Greg's Story

Figure 1. My wife Patty and I at our 40th wedding anniversary 27 days before diagnosis, with our daughter and son-in-law Amber and Dustin.

My pancreatic cancer journey began on Sunday, July 1, 2018. We had just celebrated our 40th wedding anniversary 27 days before and were looking forward to a celebratory trip to Italy at the end of summer.

I had gone to our local Emergency Room for what I thought was food poisoning.

The ER doctor started with the standard intake questionnaire. When I answered "yes" to a question about pain in my abdominal area, he put the questionnaire down and said he was sending me directly to the cardiology unit for heart attack assessment. Nothing I did nor said could change his mind.

You see, this was the fourth time I had gone to this hospital system's ER with abdominal pain…only to be sent, once again, into cardiology. Each of the previous three times, the cardiologist's final report said "Your heart is fine. We are sending you home." …but without addressing what I originally went in for.

On this fourth trip, they kept me overnight "for observation." Since it was Sunday, and their radiology department closed, they couldn't do the heart CT scan until the following morning.

Monday, the following morning, I was being wheeled out of my room for my 4th heart CT scan. The Medical Director of the ER, just coming out of a staff meeting, stopped me to introduce himself, and asked how I was doing. What came out of my mouth is not printable here. But what I communicated to him was my 2-year history of coming into their ER for abdominal pain, only to get sent directly into cardiology, going through all of the heart tests (and even wearing a Halter Monitor for two days – twice), only to be sent home each time, with reports that my heart was fine. Never once did they address what sent me into the ER in the first place.

My last statement to that ER Director was "This is NOT an Emergency Room! It is a ***cardiac unit***. You need to start call it what it really is! My heart is fine. You will only send me home once again, without addressing what I came in for!"

Half-an-hour after returning from that heart CT scan, the triage nurse came into my room and apologized. They did hear what I said this time…and checked my past, and current test records, and realized, once again, my heart was fine—it was not causing the problem I went in for. This time, they decided to order an ultrasound to look for what was really causing my pain.

Forty-five minutes later, the ultrasound tech and I saw the mass on my pancreas. She would not acknowledge what it was, but I have enough medical background to know a tumor when I see

one. A CT scan with a die-trace later that day confirmed the cancer on the neck of my pancreas. Initially staged at 3-B, we realized later that it was actually Stage-4.

Lesson #1 **Our medical systems are not perfect. You must be your own medical advocate! You know more about you than your doctors do. Listen to your body and let them know what you need them to do. If they do not listen, you are talking to the wrong doctor(s).**

Once diagnosed, this hospital system gave me less than one percent chance of being alive for Christmas…and suggested I just go home and get my affairs in order. They were willing to try surgery as early as the following week…but I later learned, this is not the correct approach.

I did go home and begin getting my affairs in order…but was unwilling to accept their prognosis.

Six second opinions (from Johns Hopkins, the Mayo Clinic, the University of Michigan Medical Center, Karmanos Cancer Institute, Henry Ford Health, and the University of Omaha Medical Center) raised my odds to just two percent. Not a lot better than one percent, but a number I felt I could work with. On the bright side, I was able to say that my odds had doubled!

Our final, "second opinion" meeting was with Henry Ford Health in Detroit. Their "team" approach convinced us to go there. In that first meeting, we met our surgeon (Dr. David Kwon), oncologist (Dr. Gazala Khan), radiologist (Dr. Jadranka Dragovic), dietician (Susan Hill), psychiatrist (Dr. Michael Ryan), a social worker, and my nurse practitioner/navigator (Tanya Kintz) who would function as my "project manager." They even gave me their cellphone numbers—a good test for whether you've got the right doctors or not. *(Note: Many Henry Ford medical staff are given company-owned cell phones.)* This alone may have saved my life twice in the following weeks.

One of the things we liked about our surgeon, was his honesty…however, it was brutal at times. Right out of the gate, he made it clear I was not, at that point, a resectable (surgical) candidate. But he had a plan for how we might be able to get me there.

At that point in time, the tumor on the neck of my pancreas was leaning up against the arteries directly behind. We could not tell if the tumor had grown into those blood vessels or not, if it had, I would never qualify for surgery.

Surgical Plan: The Road to Resectable

Step 1: Chemotherapy

Within two weeks of my diagnosis, we had researched my situation, picked our medical team, and was getting ready for chemotherapy.

Lesson #2 **My first hospital had it all wrong. You have to prepare your body and the cancer for surgery, even if you are not initially a resectable candidate.**

At the point that pancreatic cancer is most often discovered, it has already become a rapidly growing and metastatic mass. The correct approach is to try to slow down or stop the cancer's activity. Even better, try to get it to shrink.

In 2018, chemotherapy was my best option to achieve this. Attempting surgery before chemotherapy would very likely spread the actively growing and metastatic cancer everywhere—only to have it return somewhere else in my body even though the primary tumor had been successfully removed.

My Oncologist gave me two options: Gemcitabine/Abraxane or Folfirinox. I chose Folfirinox, the most aggressive treatment.

At that point in my journey, I was really scared. I had an alien being living inside my body…living off-of my body, that was hell-bent on committing suicide, and taking me with it.

Before starting Chemotherapy, I needed to have a Medi-Port installed in my chest for the chemical infusions. This was installed on July 19, 18 days after the cancer was discovered.

