. In many ways, I have adapted, but the challenges are there. Like so many, I have to be careful of what I eat and how much I eat. Some days are easier than others. Some days all my energy has to go to managing my body's needs. I have to pay attention and budget my energy. I still work and have a fulfilling career, but I struggle to be "normal" at conferences and team meals. My grandsons do not remember a time before I had cancer. Two years ago, my son opted to get a total gastrectomy as well. He did not have cancer, but the doctor had a very frank conversation with him and given our family history, he opted to get surgery by his 30th birthday, as recommended. After, my son told me he had absolutely no idea how hard this is and how painful recovery from surgery was for me. He also still struggles and my grandsons have watched their uncle have a seizure due to his blood sugar dropping unexpectedly. The research is promising and I am hopeful my cousins will not have to make as drastic a decision as my son and I did. At this point, my son is not going to have children and much of that is because he does not want to pass on the risk of CDH-1. It is my hope we can further stomach cancer research and get better treatment options in the future.

Janeth Martinez – Los Angeles I am Janeth Leon Martinez, born and raised in Los Angeles, California, and this is my story. On July 17th, 2020, I got that life-altering phone call, "You have cancer." But how could I possibly have cancer? I had just delivered a beautiful and healthy baby girl on May 8th, 2020, at 38 years old. This was my 4th pregnancy. It was completely normal and healthy, without any complications at all. Even throughout my pregnancies, I've always lived a healthy and active lifestyle. I had no symptoms or pains out of the norm until postpartum. This is when I knew my body wasn't recovering as it should. In late May 2020, an emergency room doctor told me that I had an ulcer, and that was the reason for my pain and discomfort. Never have I ever experienced such pain, and I had just delivered a child naturally without any medication. My medical team went off the CT findings that it was just an ulcer and decided to take a closer look via endoscopy with biopsies. This is how my cancer was found, through biopsies. It took a second endoscopy, this time with an ultrasound, to determine the stage. I was officially diagnosed with Gastric Cancer Stage 3b, poorly differentiated adenocarcinoma with Signet Ring Cell. SRC is the reason my cancer wasn't seen in any CT. It doesn't grow like a mass, nor is it solid. Instead, it spreads between the muscles and tissue. This makes my type of cancer extremely hard to find. I never felt that my body was failing me until chemo. My team decided that FLOT was the best chemo for my type of cancer. Four rounds of FLOT, a total gastrectomy, and four more rounds post-op are what I had to endure. The first four rounds were hard. The nausea, vomiting, and pains were immeasurable. Post-op chemo was a blur of medications to help manage the side effects while my body was doing its best to recover from surgery. It wasn't easy, but I reached the other side at 97 pounds. Weak and exhausted but strong-willed through it all. I am 42, weigh 107 pounds, and have lived without a stomach since Dec. 2nd, 2020. Three years of continuous learning how to eat and drink again. After three years of being amazed that my body has gone through so much, I am still here, not just living but thriving. In that time, I have also transformed from being a hairless mole rat to having these beautiful chemo curls. I am learning to love myself for who I am now and not dwelling on who I used to be. Grace and patience are what I strive for daily. Advocating for myself and learning as much as I possibly could about stomach cancer is what has gotten me through it all. You can't fight this alone, and it's not something you should be fighting your medical team about. I've had to request surveillance scans, blood tests, and even procedures to be adequately redone to get the most accurate results. As a woman and a POC, it is vital to speak up and let your team know what you need from them. After all, they work for you. Despite everything, I am truly blessed to be here and doing as well as I am. Nothing in life is easy, and living without a stomach brings challenges no one has ever prepared for. It takes the right attitude and mindset not to be frozen with fear or what-ifs. I am here, living in the now, and that is where I want to be—going on adventures, making memories, and enjoying beautiful friendships I've made throughout this diagnosis. This is my second Advocacy Day with DDF, and I pray that I can continue to advocate for all stomach cancer patients, past and present, for many years to come.

Jessica Alcantar – Adelanto My journey as an advocate and caregiver began when my mother, Carmen Muro was diagnosed with Stage 4 Stomach cancer in August 3, 2015. Cancer is not new to our family, in 1994 my mom was a caregiver for her father who was diagnosed with stomach cancer as well. This journey has taken us through many trials and tribulations emotionally, physically, mentally, and on top of all of that we still have the stress and frustration that come with dealing with health insurance companies; referrals, denials, finding the correct physicians, and approvals. In June 2016 my mom had a complete gastrectomy with HIPEC. The surgery was successful! Since surgery she experienced extreme weight loss, bile duct stents, neuropathy, and a twenty-six-day hospital stay. She overcomes obstacles daily, such as managing her nausea, full body pain, loss of appetite, and weakness through it all giving up is never an option, she takes on ever battle with a positive attitude and holds on strongly to faith.

Mary Kretschmer - Lathrop Two years ago, I didn't even know stomach cancer was a thing. My journey began in August 2021 when I found a lump on my abdomen, right next to my belly button. I knew it was odd, but I waited a couple of weeks until I finally made an appointment to see my doctor. When I saw her, she thought I had a hernia and sent me to get an ultrasound. The ultrasound showed a small mass, not a hernia. I was referred to a surgeon, and I was sent to get a CT scan, which showed a mass. Then I had a biopsy taken. The first biopsy I had came back inconclusive, so I had to get a second biopsy. That biopsy showed that it was cancer, and it looked like it might be colon cancer. My surgeon was looking for the source of cancer because the mass was located in the mesentery, and since the mass showed colon cancer, he sent me to get a colonoscopy, which came back clear! I thought this was great because all that needed to happen was to remove that mass, and I could get on with life! A couple of days after Christmas 2021, I had that surgery. My surgeon took out one 9-centimeter mass and two smaller 1-centimeter masses. It turned out that those masses were lymph nodes that were infected with cancer. The surgeon used a scope and looked around my abdomen to make sure my other organs were clear. When he got to my stomach, he found a tumor on the back of my stomach. He then used a scope to look inside my stomach, and the tumor was there, too. I remember waking up, and the first thing I heard was two nurses talking. One said to the other, "he found more in her stomach." That is when my life turned upside down, and I found out I had stage 3b stomach cancer. It was almost stage 4. My surgeon and oncologist argued but ultimately agreed on stage 3b. I learned as much as I could about stomach cancer. At stage 3, the statistics say there is a 30% chance of surviving five years. Stage 4 is just 5%. Facing those odds was daunting. But I told myself I am not a statistic! I was not the typical stomach cancer patient; I was only 42 and female. In general, it's men in their 60s who get stomach cancer. I was then faced with doing four rounds of FLOT chemo, a partial gastrectomy, and four more rounds of FLOT chemo. It was not at all easy! I had young children at home who needed me. I had doctor's appointments to keep up with, scans, bloodwork, and chemo. I realized that I needed to know I could survive to get through this. So, I went online and searched for survivors. I joined a few support groups on Facebook, but the one group that was my saving grace was the Stomach Cancer Sisters Support Group! I am ever so grateful for finding these women.

Janeth, Jen, and Teresa, along with all the others, have shown me the love and support I desperately needed. Finding others who could empathize with my challenges was so crucial because it was lonely when I didn't have that. Halfway through my treatment, before the surgery, I was able to attend the New Kids on the Block concert that I got tickets to for my birthday a couple of months before I received my diagnosis. That concert was just pure joy for me. This opened up a world of happiness and love I had forgotten about. I started listening to their music again, and every time I was sad, angry, or just all up in my head thinking about my diagnosis, I'd yell at my Alexa to play New Kids on the Block. I'd have dance parties by myself, turning all my sadness into happiness! Finding my joy was the thing I needed to keep going every day. While stomach cancer has been the worst thing that I have ever gone through, it surprises me how many blessings I have been given by going through it. It has taught me much about myself, the people around me, the world around me, and my connection to God. Today, by the grace of God, I am NED (no evidence of disease) – cancer-free!

Marie Milton - Ponte Vedra My journey with stomach cancer began in the spring of 2015, when my mother was diagnosed with stage IV diffuse gastric cancer. Her treatment was arduous, including exploratory surgery followed by aggressive chemotherapy. Almost exactly eight months later, just 10 days before Christmas, my mother passed away in hospice care. Her medical team assured us that her cancer was rare, typically occurring in much older individuals. They claimed that something in her body had simply malfunctioned and that there was no reason for my family to worry about genetic risks. It wouldn't be until three years later, by complete chance, that I would discover I carried the CDH1 genetic mutation—a mutation my mother undoubtedly had as well. In 2019, I spent the year advocating for my own care in a small community where few were familiar with my condition or how best to treat me. I fought for insurance coverage, referrals to out-of-state specialists, and faced resistance from family and friends who disagreed with my decision to undergo a total gastrectomy. Determined to move forward, I found a study at the National Institutes of Health (NIH) and enrolled in July 2019. On November 7, 2019, I had my total gastrectomy and began a new chapter of my life. My recovery was slow and filled with complications. After surgery, I suffered from a leak and a collapsed lung, leading to a month-long hospital stay. Upon returning home, I had to relearn how to eat, despite having no desire to do so. Shortly after my discharge, the COVID-19 pandemic hit, further complicating my recovery. Over time, I was diagnosed with severe bile reflux and an acute esophageal stricture. I ultimately underwent close to a dozen esophageal dilations and a Roux-en-Y revision surgery, which has dramatically improved my quality of life. I never imagined this journey would be part of my life. But I am eternally grateful that I discovered my genetic mutation by chance. I have always considered this information a gift. Knowing about my CDH1 mutation gave me options and choices my mother never had. It meant I could choose surgery and give myself a chance at a longer life. It also meant that my sister could be tested and learn of her own risks. Last year, my sister also tested positive for the CDH1 mutation and has now enrolled in the NIH study. Without this knowledge, one or both of us might not have been here in 10 years. I do not take this gift for granted. Today, I advocate for patient care, research, and funding, while also mentoring and supporting fellow

CDH1 and stomach cancer patients. My diagnosis has reshaped my life's priorities, and I plan to continue uplifting this community for as long as I can.

