



Life, Loss, and Dreaming of a Cure

*Stories from Debbie's Dream Foundation: Curing Stomach Cancer
2023 Capitol Hill Advocacy Day Advocates*



Debbie Zelman, DDF Founder (1967-2017)

In April 2008 Debbie Zelman, wife and mother of three young children and a practicing attorney, was diagnosed with advanced, incurable stage IV stomach cancer. At that time, she learned that her chance of surviving five years was only four percent.

In 2009 Debbie began to respond to treatment and started Debbie's Dream Foundation: Curing Stomach Cancer (DDF). She used her experience, tenacity, and broad network of friends and supporters to start a movement to raise awareness about the disease, fund research, and help other patients. As an advocate and the face of stomach cancer,

Debbie was appointed to several committees including the NCI Gastrointestinal Steering Committee and Clinical Trials Planning Committee, NCI Patient Advocate Steering Committee, and the Esophageal Cancers Guideline Committee. She also served as a patient advocate on the joint effort to develop a guideline on HER2 Testing in Gastric Cancer with the American Society of Clinical Oncology (ASCO), the College of American Pathologists (CAP), the American Society of Clinical Pathology (ASCP), the US Army Medical Research and Material Command Peer Review Cancer Research Program (PRCRP) and was appointed an American Cancer Society Research Stakeholder.

DDF is now the international advocacy leader for this under-recognized and under-funded disease and provides education and support for patients, families, and caregivers. Under Debbie's leadership, stomach cancer has been included in the Department of Defense (DoD) PRCRP resulting in \$17.4 million being invested in stomach cancer research. In addition, DDF has provided \$1.45 million in funding for stomach cancer research to date and has become the voice for those who are no longer with us.

Debbie passed away on December 23, 2017 after nearly a decade of advocating for all those affected by this terrible disease. She is survived by her husband Andy, her children Rachel, Zachary, and Sarah, and her parents Madelyn and Danny Zelman. Her legacy and mission of finding a cure for stomach cancer continue through Debbie's Dream Foundation: Curing Stomach Cancer and the thousands of people who support the DREAM.

ARIZONA

Lissett McKee – Tucson My name is Lissett McKee. I am a 60-year-old, married to my best friend for 32 years. I don't want to use the cliché saying he is my soul mate. But he is perfect for me. He has helped me through two cancers. First in 2018 breast cancer. I had a lumpectomy, radiation, reconstruction & several revisions. I have had what you would call stomach (gastric problems) all my life which I did not pay attention to. I went to see my primary care physician who thought I might have kidney stones. He sent me for an x-ray. The radiologist found the tumor. Next thing I know I was in the hospital. Before the surgery, I stopped eating little by little till I could no longer eat anything. I ended up having a distal gastrectomy. Following the surgery, I had a bad reaction to one of the medications and as a result was in hospital for over 3 weeks. During this time, I was NPO, nothing by mouth! They ended up putting in a central line to give me nutrition through a vein. I have lost about 45 pounds which is great. The only drawback nothing fits. Ha-ha! It has been a very long & hard road many ups & downs, a lot of emotions. After my breast surgery I felt a sense of, in a way release because I was prescribed a medication which would prevent the breast cancer recurring. This second time around, I was told I do not have a specific gene which would allow me to take a targeted medication to help prevent a recurrence. But if my cancer comes back then yes, I am eligible for it but it will be for the rest of my life. The medication is very toxic. Reading between the lines this means I will probably not last very long. You can imagine how important research is to me or for future patients with my dilemma. For now, I do CT's of my stomach, chest &

abdomen every three months. Yes, every three months. Which for someone my age, is not good for me. I know medicine has evolved a lot, but this still does not reassure me that my cancer will not come back. I have a very unique perspective on cancer since I worked for oncologist 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 to have a short life. I am grateful for being alive. My husband and dad are the most important people in my life...and of course, my doctors!

Paul McKee – Tucson My name is Paul McKee, for years now I have watched my wife, Lissett, live with an extremely debilitating condition known as Postural Orthostatic Tachycardia Syndrome or POTS before she was diagnosed with cancer twice in a three-year period! The first time was breast cancer. She had a lumpectomy followed by radiation reconstruction and revisions. The second tumor was discovered purely by accident! Our primary care provider had sent her for an x-ray, checking for possible kidney stones. She was lucky that the radiologist noticed an otherwise undetected mass in her stomach. A couple of endoscopies and a biopsy later she was scheduled for a distal gastrectomy. After the surgery, she had a bad reaction to one of the medications, Reglan, and had to be taken off it. This medicine helps the stomach to start working again. A week after the surgery, she had her first solid food and a couple of hours later she was released. For the next few days, she was unable to keep down any solid food which meant a return to hospital via the emergency room! She was readmitted, had nasogastric tube put in, a rather nasty experience! She remained there for two and a half weeks, pretty much all of it NPO, nothing by mouth! Through this entire time, she tried to keep positive always greeting me with a huge smile. Her first real solid food was a slice of chocolate cake that one of her doctors brought to her on her birthday! After she had recovered, the oncologist did a genetic test to see how to continue treating Lissett. Unfortunately, she did not have the mutation that would allow her to be treated by targeted therapy. Instead, she is being constantly monitored with CT scans every three months, watching for possible recurrences. We are still coming to terms with her new life, when to eat, how much to eat how often to eat and of course what to eat. The two things about this experience that stand out most to me about this experience is how lucky we were that our PCP decided to be careful and check for kidney stones and that the radiologist caught the tumor in the x-ray. The second is how proud I am of her! She is an amazing woman who has displayed incredible strength and resilience! I cannot tell her often enough about that feeling of pride!

Nicole 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, I'm an 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. I'm about to turn 44 and I'm 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.

CALIFORNIA

Cecille and John DeSimone – Rancho Palos Verdes "You are my sunshine, my only sunshine. You make me happy when skies are grey. You'll never know, dear, how much I love you. Please don't take my sunshine away." This has been the lullaby I sang to Kat from birth till about 7 yrs. of age. Katrina Ashley DeSimone was born on Aug 31, 1988, four days ahead of schedule. After 14 hours of labor, on a sizzling summer day, she came into this world via cesarean. From that moment on, our lives have been enriched forever. She was our one and only child. But then, our sunshine wasn't meant to be with us for too long- 29 years. They say we are all on borrowed time. Bloating and fullness. Those were Katrina's only symptoms aside from an insignificant rectal bleeding. She was found to have a 19 cm right ovarian cyst with a high CA - 125 blood tumor marker. Katrina was scheduled for an exploratory laparotomy with removal of right ovary and Fallopian tube and biopsies of lymph nodes and omentum on May 4, 2015. We were very optimistic that prognosis was good because frozen section/intra-operative pathology diagnosis was borderline ovarian tumor. Post-operative follow up revealed invasive mucinous adenocarcinoma (malignancy) involving the right ovary. Her disease was staged 1C most likely ovarian primary (arising from the ovary) but highly suspicious for metastasis (spread to ovary from elsewhere) judging by microscopic findings and special stains. She was to undergo ovarian cancer chemotherapy with drugs that will most likely make her lose her hair and will affect her left ovary, with a chance of sterility. After further work up-in endoscopy, a 2-3 cm tumor on her stomach was seen and biopsy confirmed in pathology as adenocarcinoma. Cells from ovary and stomach were compared and found to be identical.