Emergency #1

Everything went well with the Medi-Port insertion—until the next morning. I woke up with 5 blood clots in my right shoulder and arm. My wife (Patty) called Dr. Kwon's cellphone. He told her to drive me directly to their ER and said, "Do NOT wait for an ambulance! Just get him here as fast as you can." His staff was waiting in the ER when I arrived and took me directly to ultrasound. Within minutes of confirming the clots, I was on Heparin. By the way, those clots never did dissolve. You can still see some of them to this day.

Lesson #3 **Never go to a doctor's appointment alone. In your mental state, you will only hear half of what is said, and you will only remember half of that. You must have someone with you that can hear and remember all of it.**

My "someone" was my spouse, Patty. Without her, I would not have made it. As a medical advocate, she kept me, and my doctors, on our toes.

Emergency #2

After the blood clot emergency, I went home for two days only to wake up with blood hemorrhaging into my chest cavity from the port's insertion point—another emergency run to the ER. We stopped the Heparin and held our breath for the next week or more.

Emergency #3

After the hemorrhaging settled down, we realized the port incision was not healing. It started to swell, turning black, blue, grey, and orange. It literally looked like a space alien trying to push itself out of my body…sticking out almost a full inch.

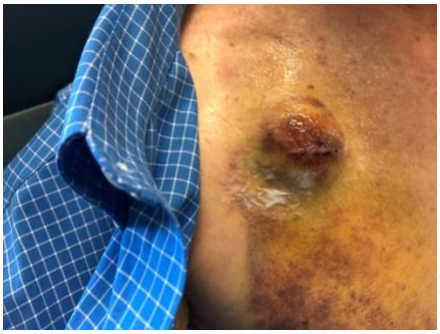

Figure 2. What the nurse saw.

On my first chemotherapy infusion appointment, on July 26, the nurse preparing me for the infusion pulled the bandage off of the port. What she saw made her gasp and step back. The suture across the top of it made it look like an alien being, grinning back at you. They sent me home saying they could not access the port. There was even discussion about putting another port in on the other side of my chest. I joked with my surgeon about looking like a car with two headlights if we did that…and suggested we just give the port a few days to heal.

At the second infusion appointment four days later, the staff again wanted to send me home…unsure they could accurately find the center of the port because of continued swelling. Missing that "sweet spot" would pump all those chemo chemicals into my chest cavity and not my bloodstream…and could be fatal. However, worried about delaying my chemotherapy any longer, I suggested a possible solution. I asked that three of their best nurses each independently find what they thought was the correct "sweet spot", and if all three agreed, we would try getting the needle into the port. All three test spots agreed, and with the attending doctor's authorization, we succeeded in starting the first infusion. This was now July 30, 28 days post diagnosis. It's ironic that I wanted that chemotherapy so bad I was willing to take the risks that I did. The "Back Story" later in this article will explain why this was so important to me.

The rest of my first chemotherapy, 5 cycles of Folfirinox, went without any further major developments…other than what is common for this chemo regimen…nausea, extreme fatigue, weight loss, thrush, insomnia, depression, loss of appetite, etc. Just the normal stuff.

Lesson #4 "Magic Mouthwash" really is magic! If you are in chemotherapy and not using it, you should be.

We stopped at the end of cycle #5 when my immune system tanked. My neutrophile absolute dropped below 1.0 and I was confined to my home for a couple weeks (practice for the coming COVID pandemic).

A CT scan two weeks later showed that the tumor had shrunk by 30%...but was still leaning against the blood vessels behind the pancreas. However, this shrinkage allowed me to qualify for radiation treatment to see if we could open up space between the tumor and the blood vessels.

<u>The Dental Problem</u>

Lesson #5 Chemotherapy changes the chemistry in your mouth so profoundly that nearly all people who go through chemotherapy lose some of their teeth, and some may lose all of their teeth.

Before moving on to my radiation treatment, I feel it is important to present a critical lesson that I learned from my dentist, Jason Vettraino, DDS.

A month after starting my chemotherapy, I was scheduled for my annual dental cleaning. The doctor (and old friend) came in and asked how I was doing. I told him about the pancreatic cancer and that I was in chemotherapy. He stopped, pulled up a chair, and asked, "Which chemo?" After telling him, his face went white and he said, "I've treated over 1,000 patients in my career who have gone through this chemotherapy. All of them lost some of their teeth, and some of them lost ALL of their teeth." He went on to explain that chemo chemicals are designed to kill rapidly reproducing cancer cells. But chemo is an indiscriminate sledgehammer. It also kills all other "rapidly reproducing cells" in the body. These include the cells in your saliva glands, tear ducts, mucus membranes in your sinus, skin cells on your fingertips, sweat gland cells, hair follicles, the nail beds of your fingers and toes, the linings of your intestines and colon…and many others.

But his focus was on the saliva glands.

Your mouth can produce six different types of saliva—and is the beginning of the entire digestive process. When these cells die, your mouth becomes very dry…and acidic! Without proper treatment, this acidic environment, especially at night, eats away dentin at the base of the teeth between the enamel crown and the gums. At some point, this dentin becomes so thin, the tooth snaps off…or bacteria gets in under the gums and kills the roots of the tooth requiring a root-canal.

The good news, Dr. Vettraino had developed a successful approach to limiting that damage and has taught this approach to other dentists all over Southeast Michigan.

