

About me:

-Rick Ulrich, 48 yrs of age (45 at time of operation) and born and raised in Daytona Beach, FL. Married to Melanie Dautle Ulrich for 16 yrs and we met in Graduate school. We currently reside in Cape Coral, FL AKA paradise! I attended Clemson University (GO TIGERS) for BS and PhD degrees in Microbiology, infectious disease microbiologist by training in defensive biological warfare at the BSL-3 level. With my complicated health issues I can no longer work in a lab with infectious diseases. Being raised on the water I spent my younger days on the beaches of Daytona Beach surfing and of course both inland and offshore fishing so my passion to this day is being around (living), on (boating/fishing/crabbing) or in the water (our pool). I am an extremely fortunate man and also love giving back/helping folks that are in need.

Message sent to my local GI doc:

-My history is that I showed abnormal blood work, in particular elevated titers for antibodies associated with inflammation (i.e. IgG 4 levels) in a lab test when I was being monitored at the U.S. Army Medical Research Institute of Infectious Diseases (USAMRIID), my DoD employer at the time (I was a civilian employee), for a study funded by the Department of Defense looking at the long-term effects on people who have had numerous vaccinations (both FDA approved and investigational) in the USAMRIID Special Immunizations Program. That was in 2004 and I had no symptoms at the time, but they noted an auto-immune type inflammatory condition of unknown origin. This should be in my records and if not I can send a copy.

-My first symptoms where I was ill enough to be hospitalized with acute pancreatitis (as diagnosed at the time when we were living in Pennsylvania) manifested in January of 2011. This was a 5 day admission on bowel rest and morphine for pain. However, I know now I had pancreatic issues 2 months before this when Mel and I were in Australia for a DoD work meeting I had, but I didn't seek medical attention there. Once I knew what pancreatitis felt like I know what happened over there.

-My second attack occurred in May of 2012 while visiting FL for a job interview that my wife had at Florida SouthWestern College. We landed at 10 am, checked in the hotel room and 2 hrs later I was in the ER with a severe case of acute pancreatitis. This was a 2 day trip to FL and we were still living in the north at the time so the ER doc treated the acute pain, prescribed oral pain meds and allowed me to return home without a hospital admission. He was not too happy about not admitting me, however...

-Later that year (August) we moved from the north to FL and my condition began to deteriorate rather fast. From October 2012 to November 2013 I was admitted to the hospital 5 times (both local in Cape Coral, FL as well as Orlando, FL). MRI's, CAT scans, ultrasounds, EUS and endless labs were performed and the root of the cause could not be found. At the time I was being treated by a local GI practice and they basically kept giving me anti-nausea meds and said watch what I eat. However, one doc in the practice suggested a referral to Florida Hospital to be seen by a world contributor to the area of pancreatic diseases, Dr. Robert Hawes (<https://www.floridahospital.com/doctor/robert-holbrook-hawes-md-1295843241>).

Dr. Hawes' analysis and his interpretations of my condition:

- I actually visited that hospital 3X in 2013 (February, March and April) 2014 and a battery of tests were performed including an EUS, ERCP, biopsies, sphincter of Oddi monometry (SOM) and, of course, a boat load of labs. Immediately following my first visit to FL hospital for an EUS and before any labs or biopsy results were back Dr. Hawes informed my wife (I was in recovery) that I have what is called "double duct syndrome". Of course we had no idea what this was as my local GI docs at the time were only keen on treating the nausea despite performing the same test as Dr. Hawes. He explained the condition is notoriously autoimmune due to the need for stents in both my biliary and pancreatic ducts to facilitate enzymatic flow into my small intestine. After this diagnosis my wife actually remembered one of my DoD doctor consults back in 2004 regarding abnormal labs that indicated some type of potential autoimmune issue that I was or could have in the future. At this point we gathered all of my DOD medical records and had them sent to Dr. Hawes at FL hospital.

