It all started on December 5, 2008. I worked my shift that day in ER,and I felt fine all day. At 2 AM I awoke with severe chest pain. I called my doctor, and than went to the ER. All the tests done showed Pancreatitis. I was referred to Columbia that day, to be scoped by Dr Welsh. His diagnosis was "you have some kind of disease in the lower stomach and its blocking the tubes going to your pancreas and liver, I took biopsies and placed stents." He then made an appointment for me to see Dr Aliperti, gastrologist for re-evaluation and stent removal. I saw Dr Aliperti, and he removed the stents, and the growth (blockage) was removed utilizing a scope. Diagnosis was Adenoma- not yet cancer- but they would watch it closely, since it went from the duodenum thru sphincter of Odi, into ampulla of Vater and up the tubes to vital organs.

I had these scopes with stents every 2-3 months, which were always diagnosised as Adenoma.

On December 21, 2009 Dr Aleperti called me. The Adenoma had turned into Carcinoid Cancer. It was decided that a surgery called the Whipple must be done to remove the cancer and all the surrounding tissue. On January 9, 2010 I underwent the Whipple Surgery. The biopsies from that came back "not nearly as good as expected," my carcinoid had metastasized to my lymph nodes and higher into my stomach. I continued to have trouble, pain and inability to eat. A feeding tube was placed in my side and I was given liquid feelings. This failed miserably. In total I had lost 60 pounds. Eventually the tube came out and they fed me what's called TPN thru a port in my right chest. Approximately 18 months later the port developed a severe infection, was removed and a month later a port was placed on my right side. I did not continue TPN, because I had been able to gain 20 pounds and was able to eat liquid nutrition shakes. Approximately 4 years after the first Whipple procedure, my stomach blocked off completely, so they did a second revision of the Whipple surgery. Along the way, I have also had Celiac blocks and Botox to my internal stomach, to help relieve the pain and nausea.

This type of cancer is very unusual. It cannot be found by any x-Ray or radiological scan, and just recently a chemotherapy was approved for treatment. I have chosen to not do this chemotherapy treatment, as my cancer doctor has not had good luck with it, so bad that some patients don't survive the treatments.

Last August I saw Dr Aleperti again, as my episodes of pancreatitis were worsening. He informed my husband and I that there was literally nothing he could do, but that my pancrease was dying. Both specialist have reach a point of 'treat to keep comfortable'. I'm guessing things are getting worse as so far this year I have been hospitalized 7 times with pancreatitis, with pancreatic enzymes being extremely high, showing damage being done. There are time at home I hurt almost as bad as when I am in the hospital, so there is no way to know how often I have a flair up of the pancreatitis. I have to take multiple medications. Some I cannot afford. I receive a cancer shot each month called Sandostatin that is the only carcinoid treatment they have, other than surgeries to cut out what they find. It helps a lot with symptoms but cost several thousand dollars. It's been several years and as one doctor put it, "this is a slow growing cancer and may not kill you right away but will make you miserable." The doctors have worked hard to help me, one of the best help is the Morphine pump that was placed a few years ago. It was placed in my abdomen, tunnels the catheter under my skin to where the needle was inserted into a place in my spinal canal, leaving the plastic IV cannula in my spine. Morphine is then delivered at a slow but constant rate.

I've had so many procedures that I forget. I do know it has totally depleted any savings or cash we had for retirement. I have Medicare now but at one point we lost our insurance completely, and thank God that we did have our retirement and savings to get us through. I have just this month hit the Medicare donut hole, and when this happens, it makes some of my medicines totally unaffordable. But God is great, and He will provide.