Additional PET-CT scan confirmed lesions elsewhere: liver and lymph nodes. She now has Stage IV gastric (stomach) cancer. Prior to starting her chemo treatments, her request was to harvest her eggs, feeling hopeful that she was going to Bay cancer. To this day, we have sole ownership of her 21 eggs safely stored at University of Southern California Fertility Center, for donation to anyone one in need. In May 2015, when she was diagnosed with cancer and then confirmed a month that it was indeed stage 4 stomach cancer, everyone hoped for a miracle. As a health professional, specifically a GI nurse, it was heart wrenching to know her odds. Devastating was an understatement. The presence of GI symptoms such as H.Pylori, gastritis nor gastric ulcers were nonexistent; her tumor didn't show any gene mutations such as CDH1 nor were there any drugs identified in the 6 gene mutations she had. Throughout her trials and tribulations, she battled fiercely and valiantly. She was gracious beyond her years and still retained her compassionate, thoughtful and loving ways towards others. She was loyal beyond compare. Even in her physical pain, she reminded me that her paternal grandmother, battling colon cancer almost the same time as her, needed help more than she does. She preceded Kat in death by one week. Charlie, Kat's beloved 6-year-old sharpei was put to sleep 2 nights before her funeral and he, too, has joined her. Kat strongly encouraged everyone to donate to Debbie's Dream Foundation to find a cure for stomach cancer and was selfless, signing up to whatever clinical trials she was eligible, even if she knew she will never benefit from it. As a parent of an only child, we will never know the answers why she was taken from us. We will never celebrate milestone birthdays; never get to meet the love of her life and take care of her the way we did; never get to plan her wedding and give her away. The prospect of going to the 75th year of the main Vatican doors open again in 2025, was one we planned because we went to its 50th year in 2000. We dreamt of taking her children traveling with us. Her journey, partly documented in her Caring Bridge, by both of us reminded me of Stuart Scott's words as he accepted the ESPY awards. He, too, was battling cancer and expired in June 2015. He said and I quote: "When you die, that does not mean you lose to cancer. You beat cancer by how you live, why you live, and the manner in which you live." Kat embodied these words, and we are comforted by the strength with which she carried on and, in the end, having the faith, surrendered when the hour came.

Janeth Martinez – Los Angeles I am Janeth Leon Martinez, born and raised in Los Angeles, CA 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. I've always lived a healthy and active lifestyle, even throughout my pregnancies. 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 pains 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 in 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. 4 rounds of FLOT, total gastrectomy and 4 more rounds post op. The first 4 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 made it to the other side at 97 pounds. Weak and exhausted but strong willed through it all. I am now 41 years old, 115 pounds, and I have been living without a stomach since Dec. 2, 2020. Two years of learning how to eat and drink again. Two years of being amazed that my body has gone through so much and I am still here, not just living but thriving. In that time, I have also gone through a transformation of being a hairless mole rat to having these crazy chemo curls. Learning to love myself for who I am now and not dwelling on who I use to be. Grace and patience are what I stive 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 that you should be fighting your medical team about either. I've had to request for surveillance scans, blood tests and even procedures to be redone properly in order to get the most accurate results. As a woman and a POC, it is extremely vital to be able to speak up and let your team know what you need from them. After all, they work for you. Despite everything, I know I am truly blessed to be here and to be doing as well as I am. Nothing in life is easy and living without a stomach brings on challenges that 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 that I've made throughout this diagnosis. This is my first 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.

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 got involved in Debbie's Dream Foundation in 2012 to fight for more research and public awareness for stomach cancer. My late husband, Doug Ferguson, died in eight months from stage 4 stomach cancer in 2011. As a hospice RN at the time, I became his advocate and later his own hospice nurse. Doug was part of the 80% of stage 4 stomach cancer patients that had no real treatment options except palliation. We were heart broken when given no hope by the medical community. But then we also found little research as well as little public awareness of this very deadly, silent killer. Thus, I have become a stomach cancer advocate attending DDF Capital Hill Advocacy Day nine out of eleven years. Of course, I did not attend in Washington DC during 2021 and 2022 but did the Zoom conference calls with the congressional and senate offices. I am so glad to be attending in person this year and so able to reconnect with my DDF friends. We all have a special connection due to this ugly cancer, which has been like a beautiful rose found growing in a desert. We were thrilled to see stomach cancer added in 2015 to the DOD Peer Reviewed Cancer Research Program. Also, fantastic news came in December 2019 that the National Cancer Institute is being directed by the National Institute of Health to create a scientific framework specifically for stomach and esophageal cancers. The NCI must report what advances in treatments and early detection tools by FY21. This would not have happened without our voices at Advocacy Day.

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

Adam Kuchinski - Washington, DC In April 2012, my 31-year-old wife Megan ran her personal best time in the DC Cherry Blossom 10 mile race. Two months later, she went to the emergency department with abdominal pain, and we eventually found out that she had Stage IV gastric cancer. She was young, healthy, and ready to fight. We saw doctors at four hospitals, including Georgetown, Johns Hopkins, and Memorial Sloan-Kettering. Everywhere we went, all we received were condolences. There were no promising trials that she could participate in, no research that indicated there could be hope around the corner. Megan fought through nine months of chemotherapy, but she was never given much of a chance. The doctors told me that I should be thankful that she made it that long. This month, March 2023, marks 10 years since Megan passed away. It also marks 10 years since the first time that I came to Capitol Hill with Debbie's Dream Foundation (DDF). I have seen the ways that DDF has helped those currently undergoing treatment, and I have also seen the impact that Congressional action can make in funding stomach cancer research. There will be 11,000 stomach cancer deaths in the United States this year, but the number of families and loved ones that will have their lives forever changed by this disease is much higher. We come to ask for your continued support and action, not just your condolences. Thank you.

Brittany Defenderfer – Washington, DC 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 cancer 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 is 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

Tanya McKay – Green Cove Springs My story has changed so much in one very short year. My husband, a former Marine and most recently a local firefighter of 14 years, was diagnosed at the age of 44 with Stage 4 adenocarcinoma of his stomach in September 2018. We went to see our primary doctor within weeks of his first symptoms of feeling full when he ate and noticing his bowel habits had changed. We learned very quickly of his prognosis. Our options were nonexistent. I had asked our oncologist how do we fight this, and her response was “we don't, we just buy some time.” We were devastated. We have three daughters who, at the time of diagnosis, were 16, 11 and 3. How can we not have options to fight with? How in this age of medicine are we supposed to accept this? Fast forward to today- I am now a new widow, a mere 6wks in. My amazing husband is no longer here. I can't say he lost his fight. A fight implies an element of fairness. This was not an equal match. My husband was killed slowly, over 14months. He left his family at the age of 45. He left behind me, his wife of over 21 years, his 3 daughters & a rewarding career as a Firefighter. His options in treatment were few, only 3 chemotherapies & he did not respond successfully to any of them. A round of radiation helped some tumors but not all. His last days were horrendous to watch. Cruel is an understatement. Now I come to D.C. this time without my amazing husband. The real fight is here. The fight for better! The fight for the people that come after us. We must do better. We must continue to push for more information, early detection & better treatments.

ILLINOIS

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.

KANSAS

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!