Steve Melen - Tiburon I was diagnosed January 2008 with stage 3B gastric cancer at the esophageal junction just prior to my 38th birthday. Three weeks later the challenges really began with removal of my stomach, spleen, half my pancreas and third of my esophagus followed by chemo and radiation. Extreme weight loss, many hospital visits, divorce and two rehabs later after getting addicted to pain medication were the next steps in my recovery. Fortunately, the story has a happy ending as I've made it 12 years and as happy as I've ever been. Getting remarried and seeing my daughter grow up to age 13 now have been a huge blessing and kind of a miracle. Being able to be a mentor and board member for DDF has added an opportunity for me to give back to others looking for hope or inspiration in their journey as a patient or caregiver for stomach cancer.

COLORADO

Cyndi Howard – Avon I have been attending Capitol Hill Advocacy Day since it started in 2013, when Debbie Zelman led the way. Over the years, I have only missed two events. My late husband, Doug Ferguson, passed away from stage 4 stomach cancer just eight months after his diagnosis. He was initially treated with colon cancer drugs, which only made him sicker. As a registered nurse, I had never seen such a vicious cancer before. I was shocked by the lack of public awareness and the medical community's limited understanding of how to treat this disease. That's when I knew I had to get involved in advocating for research. DDF Advocacy Day has made an incredible impact. Thanks to the Peer Reviewed Cancer Research Program (PRCRP), which began in 2015 with Department of Defense funding specifically allocated for stomach cancer research, people are now surviving longer. We have promising new treatments, and more survivors are emerging. However, the fight is far from over! I would love to see even more efforts focused on public awareness and prevention. So, let's go advocate and kick some stomach cancer butt!

Jolinda Wilson - Farming in Northern Colorado was the joy of my life. But raising 4 boys was an even greater JOY and the memories of work, play and challenges are forever stamped on my heart. I had always worked outside of the farm as well as putting in my hours on the farm! But one thing I never compromised was my family time. Being a Realtor and owning a Marketing Company took people skills that came easy but with any competitive field it comes with stress. Top that off with a tumultuous divorce and the stomach issues began. I was given anti-depressants and told that because I was a woman and emotions surface more than men that the sickness and pain in my body was all psychological. My hair was falling out and I knew something was seriously wrong when 2 inches (no joke) of skin peeled off the bottom of my feet. I saw doctors in Colorado, Nebraska, Iowa and Texas. All concurred, it was in my head! Through a friend I met with a Gastrointestinal Doctor in Des Moines, Iowa. Dr Laura Dakovich sat with me in her office for over an hour asking me question after question. Her very last question to me was.....”Do you ever have food get stuck ?” Yes I said, but I think it is because I eat on the run but lately it felt dry down my throat. Did I mention I had gained 40 pounds? She scheduled an endoscopy the very next morning. September 11, 2013. I drove myself to the hospital and was alone in Iowa. I woke up after an endoscopy the very next morning, to this amazing lady with tears in her eyes, "JoLinda, you have cancer, this is serious, you need to get this taken care of immediately." I flew back to Colorado the very next day and on October 29, 2013 through many appointments and fast decisions by my wonderful Oncologist, Dr. James Moore, my Gastrointestinal Dr. Michael Nosler and my Surgeon Dr Michael Roller,I had a Total Gastrectomy and the bottom 1/3 of my esophagus taken out. They took 29 Lymph nodes and throughout the surgery they did pathology. All nodes were clean! They did however find the cancer had penetrated through the sub-mucosa layer and was throughout my stomach. I sunk down to 98 pounds. Eating has become a chore but I have gained back 40 pounds! I am so glad for the quick action of my doctors and their actions. I chose no Chemotherapy or Radiation. 6 years, 2 months and 10 days I am cancer free.

On September 4, 2017, I received the call no mother ever wants. My 23-year-old son, Luke Lee Charles Wilson was killed in a tragic accident. He was the son that worked with us on the farm. He was the very core of my heart along with his three brothers. My biggest question is why did I survive this unforgiving cancer to lose my son? MY HEART ACHES DAILY and I do not know the answer to this and never will, but until I meet my sweet boy again, I will fight for early detection and push hard for the CURE for STOMACH CANCER.

District of Columbia

Brittany Defenderfer – Washington I was diagnosed with stage one non-hereditary gastric adenocarcinoma with signet ring cells on June 16, 2021. This diagnosis came as a complete incidental finding and of course shock! In 2016 I was diagnosed with the stomach bacteria H Pylori after having an upper endoscopy to evaluate the cause of belching and acid reflux. To treat this, I received three rounds of antibiotics to eradicate the bacteria, and this was effective. I no longer had any symptoms and moved on with my life.

Fast forward to late May 2021. I was eating quickly while working as a nurse in the hospital. I began to choke on the fish and potatoes I was eating and had to have the Heimlich maneuver performed. This scared me so much and I decided to call my former Gastroenterologist right away. She informed me that many people choke for no known reason and end up being okay. I was not satisfied with this answer, and I insisted that she perform an upper endoscopy. It was during this test that she found a one centimeter raised lesion in the distal (bottom) part of my stomach. The results came back the very next day and my path to a cure began. As a Critical Care Registered Nurse, I have encountered many patients with various types of cancer, but I never recalled taking care of someone with gastric cancer. I knew very little about this caner at the time I was diagnosed. That all changed within 48 hours after my diagnosis. I quickly joined No Stomach for Cancer, Debbie's Dream Foundation and Hope for Stomach Cancer to learn more. The knowledge on these sites in invaluable. I scoured the internet reading study after study. I navigated consults with three separate gastric surgical oncologists within 72 hours of my diagnosis. I attribute this quick action to understanding the medical field and having easy access to all my medical records in the various patient portals. I encourage everyone to utilize their patient portal as well. All medical records are released to you as soon as they are released to your medical team and that is the law in the United States. The first two consults I had were very hard to hear. Both surgeons informed me I would need four rounds of chemotherapy prior to a partial or total gastrectomy followed by four more rounds of chemotherapy. They were ready to place a port in me and begin treatment that same week. This is the current standard treatment for gastric cancer in the U.S. I was terrified and could not believe it was possible that this tiny lesion could require such aggressive treatment. My third consult was with Dr. Sam Yoon who was, at the time, with Memorial Sloan Kettering in New York City. He was familiar with the protocols utilized in most Asian countries where gastric cancer is much more prevalent and often found in early stages due to early detection and surveillance. He set me up for further testing within 2 weeks, which confirmed the cancer was likely stage one. He said we could proceed with a laparoscopic subtotal gastrectomy with a Roux En Y Gastric Bypass right away. A little over week after surgery I received a call from Dr. Yoon stating I had clear margins and all lymph nodes removed were negative for cancer! I did not need any further treatment! What a miracle and true blessing. I have so much gratitude for Dr. Yoon and all my medical team members. Recovery was a challenge. While in the hospital I did well. I had very little pain and I was up and walking about two hours after surgery. Once home I began to have a lot of challenges eating and I suffer from dumping syndrome after eating too much or too many carbohydrates. This continues to this day, but I am able to control it with diet. My body is forever changed, but I am so thankful to be alive to share my story.

FLORIDA

Michele Blum – Wellington My name is Michele Blum, and I was the primary caregiver for my husband, Mitchell Blum. Our journey began in September 2022 while enjoying a quiet evening watching football and eating pizza. Suddenly, Mitch mentioned he wasn't feeling well and went to the bathroom. A loud thud followed, and when I rushed in, I found blood everywhere—a moment of pure terror. I immediately called 911 and took Mitch to the hospital. After a series of tests, the doctor informed us that Mitch had a bleeding ulcer that needed to be cauterized. However, upon further examination, the doctor expressed concern about its appearance and recommended a biopsy. The results were devastating: Mitch was diagnosed with stage 3 stomach cancer. Our journey took a new turn as we met with a GI surgical oncologist and underwent an upper GI contrast study, which confirmed the cancer diagnosis. Mitch began a rigorous six-month regimen of FLOT chemotherapy, which proved effective in reducing the cancer cells. Though the treatment was successful, it came with severe side effects, including a metallic taste in his mouth, neuropathy, fatigue, and other challenges. Despite these hurdles, Mitch continued to fight bravely. After six months of chemotherapy, we were told that the cancer was localized in Mitch's stomach and that a total gastrectomy was recommended. In March 2023, the surgery took place, but things took an unexpected turn. The surgeon came out and informed me that the cancer had spread to the peritoneum, advancing Mitch's condition to stage 4. We were told to expect only six months to a year, with palliative chemotherapy and comfort measures. However, we refused to accept this prognosis. At just 57, Mitch was determined to fight, and I was committed to being his advocate. We sought second and third opinions and, through extensive research, discovered Moffitt Cancer Center in Tampa, Florida. At Moffitt, we met with a surgical oncologist who recommended further chemotherapy with Keytruda and Herceptin, both of which proved remarkably effective in killing the cancer cells. The surgeon also introduced us to the concept of HIPEC (Hyperthermic Intraperitoneal Chemotherapy) and its potential to improve Mitch's condition—something that had never been offered to us before. After completing the first HIPEC procedure, Mitch's Peritoneal Cancer Index (PCI) score dropped from 12 to 5, and after a second HIPEC, his PCI score dropped even further to 3. The results were astounding, and the surgeon was very impressed with Mitch's progress. By December 2023, Mitch was a candidate for a total gastrectomy with HIPEC and Cytoreductive Surgery (CRS). Mitch underwent a 16-hour surgery at Moffitt, and throughout the process, the hospital's nurses kept our family informed every step of the way. While there were post-surgery challenges, including difficulties with tube feeding, Mitch's condition stabilized once he was started on TPN (Total Parenteral Nutrition), which allowed his body to receive the necessary nutrients. After the surgery, the surgeon confirmed that all lymph nodes and margins were clear of cancer, and Mitch and I shared many joyful tears. As of February 13, 2025, Mitch is cancer-free. We continue to meet with his oncologist every three months for blood work, PET scans, CT scans, and Signatera testing to monitor his health. Through this journey, I have learned valuable lessons about the importance of persistence and advocacy in the face of serious illness. Never give up, never accept "no" for an answer, and always seek a second opinion. If we had followed the guidelines from the first hospital, Mitch would not be here today. Our story is a testament to the power of informed decision-making, perseverance, and hope.