He pulled out a prescription pad and started writing a list of supplies I was going to need. They are listed here in the order I used them at bedtime—the most important time to use them:

1. Prescription toothpaste—(Prevident) with a very high level of fluoride: Use twice a day.
2. Magic Mouthwash—A liquid of three ingredients: an antibiotic, an antihistamine or steroid, and an antacid like Maalox or Mylanta. Use before bed and as needed during the day. Rinse only. Do not swallow.
3. Biotene Oral Balance Gel: Squeeze ½ inch onto your finger and rub all over your teeth and gums. Spread it all over your mouth with your tongue. Do not spit it out. Just go to bed so it protects your teeth all night. Not harmful if swallowed. (Alternative: XyliMelts are manmade forms of the mucus secretions normally produced in the human mouth.)

I used these, and a few other products, religiously…and only had to have one root-canal…one of his first patients to achieve that. However, even with this regimen, I did lose up to 1/4 of the dentin at the base of a number of teeth. My dentist filled the worst of these in with dental caps to protect the dentin from further deterioration. Six years out…everything is still solid.

Lesson #6 Chemotherapy is poison. It is also carcinogenic. While it is designed to kill cancer's rapidly reproducing cells, it also

kills all other rapidly reproducing cells in the body. The goal is to kill the cancer before it kills you. It is vital that you understand what other cells in your body are rapidly reproducing so you can adequately deal with the side-effects. Remember: you must survive both the cancer, and the treatments.

I was disappointed to realize how little my medical team told me about all of the side effects I might encounter going through chemotherapy.

In their defense, their focus is primarily on the cancer. Plus, every individual suffers a different combination of hundreds of possible side-effects…so it may not be the best use of their time to cover all of the possibilities with every patient.

Therefore, it is important to know that the other rapidly reproducing cells in your body include:

- Saliva glands—When these die, your mouth becomes very dry and acidic as discussed above. However, it also hampers digestion because the six different types of saliva help begin the process of breaking down different kinds of food. So, you may need to add digestive enzymes like Creon to your medications.
- Taste Buds—When your taste buds die, you may have very little interest in food. Nothing tastes the same…and, they may never go back to normal. Trial-and-error is the best approach for this problem. From my experience, watermelon, peanut butter and mashed potatoes with gravy were lifesavers. Also, anything with anise flavor…and still is.
- Tear ducts—My eyes went bone-dry. I used Restasis and artificial tears throughout chemotherapy.
- Sinus membranes—For the first time in my adult life, I was free of chronic rhinitis. I did have to use a saline spray to prevent them from becoming too dry…bleeding when they did. When the rhinitis did return, I knew my body was healing.
- Cells lining the intestines and colon—Everyone who takes this journey will suffer gastric distress…of many different types. Some of this is caused by pancreatic insufficiency, or in some cases, a total loss of pancreatic, digestive enzymes. This might account for half of the problems, but the other half is caused by the death of cells lining the intestines and colon. These are also rapidly reproducing cells. My surgeon just happened to live near me and came to our house to discuss my first surgery. Before leaving, he opened our refrigerator door, took a quick look inside and said “No more skim milk, no margarine. I want you to use whole milk and real butter. I also want you to butter your toast on both sides. Your digestive system will work so poorly for a while you will need to increase your nutrient intake…including good fats.” While “butter your toast on both sides” may have been just for emphasis, the point he was making was that I needed to increase my caloric intake so that I would get enough nutrition to survive both the surgery and the follow-up chemo. I believe my remaining intestines and colon have made a full recovery, since I can eat just about anything I want now.

- Fingertips—This is one side-effect few people figure out. After dropping a number of drinking glasses, bottles, and coffee cups, I realized there was something wrong with just the tips of my fingers. I initially attributed the dropping to clumsiness or loss of strength from surgery and chemo. But I pulled out a magnifying glass and discovered I no longer had any fingerprint ridges that facilitate gripping. A little research on the internet confirmed my assumption. The skin in your fingertips are rapidly-reproducing cells. I have learned to put my little finger or hand under everything smooth/slippery. Fortunately, my fingerprints did grow back…another good sign of healing.

Did I also have nausea, diarrhea, constipation, gas, and associated gastric pain like everybody else?

Absolutely.

But my medical team did adequately prepare me for these issues. However, I did not suffer these as dramatically as many of my cohorts. (See the section titled “The Cannabis Question.”)

Step 2: Radiation

My first appointment for radiation was with Dr. Parag Parikh at Henry Ford Radiology and Imaging. There, we discussed the traditional 32-35-day treatment that I had already heard about and was expecting. But even before finishing his overview of this treatment, he asked if I might be interested in a new, experimental, 5-day alternative. “Yes!,” I said. He then called in Dr. Jadranka Dragovic, the Principal Investigator of a clinical trial to test the efficacy of this new 5-day regimen.

The key to this new approach was a unique machine that married a large MRI machine with a highly focused radiation machine…the ViewRay, MRIdian Linac. Although the clinical trial was not scheduled to start until December, they registered me early into the program as “patient #1” in this clinical trial.

Figure 3. The ViewRay, MRIdian Linac machine.

<u>Protocol</u>

To compress the 30+ day traditional radiation treatment into just 5 consecutive days, the dosage must increase exponentially, along with an increase in treatment time.

The radiation dosage over these 5 days was roughly 50Gy…or the maximum, legal limit that can be given to any specific area of the body over an entire lifetime.

Treatment time was expanded from roughly 45-60 minutes to an average of 165 minutes (2.25 hours).

Figure 4. In the tray, ready for treatment.