Teresa Rivera – Kansas City I am from Kansas City, Kansas and am 44 years old. I am a mother to 4 children, ages 24, 21, 16 & 14. I have the CDH1 gene and a gastric cancer survivor. My entire family has been affected by this horrible gene and disease and we have 7 family members in the matter of years. We were always in fear 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 already at a 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) & I got tested for the CDH1 gene. In his first screening he was positive and was the first in our family to actually be able to have a total gastrectomy in April of 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 10 days and NPO for 5 days. I had a feeding tube for 6 weeks, 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 lifesaving 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 in my life. I appreciate my family and my children who helped take care of me. I wouldn't be the woman and mother I am today without them. I am 6 years out and am doing amazing. I still have my issues from time to time with nausea, my food getting stuck (I eat too fast), but it is bearable. I'm alive and am able to be here for my children and my grandson. I do worry about me passing this along to my children. It is my worst nightmare. My oldest 2 haven't been tested yet but I plan to have them tested this year. I am thankful for genetic 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. I am honored to be a part of this conference and look forward to lending my voice for the fight to bring forth more funding to save more lives. It is a must. I also am blessed to be able to take part in this with my cousin Priscilla, another gastric cancer survivor who is with me today. Thank you for this wonderful opportunity!

KENTUCKY

Tom Pierce – Louisville In March 2021, a few months few before my 60th birthday, I was diagnosed with Stage III stomach cancer—specifically gastroesophageal junction adenocarcinoma. Prior to my diagnosis I was healthy and led a healthy lifestyle. I experienced no symptoms of the tumor growing inside me. The only reason it was found was that it started bleeding, leading to severe anemia for which I was hospitalized for a blood transfusion. A subsequent endoscopy to find the cause of the anemia revealed the large tumor at my GE

junction growing into my stomach. I underwent aggressive treatment, which included eight rounds of chemotherapy, major surgery to remove my entire stomach and part of my esophagus, and five weeks of radiation targeting my entire abdomen. My diagnosis and treatment have been physically, mentally, and emotionally brutal and exhausting. Two years after my initial diagnosis and 17 months after my treatment ended, I am still recovering, and although I am lucky to have survived, I still struggle physically and emotionally every day. Cancer is a dread disease, and stomach cancer is among its most brutal forms. More research and funding is needed to develop better diagnostic tools and treatment options.

LOUISIANA

Roland Boudreaux – Gonzales My stomach cancer journey started in February of 2017 at the age of 41. It all started with slight burning sensation in my stomach. Well after a few weeks the pain worsened to the point it was crippling and I needed to seek medical attention. I was fortunate enough to get into see a Gastro Specialist who performed an EGD on me right away. I was informed that I had an ulcer and immediately prescribed some medication. Within a week I received a phone call asking if I could come in a few days early for my follow up appointment and I said of course as I was wanting to get cleared as it was a Holiday week and I had such big plans to celebrate. The doctor informed me that during the EGD he took biopsies and they came back positive. So, I said; positive for what? NOT ready to hear the words that would forever change my life as I knew it. Mr. Boudreaux sir, "You have stomach cancer". I never imagined you could have cancer in your stomach. Well my life started flashing in front of my eyes and I couldn't hear or interpret anything else he was saying other than I have you scheduled to see a surgeon tomorrow morning. I rushed to try and pull myself together so I could break the news to my family and friends. Such a stressful time having to relive the conversation over and over while comforting everyone that we caught it early. I was informed I was going to need a complete gastrectomy in order to try and rid the cancer. However, I woke up from surgery to be told I was already at Stage 4 and would have to go the chemo and radiation route. I was scheduled to consult with an Oncologist at Mary Bird Perkins, in Baton Rouge, LA. My journey could have been totally different if I would have sought medical treatment earlier and knew more about stomach cancer. Unfortunately, many stomach cancer patients find out too late and are already at Stage 4 which leads to a low success rate of individuals living past the 5-year mark. Due to the rareness of Stage 4 Stomach Cancer there wasn't an oncologist knowledgeable enough locally to treat the cancer, so they referred me to MD Anderson in Houston. There I met with one of only three Oncologist who were on staff that treat patients with Stage 4 Stomach Cancer. I went through 4 months of Chemotherapy with very little results in tumor regression. Thankfully after the 4th month mark my Oncologist decided to change up my regimen and within two months the tumor showed significant shrinkage. I stayed on chemo for another two months and of course the standard protocol of care is to follow up with radiation treatment. I had daily radiation treatments for 5 weeks and after a month or so of rest and healing, I went back to MD Anderson to have follow up scans that showed the tumor almost disappeared. I was informed that if my scans would continue to show no signs of tumor growth, I would be a candidate for a new trial study called HIPEC with a complete gastrectomy. Unfortunately, my insurance company kept refusing to pay for this surgery. After almost five months and countless appeals my wife and I were successful in winning an appeal with our insurance provider and I was able to have my surgery. In the meantime, I was fortunate enough to be selected to a clinical trial being performed through NIH in Maryland. NIH is one of, if not the leader, in research and I would like the world to know more about them and how they can help so many more people such as myself. I feel like NIH can use additional funding and would like to help advocate for this. Since my diagnosis, I have been sharing my stories in order to prevent this from happening to anyone else. Most are shocked and in disbelief that you can live without a stomach. Evidence shows that we can live and be very productive if this disease is caught early on. I have sent advocacy email requests to my local State Representative, and I have been in communications with my State Senator with regards to making November Stomach Cancer Awareness month in Louisiana. I have gained commitment from my local State Representative to help get this goal accomplished. I would like to participate in this advocacy event to help ensure others have a better chance at early diagnosis and are offered a standard protocol of care other than palliative treatment; which is currently the main and/or only option for too many.

MARYLAND

Natasha Dooley – Nottingham I am writing about my brother, who lived with stomach cancer for 2 years and passed on November 13, 2020. My younger brother was diagnosed with stage 4 stomach cancer at 28 years old in November of 2018. He had just welcomed a second daughter to the world two weeks before his diagnosis. A navy service member, he had spent ten years serving in the military and went on two deployments. When he was diagnosed with cancer, he was also diagnosed with H. pylori. Doctors and surgeons at Hopkins were aggressive with his treatment, and we were afforded two years with him as he lived with cancer. Many rounds of chemo, an 8-hour surgery, countless other hospitalizations, and procedures over two years. He died on November 13, 2020, at 30 years old. His two young daughters, now 7 and 3 years old, his wife, myself, my parents, my husband, and many families and friends miss him every day. I'll move through life without my sibling, and his daughters will feel the loss through all of life's big and small moments. It is immeasurable the loss we all feel without him here. I cared for my brother from start to finish. I saw the shortlist of options when it came to treatments. I saw the statistics. I've poured over drug trial studies lesser-used treatments, grasping for anything that could help bring my brother relief and give him more time. There are no words for what it feels like watching someone die from this disease. It is simply heart-breaking. With such terrible odds and late-stage diagnoses, hearing one has stomach cancer feels like a death sentence. After my brother was diagnosed, we collectively raised money to support organizations like DDF and NSFC, knowing that without awareness and funds, this cancer will continue to be diagnosed late-stage with terrible odds. He often said he wouldn't wish this cancer on even the worst enemy. Tolerating and pushing through daily pain, even on his good days, and trying to muster the strength for his children on his bad days, too, he never let it take control. While he may no longer be here with us, I want to support the advocacy for current patients and what the future looks like for people yet to be diagnosed in honor of him. He would be proud to know his story could help impact other patients' lives.