ILLINOIS

Angela Faralli - Chicago Six months ago, I was helping my healthy 46-year-old sister prepare for her first business trip in a new leadership role that she had worked toward her entire career. Next week, I'll be driving her to her twelfth chemotherapy infusion with hopes that the trial-targeted drug and the immunotherapy that she would otherwise not qualify for will stop her stomach cancer. For every scan, we wait with bated breath. Stomach cancer is one of the most deadly cancers; the overall 5-year relative survival rate in the US is 36%, and at a late or distant stage, it is just 7%. If this doesn't work, there aren't many options. How does this happen suddenly to a healthy person with no symptoms or family history? How was this missed? Almost a year before, in December 2022, my sister experienced back pain in the middle of her back. Her general practitioner ran some tests, including an ultrasound and one for H. Pylori, and couldn't find anything, so she eventually prescribed an acid reducer, and her symptoms went away until the condition worsened and a new symptom appeared. Fast forward to August 2023, my sister threw up blood and went to the Northwestern ER. It's been a rollercoaster ever since. By the time she was diagnosed with stomach cancer and staged, only a few weeks later, her tumor had grown significantly from the original ER CT scan. If only in December of 2022 had, her general practitioner been able to order an endoscopy or a CT scan, we may not be where we are today. Unfortunately, there are many similar stories with symptoms of this deadly cancer that end up dismissed as indigestion. Up to 80% of stomach cancer patients are asymptomatic in the early stages. I've been trying to get screened since September, which has been very difficult. Six months ago, I didn't know that stomach cancer existed. Still, I'm here today - dedicated to helping improve screening, raising awareness and money for research, and helping those going through it get better options so that maybe someday this can be a manageable disease or even cured. Although the population is growing, research is consistently underfunded. Please help in this fight. You can do this by maintaining stomach cancer in the peer-reviewed cancer research program (PRCRP), passing the FY 2024 Defense spending bill with $130 million for the PRCRP and inclusion of stomach cancer, and signing a letter to the Appropriations Subcommittee on Defense requesting stomach cancer's continued eligibility in the PRCRP for FY 2025. Increasing funding for the National Cancer Institute (NCI) by passing the FY 2024 Labor-HHS-Education spending bill and funding the NCI at $9.998 billion ($2.7 billion increase) — an amount the NCI says it needs in its Professional Judgment Budget and supporting an FY 2025 funding increase that allows the NCI to continue to expand its investment in investigator-initiated research.

Jennifer Higgins-Spiers – Brooklin My cancer story began in 2009. I was 26, married for nearly two years, and building a new life in Boston. For some context about my health, I have Neurofibromatosis Type 1, which causes painful tumors to grow in my body. In 2003, a new tumor (though I did not know this was an NF tumor at the time) developed in my lower abdomen. Because the tumor was near my pelvis, I was constantly dismissed (doctors deemed my pain to be "period pain") until I met my PCP in 2009. In 2009, in addition to pain, my energy levels suddenly tanked. It hurt to move, hurt to exist. When I met my PCP, she ordered tests to find answers to everything. This included a slew of bloodwork for my lack of energy levels and a GI workup for my pain. Bloodwork showed anemia and a b12 deficiency. The GI workup included an upper GI, which showed a small mass in my upper stomach. There was no answer for my pain, but doctors were curious about this mass, though my GI assured me it looked benign. The discovery of the mass led to an endoscopy, which led to an endoscopic ultrasound. In between those appointments, though, I developed severe chest pain (later deemed to be acid reflux from a hiatal hernia) and neuropathy in my arms (likely from my b12 deficiency). Ten days after my endoscopic ultrasound, July 27, 2009, I got the news: Adenocarcinoma with signet ring cell features. Poorly Differentiated. This sent shockwaves to everyone, especially my dismissive GI doctor, who was certain my exhaustion was due to "stress" and this "mass" was benign. This diagnosis did not address my pain (that tumor was finally visualized and removed in 2011), but had I not been in pain, they likely would not have discovered my cancer until it was too late. I had a partial gastrectomy on August 27, 2009, and they confirmed I was Stage T1A. It is extremely rare for stomach cancer to be diagnosed that early with no genetic mutations involved. I also had no significant risk factors other than the fact I have a cancer history on my mother's and father's side. While I did not need to undergo chemotherapy, my recovery from my partial gastrectomy was rough. I had esophageal motility issues, so I was vomiting most of the food

I ingested. I lost 20 pounds (dropped down to 80 pounds). I had chronic aspiration from my reflux, so I often had bronchitis. My esophagus was constantly irritated, and starting in 2015, I started showing warning signs of Barrett's Esophagus. In 2019, I decided to have the rest of my stomach removed. The benefit of going through the surgery again was knowing what to expect and having the wisdom not to try to recover too quickly. The downside was having so many surgical complications due to 10 years of scar tissue. We need to be more purposeful about early detection of stomach cancer. Everyone should be tested for H.pylori. Everyone should be given an endoscopy immediately upon reporting acid reflux symptoms or belly pain. All doctors need to be more educated about the risks of stomach cancer and treatments for patients when diagnosed. I am a walking example of why we need robust early-detection protocols like there are for colon and breast cancer. I am grateful to be alive and will use my survivorship to support others and advocate!

Kristin Fitzgerald – Naperville My husband Ray Fitzgerald was a long-time Illinois Delegation staffer for Rep. John Shimkus and Governor Jim Edgar. Originally from Chicago, Ray was universally respected and liked by staff and members of Congress from both sides of the aisle. Ray was diagnosed with advanced Stage IV stomach cancer in May of 2008 at the age of 36. Ray and I fought his cancer valiantly, and, as a former Congressional staffer myself, I sent daily updates to the Capitol Hill community updating them on Ray's progress and asking for their prayers and support. Ray died in January of 2009, leaving behind three young daughters (ages 6, 3, and 1). Since that time, my girls and I have been strong advocates for cancer research, testifying before the House Energy and Commerce and Appropriations Committees and working with the National Cancer Institute to prioritize this deadly and under-researched cancer and prevent the deaths of other young dads like Ray. In the 7 years since Ray died, we have been so happy to see Congress include stomach cancer in the PRCRP, and TCGA. However, so much more needs to be done to ensure that beautiful children like mine do not have to grow up without their dad.

IOWA

Gabrielle Bouska – Yakima Growing up in a family where cancer seems inevitable can shape your life to be very different than many others. As far back as I can remember, seemingly random cancers kept taking extended family members. I suppose this drew me to a genetics and oncology research career. While working for one of the clinical genomics physicians at Mayo Clinic, I decided to make an appointment with a genetic counselor. I was tested for mutations in over 20 genes, and we were surprised by which one came back positive: CDH1. This confused my family, as gastric cancer was present in our history but not as common as CDH1-positive families typically have. Because of this, many of my family members did not take the diagnosis seriously. I decided to have a preventative stomach removal since there are no accurate ways to screen for this cancer. Unfortunately, less than a year after my diagnosis, my uncle went to the hospital for stomach pain and was found to have very aggressive and advanced gastric cancer. Treatment was not an option. Within eight weeks of developing symptoms, he passed. We must discover early interventions and effective treatment methods for these patients. Gastric cancer is the most underfunded area of oncology research, with one of the highest rates of mortality. Roughly 95% of patients with diffuse gastric cancer will die within five years of diagnosis. We need to do better for these patients and their families.

KANSAS

Benjamin Alcanter – Lenexa Working out at the gym since 1991 and always trying to maintain a healthy diet, I was in very good shape for a man my age. During the month of September 2019, I was experiencing extreme tiredness, headaches and bouts of light headiness. I made an appointment with my primary physician for a physical and blood test were recommended. The results of the blood test indicated some abnormalities, and a CT exam was ordered. Three days afterwards I received a call from a Cancer physician. He confirmed that I had stage 2 Adenocarcinoma stomach cancer and that I would need Chemo treatment as soon as possible to anticipate surgery. My heart sank deep into my chest and my mind started to fill with all kinds of thoughts and worries. My wonderful wife Debbie was sitting next to me when I received the news. We were both devastated and heart broken. After consultation with my Cancer Physician, I agreed to the Chemotherapy and opted to participate in an Immunotherapy Trial Study. In December 2019 I had surgery to have a IV Port (implantable venous access port) installed in my chest to ease administration of Immunotherapy drugs, chemo drugs and medications. For the next several months I underwent the cancer treatments which took its toll on my body. Extreme tiredness, nausea and vomiting made my life miserable. Surgery was scheduled in March to remove 60% of my lower stomach. The surgery was a success, but my hospitalization was at the beginning of the Covid Pandemic. So, during my hospital stay visitors were not allowed at all. Television was showing only reruns and no live sports or events. This added to the harsh reality of loneliness during a very tough time. I was released from the hospital to start my home 6 week recovery plan of a liquid diet working my way up to solid foods. Fast forward to August 2020. My cancer really took a toll on my body so now it was time to rebound and try to bulk back up with nutritious diet and workouts. For the next 13 months I lifted weights and ran on a treadmill 3 to 4 days a week. 13 months later in October 2021 while undergoing Post Cancer follow-up treatments, I have received some discouraging news. Through an EGD scope and biopsy, a new different rare type of aggressive cancer was identified in the upper portion of my partial stomach. This cancer was identified as a hereditary diffuse gastric cancer (HDGC). The CDH1 mutation tumor was small but as a result undergoing a total gastrectomy to remove my remaining stomach was a necessity. The remediation process was to have a 2nd surgery, 7 days in the hospital and 6 to 8 weeks at home on a feeding tube. I've been through this before, but believe me, I knew it would not be easy. On November 4th my surgery was a success This time during my 7 days in the hospital there were no Covid restrictions, so I was allowed visitors and there was live television broadcast which help to past the time. I was released from the hospital and started an 6-week program of tube feeding until my internal organs had healed. A couple of weeks of liquid diet, a couple of weeks of a soft diet and gradually moving to tolerated foods. In August 2022 I reached another milestone in my journey of surviving 2 bouts of cancer. I have been officially declared cancer free. I finally underwent surgery to have my Cancer IV Port removed. I want to thank the doctors, nurses and overall great staff of the Kansas University Cancer Center for their exceptional professionalism in providing me with the best cancer care. As of today, I am 40lbs lighter and have come to the realization that I will never get back to pre-cancer weight. It is very hard to maintain a nutritional diet as some foods do not taste like before cancer or are hard to digest without a stomach. It is important for me to continue my 3 to 4 days at the gym to work on my strength and energy. It has been a long tough road battling cancer twice and would have been extremely difficult if it wasn't for my amazing wife, my great kids and grandchildren. They provided me the love, support, and encouragement to be brave and fight this attack on my body. I am an incredibly lucky man to have such a wonderful family.