The protocol begins a few days before the actual treatment, by laying in a tray that foams up around your body — which is then allowed to harden. Once foamed in, the MRI machine scans to find the tumor, identifies it graphicly in software, and determines the best position and angles necessary to hit the tumor from the radiation "guns." All of these settings were then saved into my patient profile.

On the first treatment day, I was placed back into my foam "tray" to get as close to the original settings as possible. It is not uncommon for things to shift a little inside your body from day to day. In my case, a large diverticula sitting at the top of my transverse colon was now laying up against the cancer tumor. We found that it could be pulled down out of the way when I fully exhaled. However, this meant that I would have to hold my breath at the end of an exhale for a full 90 seconds or more many dozens of times for more than an hour and 45 minutes.

The first 45 minutes of each treatment day is spent doing a detailed MRI scan to locate where everything is that day, and to calibrate the radiation machine. Once done, if you move, budge, or even twitch, everything stops, and the 45-minute calibration has to be done again. On day three, an intense itch in my right foot got the better of me with an involuntary twitch…and we had to start all over again.

Although I credit this machine with playing a significant role in my survival, and highly recommend it if you can handle the protocol, if you do find yourself heading toward this treatment and they suggest or offer Xanax, take it! I refused to take Xanax the first two treatment days after nearly becoming addicted to it as a treatment for PTSD and insomnia years before…and watching a close friend die from it. I had sworn that I would never take Xanax again.

However, this radiation protocol should require it. Remember, you not only have to survive the cancer…you also have to do whatever necessary to survive the treatments as well.

For me, there were three major benefits to the ViewRay, MRIdian, 5-day treatment:

1. It got me into surgery almost a month sooner than with traditional radiation.
2. It's 1mm accuracy avoided collateral damage to tissues nearby (particularly the diverticula at the top of the transverse colon, leaning against the cancer tumor). Traditional radiation is not focused enough to avoid damage to adjacent tissue—and might have perforated this diverticula.
3. It shrank the tumor enough to see space between the tumor and the blood vessels behind — qualifying me for surgery. I was, finally, a resectable candidate.

Note: This 5-day treatment is no longer offered here. Although I did find benefit from it, the majority of patients in this clinical trial did not. It did not increase survival outcomes significantly enough to justify the difficult protocol.

Lesson #7 The cancer is NOT in control…you are.

Yes, pancreatic cancer is going to do what it does best, and really give you a run for your money. But there are dozens of things you can do that can push the odds in your favor.

Step 3: Surgery

Surgery: Whipple #1

With the initial chemo and radiation complete, and now qualifying for surgery, the "Whipple Procedure" was scheduled for January 3, 2019.

The Whipple Procedure was first performed in 1935 by Dr. Allen Oldfather Whipple at the Columbia Presbyterian Hospital.

Dr. Whipple was in the process of demonstrating a stomach surgery to visiting dignitaries when he realized the patient did not have stomach cancer—he in fact had cancer of the pancreas.

With his invited guests looking on, Dr. Whipple had few options. He would have to improvise. Whipple performed an elaborate operation that included removing not just patient's pancreas, but also the stomach, jejunum, duodenum, and common bile duct. (Due to the shared blood supply of organs in the proximal gastrointestinal system, surgical removal of the head of the pancreas also necessitates removal of the duodenum, proximal jejunum, gallbladder, and, occasionally, part of the stomach.)

With that one bold move, Dr. Whipple opened the door to surgically curing patients with pancreatic cancer. His procedure—technically called a "pancreaticoduodenectomy"—remains, to this day, the best treatment option available for many suffering from this deadly disease.

Today, most call a pancreaticoduodenectomy the "Whipple Procedure," in recognition of Dr. Whipple's great imagination and courage.

My six week wait for this surgery, was an emotional rollercoaster.

I celebrated my 70th birthday, Thanksgiving, Christmas, and New Years—all while living with the fear and anxiety that naturally comes with a pancreatic cancer diagnosis. I could not get the "2% chance of survival" prognosis out of my mind. Plus, I knew the cancer was doing everything it could to recover as well.

We arrived at the hospital at 5:20 AM the day of the surgery. I was given anesthesia around 8:30 AM so the operation could begin.

Everything went smoothly for the first 6.5 hours. After a quick visual inspection of the abdominal area with a tiny camera to make sure there would be no surprises (CT/MRI/ultrasound scans cannot see everything), the abdomen was opened up and the

surgery began. The gall bladder was removed, then the bottom of the stomach, pyloric sphincter, duodenum, and the top of the small intestines. The last item to remove before reconstruction could begin, was resecting the head and neck of the pancreas—to remove the tumor on top. Since the tail of the pancreas appeared to be good, the spleen could remain.

Once they get to the pancreas, the normal procedure is to slide a spatula-type device under the pancreas to lift it up on its top edge to resect, or cut, the diseased part out. However, the spatula would not slide underneath. Something was in the way.

Although none of the scans showed it, the tumor had grown through the pancreas, out the back side, and into the blood vessels behind. Had we known this before, I would never have qualified for surgery in the first place. Life expectancy would have been less than a year with any known treatments at that time.

In 2019, the protocol for this event in surgical bays all across the country was to close the patient back up and send them home and into palliative care.

However, Dr. Kwon called a 15-minute time-out to ask his surgical team if any of them had an idea for getting out of this bind. Pointing to blood vessels that had been removed with the other organs, one young resident asked if they could use those to rebuild the vascular tree behind the pancreas that had been invaded by the tumor.