Tristen Dawson – Catonsville Do you feel healthy? Do you feel strong? Perhaps you play on the softball team at work. Maybe you run, with a marathon under your belt and your fastest time ever in the Cherry Blossom 10 miler. You don't feel under stress, you haven't been working out as much lately, but why is it so hard to climb the stairs? In the course of two months, you transition from being in the best shape of your life to the worst. Nothing has changed. Sure, your pants are getting a little tight around the waist, you feel a knot in your shoulder and someone suggests muscle relaxers. Then, overnight, the pain in your abdomen becomes excruciating. Your sister has had her appendix out, is this what it feels like? Routine questions that could happen to anyone any day, were the only signs of stage IV stomach cancer in a 31-year-old non-smoker with no family history of disease. How do you fight something you don't know is there? With tornadoes, we develop sirens. There were no sirens, no warning signs, no risk factors. And in the end, no treatments. Cancer is a terrible disease, no matter what the type. For your stomach cancer, you are in luck! You respond well to the first line of treatment. It's okay that it was developed over 45 years ago. It's okay that after a few months the tumors stop responding to the treatment. You are a fighter. You are willing to go into any clinical trial that will give you a chance at a future. Except there are none. Sloan Kettering, Johns Hopkins, all the research centers say the same thing - I would like to put you on something else, on a trail, but there is nothing. There is NOTHING you can do. Stomach cancer has come a long way in the last 10 years. It's now eligible for research funding - a door that was opened far too late for my sister, but one that may help your family in the future. Help keep this door open. Make it so there is one day a detection system, a new treatment, a chance to fight. Life is stressful. Stomach pains are common, do you go to your doctor if you aren't eating as much in the last week? How did you feel going up that last flight of stairs?

MASSACHUSETTS

Jennifer Higgins-Spiers – Brookline My stomach cancer was discovered by accident when I was 26 years old. In February 2009, I made an appointment with my PCP because I had severe lower left abdominal pain. My complaint of pain led to months of tests that eventually found a polyp in my upper stomach instead. On July 27, 2009, I got the dreaded phone call. It was Stage T1a adenocarcinoma with signet ring cell features, poorly differentiated. This diagnosis shocked everyone- none of my doctors expected this. I was told that this was one of the most aggressive forms, and I was extremely lucky to have it caught this early. It almost never happens. On August 27, 2009, I had about 40% of my upper stomach and 10% of my lower esophagus

removed at Brigham and Women's Hospital in Boston. I then had a Nissen Fundoplication. Recovery was rough and slow. As the years went on, I had severe acid reflux issues that kept causing benign cell changes to my esophagus. I could only tolerate one large meal a day. But I was alive! After a decade of reflux issues and the fear of developing esophageal cancer, I made the decision to get the rest of my stomach removed to improve my quality of life. I don't have stomach cancer anymore. But I needed this done because I HAD stomach cancer. On February 25, 2019, I became stomach-less (This time at Cambridge Health Alliance with the same surgeon). I didn't have an aggressive treatment journey, but I had to endure a lot. With this more recent surgery, my lung collapsed, I developed a pulmonary embolism (and 6 months of Lovenox injections!), and my body festered seemingly never-ending infection. I was hospitalized for 3 weeks. On top of that, I failed my swallow test and was NPO for a total of 45 days. I was out of work for 11 weeks, but now I am back to my normal LIFE with a busy job, my supportive husband and our wild 5-year-old son. At the same time my polyp was found, I was also diagnosed with GERD, a hiatal hernia and extremely low B12/ iron levels. All symptoms of stomach cancer, but cancer was never on anyone's radar. I would never have been diagnosed if I hadn't been in pain (my answer for this pain came 2 years later by the way!). But even running diagnostic tests for stomach cancer symptoms is generally too late for patients who have stomach cancer. What does it take for stomach cancer symptoms to be taken seriously enough at an early stage? If my cancer weren't found so early, I would have a very different story to tell. We need effective early detection tools so that everyone has a chance to survive. I am here to advocate strongly for higher research funding so that other patients don't have to fight for their lives.

Kary Garcia-Robledo - Springfield My late husband, Pablo Vazquez, was diagnosed with stomach cancer at age 31. His life was taken away too soon, at age 33, leaving me behind and our eight and 12-year-old children. He first had symptoms in May 2016 and tested positive for Helicobacter pylori (H. pylori). Since he was "too young to have stomach cancer," an endoscopy was not prioritized. When he was finally able to get it in November 2016, we got the unexpected and devastating news that he had stomach cancer in an advanced stage and had spread to the peritoneal area. The chemo worked for a year, reducing the tumor to the point that Hyperthermic Intraperitoneal Chemotherapy (HIPEC) was an option. In February 2018, his stomach and four other organs were removed, but the HIPEC was not performed, reducing his chances of prolonging his life. He could eat several meals per day until June 2018, when he could not eat any longer. A trip to the ER ended up in a month at the hospital and three more surgeries. He spent his last month at home under the care of his family until his passing in August 2018. Pablo had many dreams that he could not accomplish, especially seeing his kids grow, graduate, and get married. During his cancer journey, he was inspired by Debbie's story, and he also wanted to help others going through cancer. I was his voice then, and I want to be his voice now. I am advocating for him and all other cancer patients that can't. We need more awareness and education for healthcare providers and our community. We also need early screening to detect stomach cancer in an early stage. We need more funding for research and more advanced treatments. WE NEED TO FIND A CURE.

Laura Cevik – Paxton My husband, Ray, was diagnosed with stomach cancer on September 18th, 2012. I remember the day clearly. It was just a few weeks after our kids had started Kindergarten and second grade at their new school, in the community we had just moved to. Everything came crashing down that day... and for the next three years. Ray's stomach cancer journey did not start with his diagnosis. By the time he got into the hands of Dr. Jill Allen at Mass General, they estimated that his tumor had been growing for a year. He had been to see his primary care doctor numerous times, complaining of stomach upset and bloating. They put him on antacids, told him to change his diet, prescribed Prilosec, told him his symptoms were part of aging (he was 40 at the time). I even accompanied him to the doctor because I knew that something was wrong (My husband was not someone who would normally go to the doctor). I was told by his doctor that I was "overreacting" when I pointed out his swollen belly and expressed my concern. It wasn't until Ray went to another doctor that he was finally referred for an endoscopy. And that is when they found the ulcer... and the huge tumor underneath it that had already broken through the stomach wall. By the time he was diagnosed, Ray was stage 3 C. The cancer had spread to his lymph nodes. He had a 9% chance of survival. Not only did it take over a year to be diagnosed, but we were given completely different treatment recommendations when we met with different teams of oncologists, surgeons and radiologists. One doctor wanted him to have his stomach removed immediately while other doctors said that he should start with chemo first. The confusion around treatment options haunted us throughout the three years of his battle. Did we choose the right options? Should we have taken different advice? There are no words to adequately describe what Ray went through over the next three

years.. What our kids went through. What we all went through. It is unthinkable, indescribable pain. Five different chemos, radiation, two stomach surgeries, feeding tube, j-tube, 12 stents put in his colon, countless ER visits, numerous hospitalizations for infection, neutropenia, surgeries, shingles. And finally, after every option had been exhausted, hospice. My husband passed away at home on December 20th, 2015. Five days before Christmas and 3 days before my son's 10th birthday. Not a single day goes by that I do not miss him, and feel completely heartbroken by the fact that my kids have had to grow up without their amazing Dad. Ray was a beautiful human being. He had a smile that lit up 100 rooms, not just one. He was warm, generous, kind, loving... simply the best. The best father, the best husband, the best human I have ever met. We are here on Capitol Hill to advocate for funding for stomach cancer research. As Ray's case highlights, we need earlier diagnosis through routine screening. We need understanding around what treatment leads to the best outcomes for patients. We need treatments that actually work so that these patients don't have to suffer in the way that so many stomach cancer patients now suffer. We need support for families and loved ones. We need HOPE. We need HOPE that someday a stomach cancer diagnosis will not feel like a death sentence. That surviving stomach cancer will be the rule, not the exception.