June Rempel – Wichita I was diagnosed in July of 2020, and was only the second patient my Oncologist had ever seen with stomach cancer. We don't know why I had stomach cancer. I was super healthy throughout my life and have no pre-existing conditions. I had just gotten back from a hiking trip with my kids before being diagnosed. I went from an upset stomach to excruciating pain overnight. I had a CT scan, and they found a mass. Later I found out I was stage 3 and I did not have the CDH1 gene for stomach cancer. There is still very little information and a significant lack of familiarity about stomach cancer. Our providers need more information and research to help people with this deadly disease. Early on, my Oncologist asked me if I wanted to know my chances, how long I have. I immediately said, nope! I truly just wanted to do everything possible to kick this, my husband had just passed away and my kids still needed me. I went through chemo and had a gastrectomy to remove 90% my stomach. I was one of the lucky ones who was able to have this surgery. It is interesting to say that I was lucky to have my stomach removed! My life is forever altered. I am 5' 4' and my weight dropped down to 75 lbs after surgery. I was unable to do a second round of four chemo sessions after surgery. I now take many supplements and strive each day to be healthy and maintain 80 lbs as my body no longer absorbs food well. I eat small amounts 6 times each day and alternate that with being able to take liquids. I also often deal with severe hypoglycemia and other related issues. We need to do better than that! We clearly need more research and more options to prevent, treat and cure this disease! It would be so helpful to be able to have the ability to better target stomach cancer treatments and better options for a cure than the removal of my stomach. So, though I am thankful for my outcome, I know that we can do better! Let's go for a "moonshot" and cure this deadly disease! In the here and now, I am a survivor. Through faith in God and a supportive prayer team, traditional and alternative medicine, I am healed. I choose to live each day with joy and the ability to volunteer and serve others! I have been NED (no evidence of disease) for the last 2 ½ years. I Praise God and am thankful for each day my story continues!! My goal each day is to instill hope in others!

Priscilla Brittine - Kansas City I was only 14 years old when I heard the words stomach cancer. Acid reflux is what doctors kept saying my mom had. Taking some antacids should fix that, right? Behind the acid reflux was something far more dangerous. My mom's symptoms got worse very fast. She was in and out of the hospital until she finally had more extensive testing and was diagnosed with adenocarcinoma of the esophageal junction. Once symptoms start with this type of cancer, it is usually too late. My mom was misdiagnosed, and time was of the essence. Although, at that time, little was known about stomach cancer. Most signs and symptoms mimic acid reflux. Watching my mom slowly die was one of the hardest struggles I ever had to deal with. I do not wish this cancer upon anyone. My mom had radiation. At the time, her cancer was stage II. Surgery was recommended to remove all the cancer. Surgery day came, and unfortunately, doctors said the cancer had spread all over her organs. It was further than they thought. She was given eight months to live on this earth. My entire world broke into pieces. February 1, 2001, my mom passed away. If only there had been more diagnostic testing and doctors did not dismiss it as acid reflux, her cancer could have been caught earlier. She would still be here today. My mom was only 42 years old and incredibly young. Two years later, her younger brother was diagnosed with the same cancer. He passed away at 36 years old. Fast forward to 2018, a distant cousin reached out to me about my family health history and thought I should know that the University of Kansas Hospital was doing a study on our family due to so many family members were dying from gastric cancer so young and so fast. Doctors discovered my mom's side of the family carried a gene mutation called CDH1, meaning a person had an 80% chance of getting stomach cancer and a 60% chance of getting breast cancer. My family finally had answers, and because of my cousins, they paved the way for my family to get tested, potentially saving our lives and future generations. This is where my journey started, and I was referred to an entire team of doctors. I underwent a high-risk GI upper endoscopy where 37 biopsies were removed and tested because this type of cancer hides in your stomach lining. The results were all normal. The surgery oncologist told me it was not "if" I would get stomach cancer. It was "when" I would get it. I felt like a time-ticking bomb. Removing my stomach was the choice I had to make to prevent stomach cancer.Being proactive was something I had to do for myself and my family. After losing more than a handful of family members, I knew this was not something to take lightly. As hard as it was to take all this information in, it was a no-brainer for me. A total gastrectomy was scheduled for March 1, 2019. I thought I was ahead of this race. Once my stomach was removed, it was sent to pathology and tested even further. I ended up having the beginning stages of stomach cancer all along. It was a matter of time before it was to cross over to the membrane and spread to my bloodstream. I am glad I decided to remove my stomach when I did. I get emotional to think this cancer beat me to the punch, and history was so close to repeating itself. I was one of the lucky ones, and it is bittersweet to think of my mom, uncle, cousins, and others who did not get this opportunity. Removing my stomach was not easy. The struggle was real, learning how to deal without a stomach. It took a while for my body to adjust to the new plumbing. Knowledge is power. I share my story every chance I get, hoping it will help or inspire someone. Stomach cancer is one of the most underfunded cancers. It needs more research, awareness, and, importantly, increased diagnostic testing. One day, research will bring a cure. Families would not have to deal with removing their entire stomachs or losing family members. I hope and pray my three sons will not have to endure any of this. Until then, I will continue to share my story, advocate against the fight against stomach cancer, and continue to remember those who are affected and have gone before us. Thank you to Debbie's Dream Foundation for advocating and giving me the wonderful opportunity to make my voice heard.

Teresa Rivera – Kansas City My name is Teresa Rivera. I am from Kansas City, Kansas, and am 45 years old. I am a mother to 4 children, ages 25, 22, 17, and 15. I have the CDH1 gene and am a gastric cancer survivor. My entire family has been affected by this horrible gene and disease, and we have seven family members in a matter of years. We were always afraid because it was always like, "Who's going to get it next?" In our family, once you found out you had it, it was too late, and you were already at Stage 4. You never survived it. After the passing of my dearest and closest cousin Dolores (39 years old at the time), my cousin Socorro (39 years old at the time–Dolores' brother) and I got tested for the CDH1 gene. In his first screening, he was positive and was the first in our family to be able to have a total gastrectomy in April 2016. A year later, in September 2017, after my endoscopy, they found cancer in the lining of my stomach. I was 39 years old. I had a total gastrectomy on October 10, 2017. I was in the hospital for ten days and NPO for five days. I had a feeding tube for six weeks, was sent home with an IV for my tube feeds, and had to learn to eat all over again. I had a dietician, oncologist, surgeon, etc. It was life-saving and devastating at the same time. I didn't really process what had happened to me until after the surgery and when I came home. It was the hardest thing I had ever had to do. I appreciate my family and my children, who helped care for me. I wouldn't be the woman and mother I am today without them. I am 7 years out and am doing amazing. I still have my issues from time to time with nausea and my food getting stuck (I eat too fast), but it is bearable. I'm alive and can be here for my children and my grandson. I do worry about passing this along to my children. It is my worst nightmare. My 22-year-old daughter has tested negative. I'm still waiting for the rest of them to be tested. I am thankful for genetics testing. It saved our lives. I was thankful to have double coverage when this happened to me. I worry about others who weren't as fortunate. This is my 2nd year attending. I learned so much from last year, and I look forward to bringing more knowledge with me. I am honored to be a part of this conference and look forward to lending my voice once again to the fight to bring forth more funding to save more lives. It is a must. I am also blessed to be able to take part in this with my cousins Priscilla Brittine and Socorro Velo, who are both gastric cancer survivors who are with me today. Thank you for this wonderful opportunity!

MASSACHUSETTS

Sarah O'Leary - Melrose On January 17, 2024, we lost my sister, Erin O'Leary Kinahan, at just 49 years old, after a courageous battle with stage 4 stomach cancer with peritoneal spread. Erin's cancer was linked to an H. pylori infection, but despite persistent medical visits, complaints, and testing, her diagnosis came too late—when a cure was no longer possible. Erin was an exceptional woman in every aspect of her life. As a highway department traffic engineer, she rose to the position of Senior Supervising Engineer of Project Development for Highway Department Division 6, where she was responsible for final engineering approvals and led a large team of engineers. She was a passionate mentor, actively advocating for women in STEM professions and inspiring the next generation of engineers. Erin was equally accomplished in her personal life. She was a devoted wife to David Kinahan, a police officer with the Mansfield Police Department, and a loving mother to her two sons, Sean and Aidan. Her oldest son, Sean Kinahan, has received a naval commission and will be entering the U.S. Navy as an officer after graduating from Norwich University, a private senior military college. Her younger son, Aidan Kinahan, will graduate from Bishop Feehan High School this May and plans to study engineering in college. Erin also leaves behind her parents, John and Margaret O'Leary of Wakefield, MA, her siblings, Sarah and Mark O'Leary of Melrose, MA, and countless beloved family and friends. She was a woman of many passions—she loved pugs, cars, baseball, and traveling. She was actively involved in her Wrentham community and supported law enforcement spouses. Erin's fight for her life led her to Debbie's Dream Foundation (DDF), where she learned everything she could about stomach cancer. Through DDF, she connected with support groups, mentors, and advocates who helped her navigate her journey. Even as she battled this disease, Erin remained committed to fighting for others. She registered to go to Capitol Hill on February 6, 2024, to lobby for increased medical training for early stomach cancer detection, awareness and prevention efforts for at-risk populations, more research funding for stomach cancer treatments, and H. pylori testing and life-saving care for military members and veterans. Erin never wavered in her fight, showing extraordinary courage and resilience. Her greatest wish was that stomach cancer could be diagnosed earlier and more accurately, that effective treatments could be developed, and that our military members and veterans would receive prompt testing and care for H. pylori infections. Erin's life was cut tragically short, but her legacy of strength, advocacy, and love lives on.