Dr. Kwon told her that there were two problems with that idea: 1) It had never been attempted before because of the risk of the patient dying on the operating table, and 2) No one on this surgical team was a vascular surgeon qualified for that task.

Naively, the young intern quickly addressed both issues saying: 1) The patient had given explicit permission both in writing and in person for the surgical team to do anything necessary to allow him to survive this cancer—even if it was experimental or had never been done before, and 2) She said “Let’s get a vascular surgeon on our cell phone to walk us through the procedure!”

After a short discussion, the entire team agreed that this was the best option. A vascular surgeon was contacted, and the repairs began. All of the blood vessels that had been invaded by the cancer were repaired or replaced. Long-story-short, every stitch stuck, the operation was a success!

Note: Since this first vascular repair was attempted, it has been repeated more than once again here, and has also been successful in other surgical centers around the country.

However, three days later, Dr. Kwon came into my recovery room with very bad news. He had sent the removed pancreas to the lab for a detailed analysis. They found two problems: 1) Cancer cells were found throughout the head and neck…all the way to the boundary of the cut…indicating there were cancer cells in the tail of the pancreas left behind as well, and 2) Those cancer cells were actively metastatic and spreading cancer cells throughout the abdominal cavity.

I thought my survival odds had just dropped to zero, but Dr. Kwon said that if I was willing, he could do a second Whipple surgery to remove the tail of the pancreas as well. However, the

soonest he could do the second Whipple would be in four months, in April of 2019. He pointed out that I was simply too weak to survive a second surgery anytime sooner and I would need all of my strength to recover from the first surgery, before we could do a second. The risk, of course, was that the cancer would also have those four months to spread throughout the abdominal cavity.

Seven Weeks of Hell

Little did I know what Dr. Kwon meant when he said I would need all of my strength to recover from the first surgery before he could do a second one.

When you have expansive abdominal surgery, removing large portions of the digestive system, what gets left behind goes into shock. It stops moving…the stomach doesn't churn, the intestines and colon don't rhythmically squeeze food down, etc. Medications like Reglan chemically trigger these muscles to contract, but the contractions are uncoordinated, and are just as likely to push food up, as well as down.

It takes from 5 to 7 weeks for what's left of the digestive system to relearn how to work again. During the first half of this period, I lost up to a pound of weight a day—dropping from 167 pounds to 124 (some of which was the organs/tissues removed during surgery).

During this Seven Weeks of Hell, your ability to digest any food at all is severely restricted. In the first week, I could only eat 2-3 bites per meal. My body could not yet process much more than this. But gradually, I was allowed to eat more each day until I could eventually eat as much as I wanted…after more than 3 months.

However, when you're in this condition, many patients don't want to eat. I didn't. I had absolutely no appetite! Plus, when I did eat, my digestive system couldn't digest the food and created significant gastric distress…swinging between indigestion, gas, diarrhea, constipation, etc. Fortunately, I had a spouse that made sure I did eat—even "airplaning" the food into my mouth one bite at a time when necessary.

By week five, I was also so depressed I wasn't sure I wanted to live. I needed someone to talk to, but my first psychiatrist only offered pills—which I turned out to be allergic to—pushing me even deeper into despair. A psychiatric therapist for cancer patients at Henry Ford finally helped me walk/talk my way up and out of that pit. If this is something you are dealing with, DO NOT try deal with it alone. Swallow your pride…and get help.

At the end of the seven weeks, my digestive system began working correctly, and my weight stabilized at 124 pounds. My energy level gradually returned as well. On May 18, my weight and energy levels were high enough to schedule the second surgery for April 25th.

Surgery: Whipple #2

During the second Whipple surgery, Dr. Kwon removed the tail of pancreas, spleen, and more of the small intestines. And, because cancer cells had spread throughout the abdominal cavity, everything was taken out—emptying the entire abdominal cavity. The empty cavity was then scrubbed down with sponges full of Folfirinox chemo chemicals. Only the intestines and colon were put back in.

All of the interstitial fat was also removed, along with the entire abdominal lymphatic system, and all organ support tissues (from the removed organs) which are normally left in.

Figure 5. Me at 113 pounds.

Then it was back to the Seven Weeks of Hell, all over again. This time, my weight bottomed out at 113.

This second time around, I had trouble staying hydrated and had to have a Home Health Nurse come to my home twice a week for hydration. I was too weak and immunocompromised to leave my house.

At 113 pounds, I was so weak I couldn't even walk the 60 feet to our mailbox. I made it halfway once, and realized I didn't have enough energy to get back. Fortunately, there was a chair on the porch I could stop at to gain enough strength to get back into the house. I didn't try that trick again for many months.

Again, my therapist had to help me stay focused on staying in the game. There were times I didn't feel I could go on.

Follow-up Chemotherapy

My post-surgery chemotherapy (prophylactic) began on July 22nd, 2019—almost 3 months after the second surgery.

Again, my choice was to continue with the Folfirinox since it had been so effective for me the first time around.

During this second course of chemo (cycles #6 through #13) there were a number of complications:

1. My white blood cell count dropped too low several times, and I had to go on Neulasta injections several days after every infusion.
2. My immune system tanked as well…allowing a fungal infection to get in under my toenails. It took almost three years to get healthy enough to treat this condition with a potentially liver-damaging antifungal. I had to take antifungal pills for 12 months and avoid all alcohol and caffeine.
3. One month after starting chemo again, my Home Health Nurse noticed I had a fever during one of my hydration sessions. I had a bile-duct blockage that had become infected and progressed to sepsis.