Said Cevik - Paxton I lost one of the most important people in my life to stomach cancer- my Dad. I was only in kindergarten when my dad had been diagnosed and was not old enough to truly understand what that meant for him, myself, and my family. It wasn't until second grade when I started to understand what he was going through. I was constantly surrounded with the sound of him throwing up, monitors, and pumps. I could see his health deteriorate as he became thinner than I had ever seen anyone become. Even though he was exhausted and hurting, I never saw anything but strength. He continued to be the best dad anyone could have asked for. I would sit by his bed, which had been moved into our dining room, since he could no longer make it up and down the stairs, and for hours I would pretend to be his teacher or his nurse. I would have him fill out worksheets and make him pretend to take Smarties Candies as if they would make him better. But he didn't get better- and on December 20, 2015, he passed away. I was in third grade and was still trying to grasp what had just happened. One second, he was by my side, and the next- he wasn't. It was difficult going back to school knowing everyone had a dad except for me. Everyone would tell me that he was still with us and that there was nothing more they could have done. But they lied- there was more they could have done, they just didn't have the knowledge to do so. My dad was constantly going back and forth to Boston, to try and receive the best care possible, but their knowledge on stomach cancer was not enough to cure it. If stomach cancer had the funding and research, then maybe my dad would have still been next to me today. As I've grown up, it has become harder to accept what happened, the more I start to understand the situation. In middle school we would always have fundraisers for breast cancer, where we would all wear pink to school and donate a dollar, and although I loved supporting breast cancer research, I always wondered why we never had one for stomach cancer or for any other under-researched cancer? Someone in their own community had passed away from stomach cancer, yet it was never something they found important enough to raise awareness for. And that hurt. It was hurtful knowing that all of these people weren't able to get awareness for the struggles they were enduring and that they weren't able to access care they deserved just because doctors didn't have enough information to understand it. I know my Dad fought as hard as possible to try to stay here for me, my mom, and my brother, but at some point it became too much. My Dad was my best friend and the person who I knew would always be there for me, and I know he is still his. Through his three years of fighting, he never once failed to put a smile on my face. He showed more strength and courage than I have ever seen, and he will continue to be someone I look up to. Losing someone you love is never an easy thing. I know how I felt when my Dad passed away and it is something that I would hope no one else would ever have to endure. But I know that wish is not a reality. By sharing the story of my Dad and coming here to be an advocate for stomach cancer, I hope that it will result in fewer people having to experience this illness, and fewer people having to go through the pain of losing a loved one to this disease.

Susan Ko – Weston In October 2019, my dad was fell ill on a flight overseas. At first, he thought he might have gotten food poisoning in an airport lounge, but felt so bad after reaching his destination that he returned home early. He went to see his doctor, who ordered an endoscopy after they figured out he was severely anemic. The gastroenterologist who did the endoscopy did not see any cancer, but thankfully, he still ordered a few biopsies of my dad's stomach. The pathology came back positive for cancer. Even though the prognosis for stomach cancer is grim, at 81 years young, my dad was in excellent physical condition and determined to fight for my mom, my sister and me, and his three grandchildren. Coming up with a treatment plan was a

nightmare. I was often on hold with various medical offices for over an hour, and none of them were coordinated with one another. My dad's first meeting with an oncologist was brief, and the doctor thought my dad's cancer was probably pretty early stage and was very optimistic. We decided to get a second opinion at the Dana Farber Cancer Institute in Boston. Our experience at DFCI was night and day compared to his local doctors. We were seen within a week, and the oncologist spent over an hour with us. He thought my dad would be an excellent candidate for laparoscopic surgery, which wasn't even an option locally. He suggested a course of chemo and then a diagnostic laparoscopy in order to confirm the diagnosis before the gastrectomy. DFCI also suggested genetic testing for my dad to ensure that the cancer wasn't hereditary and tested the tumor for biomarkers before immunotherapy treatment. The most important aspect of my dad's care at DFCI was having a trusted team of doctors who listened to him very carefully. My dad was adamant about the quality of life over than quantity, and they honored his wishes in every decision. He was wary about side effects from chemo, so they started him on Folfox. When he sailed through the first dose, they switched him to FLOT, which wasn't too rough, either. They aggressively managed side effects before they even happened. And nurses were always reachable with questions or concerns, and they returned phone calls promptly. After my dad's partial gastrectomy, he walked around the floor in about two days, started eating normal food on day 3, and was discharged on day 5. He managed to walk a mile on the treadmill two weeks after surgery and work out almost daily during treatment. We were hopeful for a full recovery, until three short months later, we learned that cancer had recurred in his lymph nodes, making him Stage 4. The statistics were even worse – maybe a 5-6% chance of living one year. But the landscape for stomach cancer treatment had changed dramatically. In January 2021, the NCCN recommended immunotherapy for stomach cancer and my dad began nivolumab treatment immediately. Three months later, his scans could not detect disease. Now, one year after starting immunotherapy, he is still thriving. We have learned that one reason for my dad's success is that his tumor has a biomarker that makes it particularly susceptible to immunotherapy. Although he has experienced some side effects, they are well managed. I believe that immunotherapy is the new frontier for cancer treatment and may ultimately prove to be a cure. Furthering research, and expanding access to this cutting-edge treatment, is critical. Everyone with this horrible disease should have a chance to beat the statistics, like my dad!

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.

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.

Dylan Pollack – Hoboken My wife and soul mate Shirael Pollack died of stomach cancer on September 20, 2019, leaving behind me and our beautiful daughters Gabby (10) and Dahlia (7). We are carrying on, but our lives have been irrevocably shaken by this disaster. In addition to being my wife and their mom, Shirael was an award-winning pediatric therapist, philanthropist, autism-advocate, entrepreneur, women's leader, cancer-fundraiser, and veterans-advocate who traveled the globe training our military servicemen and women how to start their own businesses after discharge. Shirael was on top of the world and rising quickly when, at 37, she was diagnosed the extremely aggressive disease. Shirael had relatively minor symptoms like slight weight loss and loss of appetite for about 4 weeks before, but that was enough time for the disease to progress to incurable Stage IV. Shirael was in great shape, didn't smoke, and had no genetic risk factors. But stomach cancer still came out of nowhere to destroy our lives. Yet despite the horror of the diagnosis, we decided from day-1 that we would play to win, not just to extend our time. Shirael battled the disease heroically for exactly 24 months (to the day), which included 39 grueling rounds of chemotherapy, a painful surgical clinical trial, and a 60-day immunotherapy clinical trial. But despite these battles, at no point did we ever once think we would lose the war, so when she died, it was as shocking to me as if it had been a car accident. If Shirael couldn't beat it, then who could? And the statistics around this disease bear that out. During her short life, Shirael made an incredibly positive impact on thousands of people, mostly children, through both therapy and educational-philanthropy; when she died, the governor of New Jersey called me directly to express his deep condolences for Shirael, who he had heard about but never met. Shirael's death is an unimaginable tragedy for me, our children, and her parents and siblings. But it's also a tragedy for thousands of others, among them veterans, children with special needs, women in need of mentorship, and kids in public schools whose lives Shirael surely would have benefited had she survived. Our collective efforts to defeat stomach cancer are not working; we need to do more. We need to eradicate stomach cancer before it takes more Shirael's away from us.