MINNESOTA

Colt Blunt - Burnsville I got sick just before Easter 2019. I thought I had food poisoning from some expired cheese or was having a bad reaction to a new probiotic. It improved quite a bit over the course of a couple days, but I still had heartburn and acid reflux, which were new things for me. Thankfully, I already had a physical scheduled in a couple weeks. My doctor took my symptoms seriously and put me on a proton pump inhibitor, but said he'd send me for an endoscopy if I didn't fully improve in 10 days. True to his word, he contacted me 10 days later, was unsatisfied with my progress, and sent me for an endoscopy to look for an ulcer. The procedure revealed what was originally thought to be an ulcer, but I got the call the next morning telling me that I, a 37-year-old man who was otherwise healthy, ate clean, and exercised routinely, had stomach cancer. Within the next few weeks, I found out the tumor was bigger than expected but hadn't spread. I was told it was Stage III and considered locally advanced. The plan was to hit me with six rounds of harsh chemo and then send me for a total gastrectomy. However, I had the surgery after four rounds due to some elevated liver enzymes and a scan that showed the chemo had largely killed the cancer already. My surgery went great, and my pathology report not only showed That the tumor had been contained to the stomach, but that it had shrunk to almost nothing. I just finished my last of four rounds post-surgery. They've been a lot tougher than the first four with lots of nausea and vomiting and weight loss. However, I'm alive and plan on continuing to survive. I truly have my primary doc to thank for catching this much earlier than is typical in the US. I owe him my life. I'm also very fortunate to have been prescribed a newer chemotherapy regimen (FLOT) that was effective in killing my cancer, and to have had such a stellar surgical team for my gastrotomy. Truly, early detection and effective and timely treatment are key to effectively combating stomach cancer, and unfortunately, we lag behind in the US in this regard, especially for younger Americans.

Zach Bouska - Kasson My stomach cancer journey began after we lost my uncle, Terry Bouska, to stomach cancer in 2019. Around the same time, my younger sister, Gabby, discovered that we carried the CDH1 gene mutation. She made the difficult but proactive decision to undergo a preventative Total Gastrectomy shortly after. Following her experience, I decided to get genetic testing and learned that I also tested positive for CDH1. However, instead of immediately opting for surgery, I pursued surveillance, undergoing endoscopies and biopsies every six months to monitor for early signs of cancer. During my first endoscopy, doctors identified signet ring cells, a telltale sign of hereditary diffuse gastric cancer (HDGC). Dr. Jeremy Davis at the NIH strongly encouraged me to consider having a Total Gastrectomy before the dormant cancer cells became aggressive. Understanding the risks, I set a personal goal to undergo my Total Gastrectomy by the age of 30. Thanks to funding at the NIH, I was able to have my gastrectomy performed last year by an amazing team dedicated to studying this genetic mutation. Now, one year post-surgery, I am grateful to say that the future is looking brighter every day!

NEW JERSEY

Melani Vincelli – Brick Like most women today, I had always put my health concerns last. So, in January of 2009 when I noticed some pressure under my breastbone, I ignored it. I thought that I was too young for anything to be seriously wrong as I was only 49. I had a stressful job. I sold technology to businesses and with the recession in full swing, I wrote it off as stress. I already had irritable bowel syndrome, so it had to be that or maybe an ulcer. In May, I was starting to have some nausea and I wasn't eating that well. I had lost almost 30 pounds, which was actually a nice surprise, but I thought a trip to my family doctor was in order. He did a full blood work-up and called me the next day to say that I was anemic. It was a bleeding ulcer, I thought. My doctor wanted me to see a gastroenterologist for an endoscopy. The endoscopy revealed I had Stage IV stomach cancer. It had metastasized to my liver and lungs, and I was given 6-9 months to live. I started chemotherapy in July 2009. After three rounds, I was cancer free. There was no trace to be found, but I finished the therapy. I had a total of six rounds of chemotherapy. I returned to see my surgical oncologist in November 2009. Following chemotherapy, I was given the option to have a total gastrectomy (complete removal of my stomach), as well as part of my liver and gallbladder removed. He told me that if I did not have the surgery that the cancer would be back within a year and he did not know why. I had the surgery and have remained cancer free. Fast forward to November 2014 when I was diagnosed with Atypical Lobular Hyperplasia in my left breast. I was genetically tested, and I am BRCA2 positive. I have the breast cancer gene.

That means that although I have an 87 percent chance of getting breast cancer with this gene, my mutation came out as stomach cancer. I am now in a regional study with a prominent hospital because I am one of six women that they know of where this anomaly has occurred. Because of this prognosis, I decided to have a bilateral mastectomy proactively. All the tests came back showing no evidence of breast cancer, but I still feel that I made the right decision. I strongly feel that all women diagnosed with stomach cancer should be genetically tested so that they can make the best knowledgeable and well-informed decisions regarding their health. After living through this, I tell my story to as many people as will listen. I believe I made it through all of this for a reason; I want to be an inspiration to others. I want just one person to decide to see a doctor after hearing my story, or maybe I can help someone live through a cancer diagnosis. I help other stomach cancer patients by being a contact with the Debbie's Dream Foundation Patient Resource Education Program. I speak one-on- one to other stomach cancer patients. I also founded Debbie's Dream Foundation's South New Jersey Chapter to raise awareness and help as many people as I possibly can.

Lissa Canavan- Lavallette My name is Lissa Canavan I am 62 years old. Around the fall of 2022, I started to notice vague discomfort, like light stomach cramping, occasional indigestion, burping, Weight loss, occasional nausea, and floating stool. These symptoms came and went, and there were only a few nights that the discomfort turned to pain on my right side below my rib cage. I went to a GI doctor who did an upper endoscopy, CT Scan, Hida Scan, and ultrasounds and found nothing. Then, I did MRCP as a ditch attempt. The MRCP showed biliary stricture, so they set up an ERCP to put a stent in the bike duct via Endoscopy combined with Ultrasound, but they couldn't get past my stomach to do ERCP because my stomach lining was hard, and the machine couldn't pass through. A biopsy of the stomach confirmed gastric cancer. Then I did a diagnostic laparoscopy, and this Dr thought it was bile duct cancer. The doctors disagreed on the primary. I started treatment for Bile Duct cancer, and it progressed after three rounds, so they put me on a stomach cancer regimen, and I have "some" regression. So, in the interim of considering altering the system chemo regimen, the DNA test came back with CDH1 Germline (VUS), so my medical oncologist made the switch to a gastric regiment of FOLFOX since CDH1 is more commonly linked to gastric cancer than bile duct cancer. So, in summary, my symptoms started approximately on 9/22. I was diagnosed with stage 4 adenocarcinoma on 4/23 and am currently "stable" according to a CT scan, but it never showed half of the mets. It only showed some LN and peritoneum mets, so I have one-third of the whole picture, and that's quite unsettling. I am hopeful and grateful for my family, life, and otherwise good health (besides that, Mrs. Lincoln, how was the play?). Living with a dark cloud with some silver linings, I would give anything to have learned a different way. Thank you.
New York

NORTH CAROLINA

Anissa Bass - Charlotte On August 10th, we lost an incredible man, Anthony Bass, to a long battle with stage 4 stomach cancer. Anthony endured over 30 blood transfusions, 10 rounds of radiation, two rounds of FOLFOX chemotherapy, and an attempted total gastrectomy, which had to be aborted due to metastasis to the peritoneal cavity. He was a loving husband, a devoted father, and a mentor to those he worked with. Anthony fought hard and remained optimistic throughout his entire diagnosis. His bravery, courage, and resilience continue to inspire his family to share his story with everyone who will listen. Statistically, African American men die from stomach cancer more than any other ethnic group in America, putting Anthony in a high-risk category. In addition to this, Anthony had cancer on both sides of his family, and his A-positive blood type—which is rare and thickens easily—contributed to the blood clots he experienced. We first learned about his diagnosis when Anthony began experiencing uncomfortable sensations and occasional dark stools. He was misdiagnosed twice and told that he had stomach ulcers. It was not until May that he finally received an endoscopy, which revealed stomach cancer. By that time, he was given only six months to live. During his treatment, Anthony received a plurex catheter, an IVC filter, an attempted total gastrectomy, 10 rounds of radiation, and two rounds of FOLFOX chemotherapy. In addition to this, he suffered from loss of appetite, severe weight loss, and constant vomiting after nearly every meal. It is so important to share our story because stomach cancer is often diagnosed when there are no other options left—leaving families with little to no resources or support. This is an incredibly difficult reality to endure. When you are at stage 4, people are already giving up on you. That’s why it is critical to advocate at every step of the diagnosis and treatment plan—because your loved one’s life still matters. We carry Anthony in our hearts every single day. We love and miss him deeply. We hope that by sharing our story and spreading awareness, we can honor his life and help others facing this disease.