The bile-duct blockage became a recurring problem…reappearing almost exactly every six weeks. After five endoscopies, it eventually resolved itself as the hole created in my small intestine that the bile duct was reattached to, stopped trying to heal the "hole."

The Cannabis Question

After word of my diagnosis spread among our family and friends, advice, articles, web links, books, and even a vial of creosote tar were sent my way promoting or claiming "cures" for pancreatic cancer. These included the use of various marijuana products.

Those who knew me knew our home was a safe, drug free zone for our children and any others who spent time here. Illegal drugs were not permitted on our property. I was vehemently opposed to the use of any illegal drugs.

I began to question my attitude after doctors at five of my six second opinions brought the issue up. Although they would not prescribe it, or even recommend it, they did comment that "some of my patients use it, and say they benefit from it." Was this a hint? At my last "second opinion," I brought the issue up and got the same response… "some of our patients use it and seem to benefit from it. We cannot prescribe nor recommend it. That's your personal choice."

I was still hesitant.

That changed after my first cycle of Folfirinox chemotherapy. The nausea-type side-effects kicked in right away. That same week, one of my business partners, a pharmacology researcher in Washington D.C. who works on NIH research grants sent me a bottle of CBD (cannabidiol tincture) with a big note that said, "Use it!" The nausea finally convinced me to give it a try. I figured it wasn't going to kill me…so what did I have to lose?

Although I couldn't feel anything from the CBD, my nausea and gastric symptoms did ease up…and I slept better. So, I decided to add it to my medical regimen. I also decided if I was going to use it, I'd do it legally…so I applied for and got a medical marijuana card and purchased the CBD only from licensed, medical marijuana clinics.

Five chemo cycles in, I noticed that all of my chemo buddies who refused to take CBD all suffered miserably from nausea, throwing up, diarrhea, gastric pain, etc.—but I didn't. Yes, I did suffer some…but not nearly to the extent they did.

Around the end of 2022, I found a clinical trial report funded by the NIH on the efficacy of using CBD with breast cancer patients going through chemotherapy. It was found that the effectiveness of chemotherapy on patients using CBD was four times greater than the control group not using CBD. The benefit was so great, that part of the study group had their chemotherapy doses dropped to as low as 60% and still maintained the same effectiveness level as the control group. However, the surprised researchers did not understand what mechanism caused this surprising benefit.

That question was answered several months later when a different research team discovered that many cancers (breast, pancreatic, and many others) put out a "smoke screen" of oxidizing

chemicals that prevent chemo chemicals from reaching the cancer…and keep the immune system busy cleaning up that mess. The cancers safely hide behind this smoke screen shield.

However, CBD is a very powerful antioxidant that neutralizes this shield—allowing both chemo chemicals, and our immune system, to reach the cancer itself. Based on this research, CBD can play a significant role in any cancer battle.

I was originally going to leave this CBD discussion out of "My Story." But in retrospect, I do believe that it's use did play a part in my survival. It did help me sleep better. It appears to have tempered and helped me tolerate the damaging effects of chemotherapy. It may have even improved the efficacy of my chemotherapy treatment. However, it is a deeply polarized and politicized issue in this country.

If you do choose to use it, here are a few words of advice:

- Do it legally. If your state requires a medical marijuana license, get it and keep it up to date.
- Only purchase CBD from licensed, medical marijuana clinics. This helps ensure you get consistent potency and purity for medical purposes.
- Only use CBD tinctures…sublingually (under the tongue). Since pancreatic cancer wreaks havoc on your digestive system, you may not get any benefit from edibles. And, I don't recommend smoking either…you already have one form of cancer.
- I have found that a full spectrum, hemp extract (lemon flavor) works best. Make sure it is in MCT oil (coconut oil). Some CBDs taste like the black gunk I scrape off the bottom of my lawn mower at the end of summer…not a taste you want in your mouth when you already have no appetite.
- It does not need to contain any THC, the psycho-active ingredient that makes you "high." Some studies indicate that THC makes the CBD work better, but I couldn't find a dose of THC low enough that didn't make me dizzy.
- Dosage is difficult to determine. Start with ¼ inch from the eyedropper, twice a day, and work up from there until you see some benefit. During chemo, I took ½" twice a day. Now, I just take 1" once a day, an hour before bedtime.

Aftermath

I am now approaching my 6-year anniversary from the initial diagnosis. And, we have just returned from our celebratory, wedding anniversary trip to Italy originally planned for 2018.

While I <u>am</u> still alive, life is much different now. One of my suitcases alone carried just my medical supplies necessary to take such a trip. As a pancreatic cancer survivor, there are some conditions I now live with that did not exist before my diagnosis:

- A very brittle, Type 3C diabetic. I can be hypoglycemic and hyperglycemic multiple times in the same day. Glucose swings can go from 50 to 400 in just 3.5 hours…rising or dropping at a rate of 30 points every 5 minutes. The new Dexcom G7/Tandem T-Slim

glucose management system helps make most of life fairly normal. But since this system is built for Type-2 diabetics, they are not adequately programmed for the rapid swings of Type 3C's and must be constantly monitored.