NORTH CAROLINA

Anissa Bass - Charlotte On August 10th we lost an incredible man named Anthony Bass to a long battle with stage 4 stomach cancer. Anthony endured over 30 blood transfusions, ten rounds of radiation, 2 rounds

of Folfox Chemo, and an attempt at a total gastrectomy which was aborted because of a metastasis to the peritoneal. He was a loving husband, devoted father and a mentor to those he worked with. Anthony fought hard and remained optimistic throughout his entire diagnostic. His bravery, courage and resilience inspires his family to keep going and tell his story to everyone who will hear it. Statistically speaking African American men die from stomach cancer more than any ethnic group in America which puts Anthony in the high risk category. In addition to this, Anthony has cancer on both sides of his family and his A positive blood type is rare and thickens easily which contributed to the blood clots he experienced. We first learned about his diagnosis because Anthony began experiencing an uncomfortable sensation in his stomach along with dark stools at times. He was misdiagnosed twice and was told that he had stomach ulcers. It was not until May, that he received an endoscopy that revealed the stomach cancer, by that time he was given 6 months to live. During his treatment he received a plurex catheter, IVC filter, an attempted total gastrectomy, 10 rounds of radiation and 2 rounds of fulfox chemotherapy. In addition to this, Anthony experienced a variety of symptoms from loss of appetite, severe weight loss to vomiting after almost every meal. It's so important to share our story because cancer, specifically stomach cancer is a disease that is often diagnosed when there are no other options leaving families with little to no resources or support, which is a hard thing to endure. The reality is when you are at stage 4, people are already giving up on you so you have to advocate in 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 very much. We hope that by sharing our story to spread awareness and honor his life.

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.

Christina Leonard – Fayetteville Almost two years to the day after losing my brother to lung cancer, and my husband's brother to heart disease, my husband was diagnosed with stomach cancer (Linitis Plastica) at only 39 years old. No one hears of stomach cancer, so we looked it up. What we saw broke our hearts. The chances of Tony beating this were slim, the chances of our kids getting it were high. No matter what, though, we were going to fight. Our now 18 (then 12) year old wrote our NC Senator Richard Burr asking him to support his daddy's fight. I never realized how scared he was about him too getting cancer or having to have a total gastrectomy just to prevent it until I read his letter. "When my family and I found out about my dad we

were all scared. I was scared knowing that my dad is really sick and had to have his whole stomach taken out. He was going to have chemotherapy and other stuff. I was scared that I too could possibly lose my stomach at 21 years old." The plea to the Senator was priceless, "Will you wear a blue ribbon in support of my dad and my family? Will you help get the word out? Will you help raise money for research and medicine to help people like my dad? Please, Mr. Senator, support my daddy's fight and those like him. Please help get the word out about stomach cancer awareness." Me, the caregiver, wife, mother, I'll keep going, but my children, they shouldn't must live in fear. My fight isn't just for my husband, it's for our children, and children's children. I watched our mothers bury their sons. Never again should a mother bury a son/daughter. Nor should a young child have to bury their mother/father. My blog on my family's journey through stomach cancer is shared at <http://deathtocancer.blogspot.com>. My blog has reached over 75,000 hits. In March of 2017, we learned that Tony's cancer returned after 5 years. I am devastated and motivated at the same time. I fear of being a young widow, I fear my children are watching there now 50 lb. smaller daddy getting thinner and weaker by the day and what it is doing to them emotionally. WE MUST DO SOMETHING. I cannot sit back and watch my husband fade without a fight. I had the honor of speaking at the NIH NINR Caregiver summit, being interviewed by Cancer Today Magazine, and Cure Magazine. I will NOT stay quiet about this disease any longer. Losing Debbie Zelman in December to this horrific disease and knowing her and Tony were battle buddies, I am doing everything I can to make memories with my husband and children, but I want him to watch our babies grow up to be men. I want to grow old together. Having no cure and little treatment options has crushed my dreams. I love my Tony with everything I have, he's fighting so hard. I must do the same. With all of this said, and this being the story I have shared for the past 6 years, my beloved Tony gained his wings Jan 22, 2019. My fears are now true. My husband died of stomach cancer at the age of 46 leaving behind me and our 5 boys.

Sue Catherine – Greensboro I am the widow of Chuck Catherine, USMC. From the moment I met him, I knew I wanted to marry him. We were engaged 3 months after I met him and married the next 12 months! We were happily married for 29 years. He was a proud US Marine, proud father and husband. Together we have 3 children: Cameron (28), Casey and Charlie (twins:25). He served in our community in Greensboro, North Carolina with our church, boy scouts and lacrosse. You could also catch him as an announcer and DJ for high school sports...He also loved hunting, fishing and anything outdoors. Chuck was diagnosed with Stage IV Esophageal Cancer in December 2018. He fought a heroic battle for 18 months at Duke University and MD Anderson, in Houston, TX. He passed away August 2019. His life was cut too short at the age of 58. By the time he was diagnosed it was stage IV. We were in the fight of a lifetime. He wanted to live to see his daughter be accepted into PA school and for his twins to graduate college. He missed those goals. We need more medical funding for tools to aid in early diagnosis and better screening tools. We need more funding for new treatments and clinical trials. Chucks treatment consisted of: radiation, chemo, immunotherapy, clinical trials and total gastrectomy. He always fought the fight and did not ever give up. He was a big fan of Jimmy V and his "Don't Ever Give Up" speech. That is the way Chuck led his life. I encourage you all to listen to that speech right now. Famous words by Jimmy V, "Cancer can take away all my physical abilities. It cannot touch my Mind, it cannot touch my Heart and it cannot touch my Soul. And those 3 things are going to carry on forever." Don't Give up...Don't ever Give up. If I can be of any type of support to anyone, or if you have any question feel free to reach out any time at 336-908-4196, Sue.Catherine@BHHSYostandLittle.com, or on Instagram @SueSellsHouses.

OHIO

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.

Angela and Dr. Paul Bosela - Copley I (Angela) am a stomach cancer survivor diagnosed with aggressive, fast-growing stomach cancer in 2007, at 55. I was extremely fortunate. The stomach cancer had eaten almost entirely through my stomach wall but had not wholly penetrated through and had not spread outside the stomach. I have been cancer-free since after a 70 percent gastrectomy and four cycles of chemotherapy and radiation treatments. Following my recovery, I have become an accomplished runner, completing numerous 5K's, 10K's, and half marathons, usually winning or finishing near the top of my age group. I ran my first full marathon in 2017 at the Pro Football Hall of Fame in Canton, Ohio, and finished second in my age group. My husband, Dr. Paul Bosela, is a professor emeritus and former Chairman of the Department of Civil Engineering at Cleveland State University and former Chairman of the Executive Committee of the American Society of Civil Engineers Forensic Engineering Division (formerly known as the Technical Council on Forensic Engineering). He was my primary caregiver during my recovery. When I was first diagnosed with stomach cancer, my husband and children did a great deal of research on stomach cancer. Although there were a lot of support groups and organizations involved with other types of cancer, there was much less information on stomach cancer, particularly in the United States. The desire to assist in the awareness and research on stomach cancer has led to our involvement with Debbie's Dream Foundation: Curing Stomach Cancer (DDF), where we serve as mentors in the Patient Resource Education Program. Despite the extent and seriousness of stomach cancer (second leading cause worldwide of cancer deaths in men and fourth among women), there is a woeful lack of information and research on this deadly disease. Per cancer death, stomach cancer receives the least federal funding for any cancer. Hence, we actively donate our time to stomach cancer support and awareness and Debbie's Dream Foundation. Along with our daughter Sheila Gambaccini we founded the Ohio Chapter of DDF.