Bridget Glover – Leland Do you have a minute to talk? We've got the results back from your genetic test and you likely have stomach cancer." That's what an OB/GYN nurse told me over the phone while I was at work one day in March in 2019. Anything she said after that was static. Think the teacher from Charlie Brown. That's all I heard until I hung up. I didn't process CDH1, or referral to Chapel Hill, genetic counseling...nothing after the dreaded 'C' word. And I was highly confused because I thought they were testing to see if I carried a gene for breast cancer because of my mom's breast cancer...where did stomach cancer come from?!?! I called my mom and cried because as far as I knew, I had stomach cancer. I went home because I couldn't focus on anything else. Fast forward a few months to my meeting with the team of doctors at UNC Chapel Hill, I find out that the test couldn't possibly tell if I had cancer, just that I had a very high risk of developing a very difficult to detect and deadly form of stomach cancer (at the time, it was thought to be as high as 82% likely)...oh, and the recommended treatment was to remove my entire stomach. This was a huge decision to make, life without a stomach? I waited 3 years before I made the decision to go for it. But not before consulting with 2 other surgeons to see if there were other options available, one said to take it out, the other said wait and see. April 15, 2022, I had a prophylactic total gastrectomy at UNC Chapel Hill to prevent developing hereditary diffuse gastric cancer (HDGC). I am one of roughly 5% with the CDH1 mutation who did not have any cancer found in their stomach upon removal. But I have 8 siblings, one has also tested positive for the mutation which puts her at risk for stomach cancer, she currently gets routine endoscopies to check for cancer cells. However, the type of stomach cancer that may develop is not easily detected via endoscopy because it's scattered cells and they bury into the stomach lining, which is why total gastrectomy is often recommended. But the other six refuse to even get tested for the genetic mutation (one passed away in 2020 from unrelated health issues, but he also refused to be tested). The idea of cancer or having to have a total gastrectomy is so scary to them that they would rather live not knowing their status. Many of them have children who are at risk of having the gene if their parent carries it. More research needs to be done so that the fear can be removed from stomach cancer. Funding needs to be provided so that early detection can become possible and a surgery like total gastrectomy isn't one of the only options available. I'm so happy I did it, and if I had a choice, I would have done it when the doctors first told me to do it in 2019, but there needs to be nonsurgical ways to treat or even prevent stomach cancer from developing. What brought me to DDF is my family. I would love for medicine to advance so that they never have to go through the things I do living without a stomach.

OHIO

Linda Erbland - Toledo Not many with stomach cancer can call themselves a survivor since most of those diagnosed in the United States are terminal or thriving, with very few of us with stomach cancer getting to be alive and cancer-free. I am entirely free of cancer, and here is my story. In October 2022, I was diagnosed with a gene mutation called BRCA2. In 2015, I had breast cancer and did not qualify for genetic testing. So, in 2023, I began my surveillance and the recommended surgeries to prevent a second cancer. After many screenings, I was found to have stomach cancer. The depth was two millimeters into my stomach lining, and on July 3, 2023, I had an endoscopic resection. All my follow-up endoscopic checkups and scans have shown I am clear of cancer. As I read about stomach cancer, I realized I was so lucky and wondered why we do not do screening regularly to prevent such a high number of deaths. My initial endoscopy was done with my colonoscopy, and it was the procedure that found my one-centimeter cancerous polyp. I wondered why others could not get a screening endoscopy at their initial colonoscopy. I am still left without any good answers to my questions.

Martin Baba - Columbus I am participating in Debbie's Dream Foundation's 2023 Advocacy Day as a gastric cancer survivor. This will be my sixth year joining fellow patients, survivors and caregivers in an event that is vital to further progress, breakthroughs and treatment options for patients and their loved ones that have been afflicted by stomach cancer. I look forward to renewing old acquaintances, meeting new participants and recognizing and honoring our lost warrior advocates when we convene in Washington, D.C. I also look forward to strengthening our relationships that we have forged on Capitol Hill. As part of the Ohio delegation, we have enjoyed reliable bipartisan support from many of our congressional members including DDF's 2018 Congressional Champion, Sen. Sherrod Brown. I am also thankful that my congressional representative, Rep. Steve Stivers, has been a great supporter of our mission for greater stomach cancer awareness and research funding. As an adult I have had a somewhat unique medical history in that I have experienced two different primary cancers. Initially, I was diagnosed and treated for a rare form of Non-Hodgkin's lymphoma in 2006; and then I was diagnosed and treated with Stage III-B diffuse gastric adenocarcinoma in 2011. As a lymphoma patient, I had a wealth of resources and options available to me: clinical trials, cutting-edge standard treatment, a vast array of patient resources and camaraderie, and an overall sense that my Stage IV lymphoma diagnosis was treatable. As a gastric cancer patient, I saw that there was a stark difference in terms of patient resources, treatment options and positive outcomes. Most gastrointestinal cancers, including stomach cancer, regrettably remain as the deadliest cancers. Collectively, we can change that unfortunate designation by asking our congressional members to support much-needed funding for this horrible disease. When Debbie Zelman created her foundation, there was no organization specifically advocating for gastric cancer and no one asking our congressional leaders for the impactful federal research dollars that are absolutely necessary for realizing discoveries in terms of diagnosis and treatment. Stomach cancer now has found its footing on Capitol Hill and we need to continue Debbie's mission by taking bigger strides and leaving a larger footprint as we honor her legacy.

PENNSYLVANIA

Patricia Fitzgerald – Feasterville March 2022 was supposed to be a month of celebrating my birthday, and most importantly I would be celebrating 10 years beating Stage 3 Breast Cancer. Instead, it was a battle I could not believe I would fight again. It began with consistent side pain eight months prior to my diagnosis. July 2021, I had a dull pain that would sometimes send a shooting pain in my left side just under my ribs. I went to my family doctor, and he took blood work. By August the pain would come and go every day and my blood work came back "off". I asked my family doctor why. He didn't know so he sent me to my hematologist. My doc couldn't see me until December. He took more blood work and felt where my pain was but couldn't feel anything so he sent me for an ultrasound. The ultrasound came back clear, but my bloodwork was still off, (high red, white cells and platelets). He says "it's off a little. Let's reevaluate in 3 months''. I was a little concerned and went back to the family doctor and asked him questions about why my blood is off and why am I in pain. He said it was acid reflux and "maybe this is just how your blood is' '. Feeling blown off, I made another appointment with my endocrinologist. My diabetes numbers were good, and my thyroid no longer needed medicine. She didn't feel anything in my stomach but suggested I see a gastroenterologist. I had a scheduled routine endoscopy and colonoscopy. The gastroenterologist biopsied an ulcer that looked "angry". The results showed Stomach Cancer. What! Cancer of my stomach? The organ that feeds my entire body? I was scared. I had to tell my three children, "Mom has cancer again." I was headed into the toughest battle of my life. After many more doctor visits and specialists my treatment plan began. I began chemotherapy in April. I received 8 rounds of "FLOT" from April to July. September of 2022, I had my stomach removed and a tumor that had grown through my stomach wall. During this whole cancer journey I had to be an advocate for my diagnosis and treatment. Now I find myself fighting for help and support to live without a stomach. I had a vertical sleeve/

gastric surgery for weight loss eight years prior to being diagnosed with stomach cancer.

During my weight loss journey, I received guidance and support from the hospital, doctors, nutritionists, behaviorists, and support groups that were all available through my medical team and hospital. Shockingly there is not that support for gastric cancer patients. After my stomach was removed, I was sent home to start my stomachless life and I had no idea what to do. The only advice my gastroenterologist gave was "Cancer's gone, eat what you want". I was beside myself; I could not believe gastric cancer patients are not offered the same guidance and help as weight loss gastric surgery. It has been 6 months since my stomach was removed, a year since my diagnosis and today I fight every day to stay hydrated, eat nutritious food, and enough calories to sustain a person. I am considered malnourished, iron deficient, vitamin deficient and receive hydration infusions twice a week, B-12 shots monthly and iron infusions. I have lost a significant amount of weight and the numbers on the scale continue to drop. My battle with stomach cancer has become a daily routine in my life both physically and financially. I thank God for Debbie's Dream Foundation and their support. They have been an amazing support to my family and me. I have learned more about nutrition and quality of life living without a stomach. The support groups, workshops and seminars have been so educational, inspiring and motivating. My hope is that my cancer journey(s) can also be an inspiration to others.

SOUTH DAKOTA

Karissa Eifert - Rapid City - My journey with stomach cancer began in the spring of 2015, when my mother was diagnosed with stage IV diffuse gastric cancer. Her treatment was arduous, including exploratory surgery followed by aggressive chemotherapy. Almost exactly eight months later, just 10 days before Christmas, my mother passed away in hospice care. Her medical team assured us that her cancer was rare, typically occurring in much older individuals. They claimed that something in her body had simply malfunctioned and that there was no reason for my family to worry about genetic risks. It wouldn't be until three years later, by complete chance, that I would discover I carried the CDH1 genetic mutation—a mutation my mother undoubtedly had as well. In 2019, I spent the year advocating for my own care in a small community where few were familiar with my condition or how best to treat me. I fought for insurance coverage, referrals to out-of-state specialists, and faced resistance from family and friends who disagreed with my decision to undergo a total gastrectomy. Determined to move forward, I found a study at the National Institutes of Health (NIH) and enrolled in July 2019. On November 7, 2019, I had my total gastrectomy and began a new chapter of my life. My recovery was slow and filled with complications. After surgery, I suffered from a leak and a collapsed lung, leading to a month-long hospital stay. Upon returning home, I had to relearn how to eat, despite having no desire to do so. Shortly after my discharge, the COVID-19 pandemic hit, further complicating my recovery. Over time, I was diagnosed with severe bile reflux and an acute esophageal stricture. I ultimately underwent close to a dozen esophageal dilations and a Roux-en-Y revision surgery, which has dramatically improved my quality of life. I never imagined this journey would be part of my life. But I am eternally grateful that I discovered my genetic mutation by chance. I have always considered this information a gift. Knowing about my CDH1 mutation gave me options and choices my mother never had. It meant I could choose surgery and give myself a chance at a longer life. It also meant that my sister could be tested and learn of her own risks. Last year, my sister also tested positive for the CDH1 mutation and has now enrolled in the NIH study. Without this knowledge, one or both of us might not have been here in 10 years. I do not take this gift for granted. Today, I advocate for patient care, research, and funding, while also mentoring and supporting fellow CDH1 and stomach cancer patients. My diagnosis has reshaped my life's priorities, and I plan to continue uplifting this community for as long as I can.