As my wife recalls, remember I was in recovery, Dr. Hawes said I had "smoldering pancreatitis" which was apparent from the tests he performed over 3 visits (with sedation and procedures) as well my history. He truly thought that I never had just acute pancreatitis, he felt the pain lessened until it was tolerable but the inflammation was still present and built up over time (obviously with a chronic condition). He also said the acute attacks were increasing the level of my pancreatic damage which in turn increased the development of the chronic condition. He went on to say my immediate problem at the time was because the pancreas treatments were started too late and the damage was already so severe (this is because my other GI docs before kept insisting that anti-nausea meds were the cure) that a normal recovery was not possible. The term "pancreatectomy" at this point by his team began popping up in consults...

For treatment, Dr. Hawes immediately put me on prednisone to help with the chronic pancreatic inflammation and I did get some relief. He did not give any refills on the prednisone and told me to consult with my local GI docs for medication refills and he said that he was sending his results and interpretations to my local docs. Well, my local GI docs said they are not very familiar with autoimmune pancreatitis and have only heard/had a couple of cases, etc. They also did not like the fact that Dr. Hawes placed me on a relatively high dose of prednisone, they said the benefit does not outweigh the risk associated with the long term side effects and they did not give me any refills and began to taper me off of what I did have left. During the prednisone tapering I felt off (for lack of a better description): tired, loss of appetite, feverish and increased pain. I thought this was just the side effects but about 3-4 days after stopping all prednisone I had the worst case of pancreatitis to date and it landed me in the hospital for 16 days. I should note I started to begin with episodes of jaundice during pancreatic attacks.

Meanwhile my pancreas issues continued, in fact, I was admitted to the local hospitals roughly 13-16 times over 2012-2015, with most admissions being from 2013-2015. One GI doc actually said "Mr. Ulrich we need to name a wing at the hospital after you".

KEY TURNING POINT AND WHAT GOT ME TO UCHICAGO:

I believe it was my 12th or 13th case of acute pancreatitis and I had been trying to do the typical bowel rest along with oral pain meds that I had been prescribed in the hopes that the pancreatitis would pass. However, after 24-30 hours or so I ended up driving myself to a different hospital, it was local to our area but was actually in Fort Myers instead of the Cape Coral Hospital. There I was seen by a new team of GI docs and they actually stayed at my bedside in the emergency room for about 45 minutes reviewing all of my medical files; Dr. James Penuel in particular (<http://digestivehealth.com/>). Dr. Penuel has been in practice for over 30 years and his words to me were “Rick we have to get you the hell out of Lee County”, that is the county that Cape Coral and Fort Myers is within. He did put me back on prednisone and also tried Mercaptopurine, both of which provided some relief. In the meantime he referred me to the Jacksonville, Florida Mayo Clinic and my wife and I immediately scheduled to be seen by a second expert in the area pancreatic diseases, Dr Massimo Raimondo (<https://www.mayoclinic.org/biographies/raimondo-massimo-m-d/bio-20054330>). He scheduled an EUS to perform his own exam and after about two weeks I got the results back via a phone call from Dr. Raimondo. He informed me that there was nothing that the Mayo Clinic could do for my extreme case of chronic and acute pancreatitis. He also said that I need to get an immediate pancreatectomy and if I don't I would have around a year or so to survive. Of course, there's only a handful of hospitals that perform a pancreatectomy with autologous islet transplantation and I asked him if it were him or a family member and without any reservations he said the University of Chicago. As you can imagine this was devastating news and we immediately scheduled to be seen by the pancreatic team at the University of Chicago. I was given the green light for the surgery which was in May 2015 and was told that they will work on getting things approved with my insurance company. Well, in the meantime my condition deteriorated rather fast and I ended up on home infusion services with a PICC line in my arm and around the clock fluids as well as pain and anti-nausea medications for approximately 2 months. The procedure was approved and scheduled for August 17, 2015 and the rest is history.