OREGON

Ashley Chavez – Springfield My stomach cancer story is a little bit different than others in this group, as I have never had stomach cancer, and neither has anyone else in my immediate family. I was recommended to get BRACA testing done by my gynecologist, as my mom had passed away from breast cancer when she was 35. I got the testing done and when the results came back I was negative for any BRACA gene, but was positive for CDH1. After I had my genetics results everyone in my immediate family also got tested. We assumed the CDH1 gene was from my mom's side since she had breast cancer, but to our surprise it was from my dad's side of the family. My dad and grandfather both also have the genetic mutation. I chose to have a prophylactic total gastrectomy at OHSU in Portland Oregon 6 months after finding out about CDH1. I have lived a fairly difficult life in the 5 years since my gastrectomy. I've had over 15 surgeries since then, and too many hospital stays to count, including a prophylactic double mastectomy, countless esophagus dilations, feeding tubes, constant issues with kidney stones, severe osteoporosis, and my newest accessory, my port that I use for weekly IV hydration. I've lost 80 lbs since my gastrectomy. My dad and grandfather have decided to not have the total gastrectomy, and instead chose to be monitored.

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 CAROLINA

Mike Fields – Irmo My name is Mike Fields and I am 65 and living just outside of Columbia, in Irmo SC. In Dec 2017 I Collapsed in the middle of the night and was rushed to the Hospital. The doctors initially thought it was a ulcer causing blood loss. In Jan 2018, I had an endoscopy. My doctor said it was cancer but would wait for test to come back. All tests were negative, so Dr. Jenkins insisted we do a second one. That one came back negative as well. Dr Jenkins then insisted I go to MUSC (Medical Center of South Carolina) for a 3rd deeper sample as well as a sonogram. MUSC in Charleston found both esophageal and stomach cancer. It was also in the stomach lining and was at State 3b-4. My doctors believe that I had this for 1-2 years prior but was undetected, believing that the issues were due to indigestion and acid reflux. They said that the symptoms were probably hidden due to my use of Prilosec and other Reflux RX. I went though 6 weeks of Chemo and 20 Radiation treatments at SC Oncology in Columbia and then traveled to MUSC for a partial esophageal removal and my entire stomach taken out. I never believed that it was even possible to live without a stomach before this and yet I am now 4 1/2 years cancer free and doing very well. I did lose 75 lbs and obviously I have had to change the way I live but feel extremely blessed every time I sit down to a meal, to still be here today. My

Oncologist has said that they no longer even treat this cancer the same way that they did 5 years ago due to the high mortality rate. I asked why since it seemed to work. His response was "It worked for you!" At my last visit in January he informed me that there were no other survivors from those that took the type of treatment that I did and he continues to be amazed at just how well I am doing. Although my story may seem different than most that have been through this, it is important that you understand that survivors like me are very rare. And if it weren't for a Doctor Advocate that insisted, we continue to look deeper, the outcome would have been very different. There is a major need for more research and earlier detection of this deadly disease.

Virginia Jablonski – York My story began in 2019 with an annual GYN appointment discussing family history. My father passed from Pancreatic Cancer at 52 and his mother passed from Melanoma at 48. This led to genetic testing which revealed my CDH1 genetic mutation. Once this was discovered I was encouraged to look more into my family tree to see if there had been a history of Gastric Cancer. Several of my father's uncles and a first cousin had passed from Gastric Cancer. They were not tested for the gene as it was not identified then. My father's nephew was tested and learned he carries the gene as well which further confirmed CDH1 being on my father's side of the family. My siblings were also tested. My sister tested positive, and my brother tested negative. Upon learning about my CDH1 mutation I began researching the mutation. The website, No Stomach for Cancer, was a great resource and led me to NIH clinical trial being conducted. I joined the study and made my first trip to NIH in February 2020. That summer I had my total gastrectomy performed by Dr. Davis. I was blessed with a positive recovery without setbacks. The learning process for reintroducing food was very slow and tedious. I kept food journals and monitored my side effects of foods in efforts to navigate what worked best for me. My initial pathology came back with no evidence of cancer. A later pathology did reveal Stage 1 cancer present. Thankfully the gastrectomy was the treatment, and additional chemo or radiation was not needed. The next part in my journey was the road towards double mastectomy. I had several "suspicious" MRI scans over following two years. Once my weight stabilized and I adjusted to my "new normal" I moved forward with my double mastectomy. I had this procedure in June 2021 and cancer was not detected in the four quadrants that were biopsied. That recovery was more difficult due to my body absorbing the pain medication so quickly. I had a revision in October and the pain management was modified and the procedure went much smoother. I would also like to share my sister-in-law's battle with stomach cancer. Mary was the one who assisted me in navigating my CDH1 journey and found the NIH CDH1 clinical research trial. She was there for my first surgery and first days post-op. Little did we know when I began my journey, her battle with stomach cancer would begin when I was 6 months post-op. She was diagnosed Stage IV in January 2020. Dr. Davis was an integral part of her battle and treated her in a separate trial. She battled this all while COVID was at its peak and therefore many of her trips and even her surgery were done alone due to all the safety protocols in place during that time. She survived the aggressive treatments and was able to have the gastrectomy surgery. The surgery was successful, and all her lymph nodes came back clear of cancer. However, in the summer of 2021 she began having excruciating back pain and cancer was discovered in her spine. She fought hard and was such a warrior, but she left this earth July 31, 2021. Mary will forever be part of my journey and I miss her every day. I'm not facing anymore surgeries at this time but continue to be impacted daily as a total Gastrectomy is such a life changing procedure. This journey is a marathon not a sprint and there will bumps along the way. However, my family is my why in this journey and why I will continue to do what I can to be proactive.

TENNESSEE

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 mode. 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

Adam and Charlotte Cantu – Missouri City Adam was diagnosed with advanced gastric (stomach) cancer on November 8th, 2019. To say we were shocked is an understatement. I don't think anything can prepare someone to hear that news, for themselves, for their spouse, for anyone they love. Adam had been experiencing some minor stomach discomfort for a few months, but then began to feel as if he was feeling full after not eating a lot, and it progressively got worse. He started to lose weight rapidly, and after a check-up with his primary care physician, tested positive for a bacteria called Helicobacter Pylori (H. Pylori, which I later learned can cause cancer), and had an endoscopy a few weeks later. A large tumor was found in his upper stomach area. Biopsies confirmed cancer, and following several other diagnostic procedures, he was confirmed Stage IV as the cancer had spread to his abdominal lining and several lymph nodes. So now, my 46-year-old, hard-working, otherwise healthy husband, is embarking on a literal life or death journey. We have a blended family of 6 with six children ranging in age from 6 to 16. Our family is strong in our Christian faith, so we have not spent a lot of time asking, 'Why him, why us' but we have asked 'how and what and when' and that is where a significant concern comes into play. I am a 40-year old wife, and mother, and this is a devastating diagnosis. When you look at statistics about stomach cancer and the associated trends, this is a critical health concern that is affecting younger and younger adults. In fact, of all new stomach cancer diagnoses in the U.S., at least 30% of these are aged 20-50 – this is shocking, especially when you consider the fact that there are essentially no early detection mechanisms in place at that age, or early preventative education around confirmed risk factors and treatment, such as infection with the Helicobacter pylori bacteria. H. Pylori infection, such as was the case with my husband, is a known causal agent of stomach cancer, but presents with symptoms that are likely diagnosed as other very common ailments such as indigestion or GERD. According to a study that was published in the October 2019 of the Journal of Surgery, Early Onset Gastric Cancer (EOGC) has been steadily increasing as a proportion of all gastric cancer cases for nearly three decades! It was also called out that EOGC is also genetically and clinically distinct from later-onset gastric cancer. If these statistics are not alarming enough, consider the statistics on stage and survival rate of these cases – 80% of stomach cancer diagnoses are Stage IV according to Cancer Treatment Centers of America with a 5-year survival rate of 4%. This is why additional funding is desperately needed to identify risk factors for EOGC in order to inform public health policy on risk reduction strategies and for advancement in treatment options. My husband, who is already a Stage IV diagnosis may never benefit from additional research or advance treatment, but I would like to honor him and the thousands of other cancer patients, survivors and their families by being a voice of advocacy for more attention to this devastating disease.