TENNESSEE

Millette Milliken - Nashville What should have been a weekend with family preparing to celebrate Resurrection Sunday in 2010 was the beginning of my stomach cancer journey. My sister had gone to gas up the car and headed to KY to pick up my mom. As I was lying in bed, I felt dizzy and nauseous. I made it to the restroom, but the nausea went away briefly. After I laid back down, the nausea came back. I made it to the sink and threw up blood. I called my sister, who was still in town, and asked her to take me to the hospital. My first God moment came when we pulled up to the emergency room, and no other patients were there. I was able to walk straight back, where I threw up blood again. The doctor asked what I had to eat the night before, which was barbecue ribs. She thought what she was seeing may have been that. After testing, she later came back to confirm it was indeed blood. The entire dizziness and nausea episode lasted for only one hour. I did not have any symptoms before and have had none since then. The following week, as I prepared for a business trip, I received a call from my doctor letting me know they found active cancer cells in a polyp in the upper part of my stomach. Everything from there was a rollercoaster. It was May of 2010; my son was about to graduate high school, and I was preparing to receive my degree. On top of this, we were displaced from our home for a few days due to the Nashville Flood. The following weeks were filled with various scans ordered by my surgeon. When the final pre-surgical tests were done, I had also been diagnosed with a benign nodule on my lung and a cancerous polyp in the GI junction. It had not penetrated my stomach but was in one lymph node. According to my surgeon, it is in an interesting spot. I remember him telling me I was an interesting test subject because there was no medical data to help them know how to treat me. Huh? Test subject? Really? No medical data out there? Am I a guinea pig? I was staged at 2-3. I am a woman of faith. At the moment of the diagnosis, the words to a song came to my mind. It was as though God brought me back to reality. "I trust You, Lord, I trust You. Whatever Your will is for me, I'll trust You." Those words of worship spoke to me. Was I going to trust God as I said I did? What would worrying do? There was absolutely nothing I could do to fix anything. That is when I indeed chose God to guide my footsteps. Following surgery, radiation, and chemo, I received my cancer-free diagnosis in December 2010. I'm humbled to be an advocate for those who do not have a voice and grateful to be an encourager to those who ever had to hear those words, “You’ve got cancer,” regardless of the type.

Paula Hocking - Maryville I was diagnosed with stage three stomach cancer in September 2020. During treatment, it was discovered that I had an H.pylori infection that I most likely picked up as a child in Romania. A simple test and treatment could have saved my stomach, but unfortunately, no one suspected I had the bacteria, even though it’s common in third-world countries. Most of my doctors have never had a patient without a stomach, so a lot of things have been missed or misdiagnosed and made my recovery more difficult. I worked as a nurse before having cancer, and I do a lot of research and pass whatever helpful information I find on to my medical providers, but it shouldn’t have to be this way. Better, reliable information that is easily accessible should be available for doctors and dietitians. I’ve been blessed to have a supportive family and church. Many people have helped and prayed for me over the past few years. I’m thankful to be alive and cancer-free, but living without a stomach is challenging. Before having cancer, I worked full-time and stayed very busy and productive. I thank God that there are a lot of things I can still do, but I’m at the mercy of my “seahorse” digestive system, which is very unpredictable and unreliable.

Stacy Martin – Hixson I am 44 years young. I am a cancer survivor. Unlike most people, though, I didn’t find out I had cancer until it was already gone. On February 6, 2019, I learned I had the CDH1 genetic mutation. From that moment on, I was in survival/problem solving made. I had all of my initial assessments done at the Mayo Clinic, as that is who I was working with on the genetic testing. Then I found the NIH and was lucky enough to be enrolled in their study. Ultimately, I decided to have my total gastrectomy done there on September 12, 2019. When the pathology came back on my stomach, they found 17 signet ring cell carcinoma spots. I had Hereditary Diffuse Gastric cancer. It was confirmed that the biggest risk I have taken in my life just paid off. Because this is so rare, 20 years after its discovery, they still do not know what causes the mutation to start growing cancer or what accelerates the growth. I know that if I had not done this, I would not be alive. It was the right decision to make and just in time. It has now been almost 2.5 years since my Total Gastrectomy. I have had three other surgeries, including a Double Mastectomy. Confidently I can say that I am doing better than I was before all of this happened. I am healthier. I am happier. I am more active in general and in my community. My quality of life has increased. I have started a small business, Seahorse Snacks, to share my love of food and story with the world. Most importantly, I no longer have to worry about any CDH1 related cancers. The NIH is an amazing place for people with the most challenging medical problems to solve, and it’s filled with staff who have worked their whole lives for moments like these. I think everyone learned the importance of medical research and science during this everlasting pandemic if nothing else. I can share my story with people and help them on their journeys. I hope that because of my journey and my contribution to the research, there will soon be other options besides giving up your stomach and that HDGC can be detected early and treated effectively. Until then, I will continue to advocate for education and funding for research and genetic testing so other people can live up to their full potential and see how their amazing lives can be. Who knows what contributions my fellow seahorses and their families will have for the world.

TEXAS

Rebekah Rogers - Diana After being misdiagnosed for five years with anxiety and stress, I was diagnosed with stage 4 papillary thyroid cancer in December 2023. My diagnosis came after I nearly died from the Delta strain of COVID-19 and was on oxygen for two months. Given my age and family history, it was unusual for me to have such an aggressive cancer, so I decided to undergo genetic testing in search of answers. My test came back clean. Fast forward through my long and complicated medical journey, and in July 2023, I discovered that I carried the CTNNA1 gene mutation. At that time, I chose to undergo surveillance. My sister, Rachel, also did genetic testing, and upon her baseline biopsy, it was discovered that she already had cancer. I moved away and left my family for several months to be her full-time caregiver. After returning home, it was time for me to undergo my surveillance biopsy again. Unfortunately, in October 2024, they found cancer. I have not yet had my stomach removed and have been pursuing alternative treatments while searching for a surgeon who not only performs the operation but is also researching CTNNA1. For those who know me, I am a fighter and will beat this. I am honored to advocate for stomach cancer prevention, early detection, funding, and research.

Pamela Pierce - Forth Worth Three years ago my life completely changed. I had been a long-time sufferer of GERD and had been taking what was supposed to be a short-term heart burn medication for 10 years. I was being seen by a nephrologist who noticed that my iron was low; he set me up to get an iron infusion. While I was sitting there for my infusion, I started having a conversation with the nurse there, I told her about my long time GERD situation. The nurse asked if she could share my story with a doctor she knew. After a short while she came back and gave me a number saying the doctor wanted me to give him a call. After a call to Dr. Roberts and quick visit to his office he had a plan of action. Do a scope, make sure everything looked good and perform a Roux-en-Y to rid me of my GERD and dependence on the medication. With his scope he found a growth in my stomach. After months of different scopes and a biopsy of the growth, I got a call from the doctor, the results were cancer… stomach cancer. I couldn’t’t believe it, I was in a daze, it felt like my world was crumbling down around me. It was one of the worse things I had ever heard in my entire life, I held my daughter close to me as we contemplated what this meant. My story wasn’t over; it seemed like the universe was looking out for me. Within a week of receiving my cancer diagnoses, Dr. Roberts had me set up for stomach surgery. He removed 85 percent of my stomach, and 16 lymph nodes; he wanted to remove any chance the cancer would have to return. I spent a month in the hospital recovering and learning how to live without most of my stomach. It’s been a very tough road. Foods that I loved; I can no longer eat. I have trouble adjusting to the new portion size and ensuring that I get the right amount of nutrients from my meals. I worry sometimes that It was too easy for me and that in the five years of remission that the cancer will return. I have my daughter by my side every day; without her, I don’t think I would have made it through any of this. I’m so thankful for my guardian angel and to God for aligning everything just right that it all fell into place. If one thing had been different, I'm not sure it would have been found until it was too late.

Yolanda Day – San Antonio I am a 64 year old female. In 2019 I started noticing that I was getting very tired very easily. In 2020 it got so severe that I got out of breath with simply bending down. My husband and I go dancing often so when I couldn't get through one song, I knew there was a problem. After tests for heart problems were negative, I had lab work done. They discovered through the lab work that my red blood cells were low and I needed a blood transfusion. I went into the hospital for 4 days to get the transfusion and to determine the source of the low red blood cells. They couldn't find a source so they suggested I get an endoscopy. The endoscopy discovered the tumor in my stomach. It was malignant. I had chemo and radiation in mid-2021 and had my stomach removed Dec 2021.