Lesson #8 **When it comes to blood sugar levels, low is much more dangerous and damaging to the body than high. Dropping to 47-50 multiple times has nearly put me in a coma…and can be fatal. Fortunately, when a Type 3-C goes high, it is usually only temporary…and will come down before causing any permanent damage.**

- Anyone who loses the bottom of the stomach and the pyloric sphincter to the Whipple surgery, will suffer from delayed gastric emptying. This significantly complicates glucose and insulin management. For more than five years after my surgeries, my blood sugar would plunge for hours after eating high carbohydrate meals. The higher the carb count, the more serious the drop. Then, around three hours after the meal, my glucose count would rapidly jump to over 250-380. This pattern is opposite what it should be…and none of my doctors had a clue why.
  Last month my endocrinologist came back from a conference where a presentation about a new, type 3C programmed version of my insulin pump was made. The presenter mentioned my particular glucose/insulin pattern as one of the reasons for this new device. He stated that the way the small intestine is attached to the bottom of the stomach after that bottom, pyloric sphincter, and duodenum are removed, creates a very small hole for food from the stomach to pass through. The muscles that normally push food into and through the digestive system are also gone. Gravity is now the primary mechanism for moving food from the stomach into the small intestines.
  However, recommendations for insulin delivery are still "calculate the total carbs for the meal and enter into your insulin pump 15-20 minutes before the meal." This instruction is correct for all other diabetics, but NOT type 3C's.
  Because we suffer delayed gastric emptying, it often takes 2-3 hours for a meal to pass into the intestines. By this time, all of the insulin taken for the meal has done its job and dropped my blood glucose—often into a dangerous plunge. Then, as that meal does enter the intestines, the blood glucose begins to rise, but now without any insulin to control it.
  Until an insulin pump is available, programmed specifically for type 3C diabetics, I will calculate my total carbs for a meal, eat the meal without taking any insulin, and wait until I see the blood glucose begin to rise. Then, I enter into the pump only half of the carb count and wait for it to rise again before entering the final amount. This way, my insulin delivery will better match my glucose absorption.
- The diabetic neuropathy in my feet made walking through Italy a challenge—paid for with night cramps in my feet, and bone-deep aching and itching.
  For pancreatic cancer patients, the most common cause of neuropathy are platinum-

based drugs like oxaliplatin. Once peripheral neuropathy occurs, there are very few drugs to treat it. One is an antidepressant called duloxetine—however, more research has been called for.

More than two-thirds of all chemo patients will experience some level of neuropathy, with 30% still experiencing it six months after chemotherapy ends. With so few treatments available, current research focuses on prevention instead of treatments. Clinical trials being conducted now include exercise during chemo, scrambler therapy (a form of non-invasive electrical stimulation), compression therapy, and cryotherapy. If you are in, or are headed towards chemotherapy, check to see if any of these trials are running in your area.

- I take more than 700 pills a month—mostly digestive enzymes (CREON) and vitamin/mineral supplements due to the organ losses from surgery. With so much of my digestive system removed, getting necessary vitamins, minerals, and other nutrients is challenging. Supplements have been able to bring all of these into normal ranges, with the except of vitamin A. This deficiency could be corrected with injections, but it is not covered by insurance and costs over $6,000 per month.
- I am very immunocompromised—I now carry antibiotics with me everywhere. *(Which I had to use in Italy for an infection that started to get out-of-control.)* Not having a spleen complicates many issues. The spleen is responsible for managing your immune system. When you get a vaccine, it trains the t-cells in what pathogens to look for. It is the only part of your immune system that can recognize staph, strep, meningitis and many other infections. I found a massive staphylococcus epidermis infection in my bladder by accident that had been there for more than three years—from a catheter after my second surgery. Without a spleen, your liver tries to take on some of its blood-cleaning duties. However, it is hard on the liver, and I now have fatty liver disease. That is why you have to be very cautious with any substances that are hard on the liver, like alcohol, caffeine, or medications like antifungals.
- Still suffer minor “chemo-fog.” Brain-training programs, such as Posit Science’s Brain HQ program called Double-Decision, have helped significantly…but they cannot repair all of the damage from the two years of chemo, radiation, and surgeries. To compensate, I use many mnemonic devices like to-do lists, post-it notes, and the best memory device of all time…my cell phone. Anything I absolutely need to remember; I shoot a photo of it. While my memory is not “photographic,” my camera’s is.
- Just like managing insulin and blood-glucose (BG) I must also manage how much energy I expend on a moment-by-moment basis. This condition may be unique to me. In addition to the normal organs lost to the Whipple surgery, I also lost all of my interstitial fat—the body’s energy storage system. Without it, I can burn up all of the glucose (energy) in my muscles in just seven minutes of strenuous exercise or yard work. Doing more than 15-20 minutes of exertion requires a constant intake of carbohydrates.

  My Lifetime Fitness workouts require a marathon runner’s lunch with lots of carbs. Then, I eat a full-size candy bar on the drive down. My pockets are full of hard candies which I eat throughout the workout. Cans of fruit juice are always in my gym bag for

emergencies. This high carb intake then has to continue for two hours after the workout.
Also, since your brain can use up to 50% of your glucose energy, I keep a jar of candies by my office desk, and a recliner in front of it. If my glucose begins to drop while at work, I pop a couple candies and sit in my recliner until the sugar kicks in and I can go back to work.