Kelle Brown – San Antonio My name is Kelle Brown, I am from San Antonio, Texas, and I am CDH1 positive. My journey started in 2016 when my younger sister, Karmen, was diagnosed with Stage IV metastatic gastric cancer and passed away only 52 days later at the age of 36. My mother had been diagnosed with lobular breast cancer some years prior. After realizing that, my sister's care team put two and two together and suggested that I be tested for the CDH1 gene mutation. After my request being rejected several times, I was finally given approval to get the genetic testing done. I was contacted the day after my birthday with the news that I had tested positive for the gene. After testing positive further testing and discussions began. After a year of surveillance, I had my total gastrectomy on January 23, 2018. The pathology came back with a diagnosis of Stage 1B signet ring cell adenocarcinoma. I had mixed emotions but was satisfied that I had made the right decision. Since then, I have several other family members test positive, to include my

mother, but I remain the only one to go through with the total gastrectomy. After surgery I returned to work 8 weeks later and have had only minimal complications. I promised my sister and the rest of my family that I would do everything that I could to bring awareness to hereditary diffuse gastric cancer.

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 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 63 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.

VIRGINIA

Suzanne Mulet– Fredericksburg I have been in the Marine Corps for 13 years, joining at the age of 30! I went on one deployment to Afghanistan in 2011. I grew up on a small Ohio farm milking cows until I was nine, and then we switched the operation to beef cattle. My family has not history of stomach cancer, and only a couple family member who were older and distant (besides grandma with melanoma) have ever been diagnosed with any cancer. I was extremely lucky when my cancer was found. I have suffered from heartburn and IBS for a while, and even had three trips to the ER with no diagnosis except possible Crohn's disease two years prior to my stomach cancer diagnosis. In 2019 after about a week of suffering episodic heartburn, I was overcome by an intense burning in my sternum after sipping on some coffee. I tried Tums, but the pain kept rising over the next hour. When I got to work, I told my boss I needed to go to urgent care to try to get my pain under control (I thought an emergency prescription of Nexium would work) , and as I was driving to urgent care, I changed directions to go to the ER instead because the pain was unbearable. The nurse thought it was my gallbladder and even commented, "I'd be surprised if you left with your gallbladder today." After a negative CT scan, the ER doctor said he thought it was "functional" pain because they could not see any reason for my intense pain. The ER doctor wanted to send me home after getting the pain under control, but after a phone call with my mom (a retired nurse), she said I should ask them to do an endoscope. I asked the ER doctor if I could insist on one, and he said, "Yes, but I am 98% sure I won't find anything." After I woke up, he said I did have a small area that looked swollen, and he took a biopsy. He said he did not think that caused my pain,

though. I spent the night in the hospital for observation to make sure the pain was under control. I was released, and went straight to work without any problems. The next day on my way home from work, the ER doctor (who was also a gastroenterologist) called me and said he couldn't believe it, but I had cancer. He said in the 26 years he has been a doctor, he never heard of anyone my age or gender having stomach cancer present like it did in me. In retrospect, I cannot believe the protocol would not have been an endoscope when the CT scan showed nothing. I was stationed in Ames, Iowa at the time as an NROTC instructor at Iowa State University, so I was about three hours from Mayo Clinic in Rochester, Minnesota. It was a no brainer to drive there for treatment! After going through a bunch of tests and a PET scan, they also found a lesion on my liver, nodules in my lungs, and a cyst on my adrenal gland. The next several months, I had biopsies of all the findings, which turned out to be negative for cancer! That meant, I only had the small spot on the top portion of the stomach (tucked in behind the esophageal junction). The doctors could not tell how deep the cancer was, but they thought it was small enough that they could do a resection, which would just be cutting out the afflicted tissue. When the surgeon went in, he realized it was too deep to resect the tumor. The next step was to do a total gastrectomy because of the location of the cancer. My husband and I had a hard wrapping our heads around the thought of me living without a stomach. The Mayo doctors were amazing, though and reassured us I would be great. I underwent the total gastrectomy on 31 July 2019 and stayed in the hospital for about 10 days. I remember having a ton of third space swelling, which was disturbing. It wasn't until after my total gastrectomy that the doctors staged me at 2A (pT3 pN0). I went through 8 rounds of adjuvant chemo to be safe, because they were not sure if the cancer had gotten into the blood stream. I went through genetic testing, and they determine it was not genetic cancer. I am still in the Marine Corps, and would consider myself pretty much back to normal. I do have trouble with my diet and seem to crave and eat sweets more than ever. I also have sugar spikes and drops, which seem to affect my mood and comfort. If I could get the diet portion worked out, I think my quality of life would be back to normal! I am thankful for my guardian angel mother, loving supportive husband, and huge family and friend support network! They made this journey bearable!

WISCONSIN

Lisa Bartoszewicz— Menomonee Falls On my 35th birthday in October 2020, I started experiencing some symptoms of acid reflux and the feeling of food stuck in my throat. I saw my physician, who started me on some medication, but I was still not back to my usual self after a few weeks. My doctor had me tested for H. Pylori right away (negative) and sent me for a few other tests, which suggested that I may have an ulcer. On December 31, 2020, my world changed when I went for an upper endoscopy. The results revealed that there was indeed an ulcer, that I had become anemic, and most shockingly, that there were two tumors in my stomach. My husband and I spent the holiday weekend processing all of this and anxiously awaiting the biopsy results. The following Monday, we got the call that nobody wanted to hear: the tumors were cancerous. At the beginning of 2021, my rollercoaster journey with stomach cancer began. I quickly learned that cancer had spread to my lymph nodes which unfortunately made it a Stage IV diagnosis. I went through nine rounds of chemotherapy and initially saw some excellent results with the tumors, but the lymph nodes were stubborn. In June, I began mentally preparing for a total gastrectomy. Unfortunately, the scan the week before my surgery showed some disease progression which resulted in canceling the surgery just four days before. I then started on chemo/immunotherapy combo for eight rounds. Again, I saw promising results, making me a candidate for a total gastrectomy. In mid-November, I had my stomach removed, along with quite a few lymph nodes. Since then, I've continued immunotherapy to keep working on cancer still left in the lymph nodes after the surgery. I'm so thankful that my husband found Debbie's Dream Foundation and suggested I reach out to them. At my initial diagnosis, I felt very lost and alone. DDF and all the fellow stomach cancer survivors I've met through DDF have been extremely helpful and encouraging. As a young mom of a toddler, I didn't fit the typical profile for stomach cancer, but I've been able to connect with others in a very similar situation. I hope my story will help provide hope for others and bring awareness to this aggressive cancer. I wish that medical advances can be made in the near future so I can watch my son grow up.