UTAH

Kendle Salisbury – Washington In 2018, I was diagnosed with stage 2 breast cancer after a routine mammogram. After undergoing a lumpectomy and radiation, I was cancer-free! In February 2023, I started noticing discoloration on my stomach, but two dermatologists were unable to diagnose the cause. I went back to my family doctor, who ran blood work and noticed I had a low white cell count. Concerned, he referred me to an oncologist, especially since I had also started experiencing pain in my left rib area. The oncologist ran additional tests, including blood work and an ultrasound, but everything came back normal. He advised me to return in a couple of months for further bloodwork. In September 2023, a swollen lymph node appeared in my neck. I returned to my family doctor, who ordered an ultrasound. The results prompted a biopsy, as the lump was hard and concerning. The biopsy revealed shocking news—it had originated from my stomach. I was in complete disbelief. How could a lump in my neck come from my stomach? My doctor ordered a PET scan to check my abdomen. On October 9, 2023, I met with the oncologist, who delivered devastating news—the scan showed multiple metastatic lymph nodes in my abdomen, as well as a mass in my stomach. I was diagnosed with stage 4 stomach cancer. The oncologist was not optimistic and told me to get my affairs in order and contact hospice. But I refused to accept this. I had beaten cancer once before, and I was determined to beat it again. I switched oncologists and found one who believed in me and was willing to fight alongside me. I started chemotherapy in November 2023, and by April 2024, my PET scan showed no evidence of cancer! Thankfully, my scans continue to show no evidence of disease. However, because gastric cancer is so aggressive, I need to continue chemotherapy treatments every other week for the rest of my life. If it keeps me alive, it is worth it. If pre-screenings for stomach cancer were as available as they are for breast cancer, we might have been able to catch my cancer early—just like we did with my breast cancer. My hope is that we can secure funding and support for gastric cancer pre-screening testing so that more lives can be saved.

Jill Singleton - South Jordan My younger brother, Morgan, was diagnosed with hereditary diffuse gastric cancer on New Year's Eve 2020—a devastating ending to an already difficult year. Morgan was in his early thirties and incredibly athletic. Just the previous New Year's, he had ridden his bike from Yuma, Arizona, all the way into Southern Mexico. He was already feeling unwell at the time, but he pushed through and made it. I was convinced it would be the same with his cancer diagnosis—that there would be a way for him to fight through and beat it. I was floored when he met with his oncologist, and they told him he was already at stage 4. Morgan refused to accept defeat. He searched for answers, clinical trials, surgeries—anything he could do. He requested genetic testing, but the doctors were hesitant. If this were genetic, they argued, we would already know. There would have been a history of stomach cancer deaths in the family, and we had no such history. But Morgan insisted they test him anyway. The results came back: he had the CDH1 mutation. It was genetic. His doctors were shocked. Our family immediately came together. CDH1 is an inherited mutation, and those who carry it have a 50% chance of passing it on to their children. If a person with CDH1 has a family member with stomach cancer, they have an 80% chance of developing gastric cancer. If they are a woman, they also have a 60% chance of developing lobular breast cancer. The biggest challenge with hereditary diffuse gastric cancer (HDGC) is that it does not show up on scans or blood work. The only way to detect it is through biopsies of the stomach lining, and even then, it is often missed. Most people who receive this diagnosis are already stage 4 and out of options. After Morgan's results, our entire family underwent genetic testing. My mother, myself, and one of my sisters tested positive. Out of five siblings, three of us carried the CDH1 gene mutation. Thankfully, none of our children inherited it. My uncle also tested positive. Looking at our family history, we now believe my grandfather likely had HDGC as well. He passed away in his early 50s, and while we believed it was lung cancer, we now suspect that it was stomach cancer that had metastasized. The recommended treatment for people with CDH1 is a total gastrectomy (complete removal of the stomach). They also advocate for a double mastectomy in women, but at the time, it wasn't strongly recommended. However, after reviewing my history of infertility and 15+ years of hormone-based fertility treatments, my doctors strongly advised me to undergo a double mastectomy as well. Morgan passed away in October 2021. Just two weeks later, I had my total gastrectomy. When the biopsy results came back, they found two spots of cancer in my stomach. Eight months later, I had a double mastectomy, and the biopsy revealed pre-cancerous cells in my left breast. There is no denying that my brother's determination to seek answers and push for genetic testing saved my life. He saved my mother, my uncle, and my sister as well. Living without a stomach is hard. Living without my brother is harder. But I thank God every day that I had the opportunity to stop the cancer before it was too late. My daughter needs her mother. My husband needs his wife. I pray for better screening methods, so we can stop dismissing these symptoms as simple acid reflux. We need to start diagnosing this cancer before it's too late. And maybe one day, those with CDH1 won't have to undergo life-altering surgeries just to ensure they live long enough to watch their children grow.

VIRGINIA

Raquel Milano - Arlington My mother had been going to the doctor regularly for years, repeatedly complaining of stomach pain. Each time, she was told it was fibroids. For months, she continued to express her concerns, but it wasn't until much later that she was finally given an endoscopy. By then, it was too late—the procedure revealed she had stage 4 stomach cancer. We lost her far too soon.

Carissa Hocevar - Richmond February 2020 found me working abroad as a Certified Fundraising Executive (CFRE) for nonprofits with a 20-year career. I led a 1500 km awareness cycling trip from Angkor Wat to Saigon, then two weeks of staff meetings to cancel all 2020 events due to COVID-19. When I got home, I thought I was just overly exhausted or fighting a bug until I had such excruciating abdominal pain that I ended up in the ER. They found an 18 cm growth on my ovary, which immediately tested to be stomach cancer. At that point, they then removed all unnecessary organs and tissues while also calling in a GI surgeon to find the originating spot, which was a tiny stomach ulcer. I had Signet Cell Carcinoma of the stomach in Stage 4 at age 40, with a 4% chance to live five more years. A month later, I performed a 1" wedge resection from my stomach. I then started nine months of chemo, both oral and IV, which was the only option then. Six months later, they noticed another spot in my stomach, which turned out to be a recurrence. All parties agreed the only option was a total gastrectomy, which happened a few days before Christmas in December 2021. I was released from the hospital on New Year's Eve with a massive infection, as well as leakage at the internal incisions. My best friend forced me back to the hospital, where I had emergency surgery to correct the issues mentioned above. I woke up on New Year's Day with 40 staples covering my abdomen. For the next few months, I never began recovering, which generally happens after one month. I just kept getting worse till they found fluids had been left & had caused two abscesses, an initial in my abdomen that had spread to cause another in my lung. All that landed me back in the hospital for another two weeks in March 2022, weighing only 80 pounds. I started Keytruda (immune therapy) before abscesses were discovered & continued that for six months until I began to have ER visits following each treatment. So that was stopped six months early (should have been a full year), but there's not yet a protocol with Keytruda for my type of cancer. We hope and think it's enough. The availability to even treat with Keytruda was a new research advancement, and my treatment will help create a proper protocol for use with my type of stomach cancer. We've run two Signatera ctDNA tests where they check for the specific DNA markers for the exact tumor in my blood. Both have come back clear, as have the scans every three months. This is also a new research advancement that was unavailable two years earlier with my initial diagnosis. If the research had been better funded earlier, the Signatera test could have caught my recurrence early, perhaps avoiding a total gastrectomy. I'm still battling with weight & being able to eat. I'm stuck at 95-98lbs. I may not ever gain all of it back, as gaining weight has never been easy for me. I still have semi-regular ER visits, but that's getting better as I learn how to live without a stomach & my body adapts. I sleep a lot still. I'm on disability & work part-time as I'm only allowed to earn a very small amount with disability. I'm not yet able to return to the high pressure of what I was doing, so I am trying to find something reasonable for now. Being forced to maintain work for insurance purposes during my first diagnosis was extremely tough. For my second diagnosis, I was unable to work & had no choice but to seek help from limited government options. Now, I face a recovery period where my disability payments cut off my access to other programs such as

EBT (food stamps) and utility assistance. We must work together to continue research options and make them available sooner to patients. We also must work together to improve the support options available to these patients so that the research advances can actually benefit them.

Jonathan Porter - Chesapeake Senior Chief Hospital Corpsman Jonathan Porter dedicated his life to service, providing critical medical care to both the U.S. Navy and Marine Corps in some of the most challenging environments. His commitment to saving lives and ensuring the well-being of his fellow servicemen and women exemplifies the spirit of military service. In 2023, Jonathan's life changed dramatically when he was diagnosed with stage III stomach cancer—just five years after being treated for an H. pylori infection, a known risk factor for gastric cancer. True to his resilient nature, Jonathan has faced this diagnosis with remarkable strength and determination, never wavering in his fight. His story has become an integral part of Debbie's Dream Foundation's advocacy on Capitol Hill, where his battle with stomach cancer was featured in our letter to the Senate Armed Services Committee, supporting efforts to mandate H. pylori testing for military members. Jonathan's courage, both in his military service and personal fight against cancer, continues to inspire those around him, demonstrating the power of perseverance and hope.

Cecilia Carr - Warren I was diagnosed at 46 years old with triple-positive stage 1a ductal breast cancer. My treatment involved chemotherapy, surgery, radiation, and additional surgery—a grueling journey, but one I fought through. Four years later, a distant cousin I had never met reached out to me through Ancestry.com. She had recently lost her mother to hereditary diffuse gastric cancer (HDGC) and strongly urged me to undergo genetic testing for the CDH1 mutation. She didn't want anyone to suffer the way her mother had. After meeting with a genetic counselor, I was tested and confirmed positive for the CDH1 mutation. With this knowledge, I chose to undergo a total prophylactic gastrectomy at Memorial Sloan Kettering (MSK) with Dr. Sam Yoon to prevent the development of stomach cancer. A few years later, I joined the NIH CDH1 study led by Dr. Jeremy Davis. I was an active participant, advocating for new patient enrollment, mentoring fellow "seahorses" (people without stomachs), and even escorting patients to their appointments since I lived just an hour away. Sadly, the study ended abruptly before the presidential election, and Dr. Davis transitioned from the NIH to the University of Maryland. While his work will continue, what was supposed to be a lifelong study is no longer available. This fight is not over for my family. My 22-year-old son has also tested CDH1 positive and is currently under gastric surveillance. Signet ring cells—a hallmark of diffuse gastric cancer—have already been identified through endoscopy. My sister is also CDH1 positive. She had the same total gastrectomy as I did, but her postoperative experience has been incredibly difficult. She now weighs just 73 pounds, relies on a feeding tube, and faces a dramatically reduced quality of life. Our stories highlight the urgency of continued stomach cancer research and support for individuals with hereditary risk factors. We need more awareness, better treatment options, and ongoing advocacy to ensure that no more families have to endure this devastating disease.