- Osteopenia—At the beginning of 2023, I developed a slight pain in my left wrist. Nothing serious…and it only hurt once or twice a week. Over the course of that summer, it gradually got worse. By September, an x-ray showed that one of the major wrist bones was cracked all the way through. A cast was put on, but after two months, it had not healed. A bone density test showed osteopenia—a precursor to osteoporosis.
With the bottom of the stomach, duodenum, and half of the small intestines gone, my body can no longer absorb calcium—from food or supplements. Also, I have to take medications like Prilosec to control stomach acid. The mechanism for stopping acid production is in the bottom of the stomach—which often gets removed during the Whipple. The problem is that these medications prevent your body from metabolizing what calcium it can get.
Forty-five days after getting my first, annual injection of Reclast (a treatment for osteopenia for patients who cannot or do not benefit from oral supplements), the bone fracture was gone.
If you have had the Whipple surgery, and lost the bottom of your stomach, you should get tested for osteopenia.

Figure 6. Celebrating being a "Survivor" with my fellow survivor and mentor, Sheila Sky Kasselman, founder of the Sky Foundation. Unfortunately, Sheila passed away from pancreatic cancer on Saturday, February 25, 2023, two hours after my last visit. She is sorely missed! She enjoyed more than 17 years—cancer free.

The Back-Story

Problems with Medical Profession

My first introduction to pancreatic cancer was in 1981 when my father called to tell me that my mother had been diagnosed with advanced adenocarcinoma of the pancreas. My wife and I flew back to Pennsylvania from Nebraska to see how she was doing. She was in exploratory surgery when we arrived. At the end of what turned out to be a very short surgery, the doctor told us that it had spread everywhere…he didn't see a single organ without lesions on it. Prognosis: 60 days. She died on the 60th day.

At her funeral, relatives from all over the country came up to give us their condolences saying how unfortunate it was that she got the "family disease." What I discovered was that 30% to 50% of all family members had died from adenocarcinoma of the pancreas. It was not a topic anyone wanted to talk about—like other families with devastating inherited diseases.

After my mother died of it, her older brother died of it, then her younger brother. That's 75% of her generation. Also, while I was still recovering from my second Whipple surgery, my younger sister got it and died 18 months later — bringing my generation to 50%.

Beginning in 2012, and because of our unusual family history, I began asking my doctors If I could be tested for pancreatic cancer. Over the following 6 years, I asked 21 doctors for any test whatsoever…CT, ultrasound, CA 19-9, etc. The CA 19-9 costs only $38 retail, but you can't get it without a script. All refused. The most common response was "Greg, you're as health as a horse! I can't justify ordering a test for something I don't think you have."

It is true, after learning about my family history, I did everything I could to NOT come down with this disease—working out, eating a Weight Watchers diet, avoiding alcohol, not smoking…everything I thought my relatives and ancestors didn't do.

Two years before my diagnosis, I started suffering severe chronic fatigue, and my heart would flutter many times during the day and even stop completely for up to a minute and a half. Then, it would pound like hell and gradually fall back into a normal rhythm.

As you can imagine, my cardiologists had a field day. However, every test result came back normal, with stellar stress test results.

> **Lesson #9** **Heart flutters and stoppages turned out to be a symptom of metastatic cancer. Few cardiologists know that when cancer metastasizes, the body sometimes thickens the blood to make it harder for spreading cancer cells to attach to new locations. It is also suspected that by slowing the cancer cell movement, it gets easier for t-cells to attack them.**

In the 12 months before my diagnosis, another major symptom surfaced. I made a total of four trips to the emergency room (ER) suspecting food poisoning. Each time getting diverted into

cardiology, as I mentioned in more detail earlier. Also, during this year, I went to my GP six times suspecting pancreatic cancer and asking for any kind of test, only to be told "No."

Demanding a reason in that last appointment, she told me that she could lose her certificate for insurance coverage if she ordered a test that the insurance companies determined was "unnecessary." She was absolutely unwilling to budge…even knowing my family history.

On July 2nd, the morning my pancreatic cancer was confirmed, my GP came into my room at the hospital. My name had shown up on her roster for her morning rounds. Surprised, she asked me what I was there for. I said, "pancreatic cancer." Her face turned white, and she was speechless. She left without really saying anything. Months later, after leaving that hospital system, I made an appointment to see her one last time. Not in anger or to chew her out. But the odds are that she would see at least a dozen pancreatic patients over the course of her career. I wanted her to promise that she would do the necessary tests to catch it early…soon enough to have more treatment options. She would not promise. Hesitance to do the necessary tests, in spite of hereditary evidence, is like a systemic disease infecting some areas of our medical system.

When I talked to my family members all over the country, they too had similar difficulties getting tested.

When the genetics department at the University of Michigan (who sequenced my DNA) heard of our family's plight, they wrote a formal letter on their letterhead detailing our family's genetic history, and preponderance for coming down with this disease. Given this letter, any doctor who refused pancreatic cancer testing, could be sued for malpractice. Since this letter went into use by my family members, no one has been denied the tests.

Footnote: Every single member of my family who has been tested discovered that they do have pancreatic cysts, growths, and lesions on their pancreas. All are now getting annual testing to monitor these conditions. Any one of them could become cancerous.

Lesson #10 **Remember Lesson #1: You must be your own medical advocate! You know more about you than your doctors do. Listen to your body and let them know what you need them to do. If they do not listen, you are talking to the wrong doctor(s).**

Bottom Line

Was it all worth it?

Absolutely!

As I frequently tell my friends…Life After Whipple can be complicated, but it can also be very good!

The alternative is not.

Figure 7. My wife Patty and I celebrating our 40th through 46th wedding anniversaries, and my survival, in Florence, Italy in front of the Ponte Vecchio on April 10, 2024.

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Life After Whipple website: https://www.lifeafterwhipple.com/