Eric's wAIHA Story
I was diagnosed with warm Autoimmune Hemolytic Anemia around September 2011.

In February 2011, I had a bad case of the flu just before Super Bowl weekend. I was well enough to attend a Super Bowl party, but I remember not feeling myself.

A few weeks later, I had my regular annual physical with my internist. We were away celebrating a friend's 50th birthday, sitting at the pool, when my internist called and told me that my blood work was totally out of kilter (he used the term "pancytopenia"). My wife, Liz, who is a pediatrician, was nervous, and just like when our kids were little, I only got nervous when she got nervous.

I was very lucky that one of my closest friends is a Hematologist/Oncologist. The next day I went to see him, he set me up for all sorts of scans and bone marrow biopsies, and we were off trying to figure out what it was and was not.

Over the next few months he became confident that I did not have any sort of acute blood cancer. I still did not feel myself (I was tired, not hungry, not sleeping well, and not in a good mood). Most the blood tests became normal except for the hemoglobin/hematocrit. My spleen was very large. My friend thought I had AIHA (but my Coombs tests, which are typically what seal the AIHA diagnosis, were negative. Over the summer, I had one Coombs that was barely positive. In August 2011, my hemoglobin was going down, and I had a blood transfusion. I felt better after that.

In September 2011, my friend/hematologist wanted me to get another opinion, so he referred me to another hematologist who is more of a "benign hematologist" as they are known – don't typically treat blood cancers. She confirmed the diagnosis of AIHA. She began me on Prednisone and I felt a little better.

My friend/hematologist thought that if I had a splenectomy (which was thought to be the primary treatment option back then), I might be "cured" and I would not have to be on chronic Prednisone the rest of my life. I had the surgery in February 2012. It was a very difficult few days in the hospital followed by about 3 weeks of recovery at home. But after that, I felt pretty good. I was on a very low dose of Prednisone (less than 5mg per day) and that lasted for a few years.

In June 2015, while travelling in Italy, I got sick again (tired, peeing a lot, not sleeping, could feel my pulse in my temples). Upon my return, my hematologist and I began to try many of the treatments that are recommended for AIHA. I started on a pretty high dose of Prednisone and then weaned down to about 15mg or so per day. And like clockwork, my hemoglobin responded, and I felt better.

The goal then became to find something that was not as harmful as Prednisone that could control the hemolysis and my hemoglobin levels. Over the next couple of years, I had a couple

of courses of Rituximab and also tried courses of Azathioprine and Danazol. When I was hemolyzing and my hemoglobin was dropping, I needed to increase the Prednisone.

The Rituximab was well tolerated, but it did not help me – I still needed 15 or more of Prednisone. I did not tolerate the azathioprine at all. It made me nauseous. The danazol did a relatively good job of keeping me on 15mg or so of Prednisone, but the goal was to find something that would allow me to be on much lower or no Prednisone.

I also had available to me via my employer's (IBM's) health benefits plan a program called Best Doctors which facilitates patients getting second opinions. I wanted to go outside the NY hematology community to see what others thought in terms of my diagnosis and treatment. In April 2016, I saw a hematologist/oncologist at Dana Farber in Boston who after many tests did not come up with anything different than what I was told before in terms of my diagnosis.

I then became obsessed with doing research on AIHA. There is not much published, and my wife being a physician, had access to medical journals. I found out about some of the clinical trials that were starting up with all sorts of drugs to treat AIHA. I noticed that Dr. David Kuter at Mass General in Boston was the lead doctor on a couple of them.

I made an appointment to see Dr. Kuter in December 2017. He gave me (and my hematologist) the "state of the art" on the treatments available. The next time I had a deep crash of my hemoglobin, in June 2018, we tried one. Shots of Procrit. Those worked quickly and very well and my hemoglobin went as high as it had been since all this started in 2011.

I also started a diet program around this time and lost weight. I went from about 228 lbs. to about 168 lbs. in a few months. All that Prednisone and feeling sorry for myself made me gain weight (I was probably in the high 190s/low 200s before I got sick). I felt as good as I had felt in years. I was still on about 10 – 15 mg of Prednisone, though.

By the middle of 2019, I had another crash and it was time to see what else was out there. I connected with Dr. Irina Murackhovskaya at Einstein/Montefiore, who was doing some clinical trials for AIHA drugs. We decided to go for the Parsaclisib trial with Incyte Corporation. I had to get my hemoglobin below 10 to participate, and I needed a positive Coombs test, and we managed that closely.

In October 2019 I started the trial.

The first few months went well. My numbers all got better pretty quickly and I felt good. But by the first few months of 2020, the numbers started trending back to where they were prior to the trial. My Hgb was still pretty good and I still felt well overall however. It was as if the drug was only really keeping my Hgb steady while I seemed to be hemolyzing in the background.

I chose this trial because it was open and I would definitely get the drug (not a placebo).

Then COVID hit in early March 2020. I worked at home exclusively. Was venturing out rarely and always masked up/gloved up. Once the trial period ended, the drug company allowed me to continue with the drug. I had to go to Einstein every few weeks for various blood tests and then every few months I had other tests too. It was fine because there was no traffic and the hospital was mostly quiet.

By the summer, my Hgb started to go back down a bit, but was still pretty good. I started increasing my Prednisone dose again. By the Fall (October), Dr. Murakhovskaya told me that Incyte was no longer supporting me getting the drug because it really was not controlling my hemolysis markers. I stopped taking it about the middle to the end of November.

In early December 2020, I did not feel well. Went to urgent care. Did not have COVID and did not have strep throat. My legs felt like lead weights. Over the next few weeks, my Prednisone started dropping pretty quickly. By Christmas week, I was feeling as sick as I had felt in a long time. My Hgb dropped below 8. On 12/31/2020, I had a blood transfusion and I increased my Prednisone to 60mg per day (the same as the highest I ever had in the past). I was not seeing anyone in person due to COVID – only via Zoom. I could tell from the Zoom chats that I did not look well.

Right after the transfusion I felt 10x better. After a few days, I felt much better. We went to the NY Botanical Gardens to a nighttime event on a cold but dry evening. I remember feeling so much better to be outside. Remember during COVID we were inside most of the day. We got pizza from Sal's and brought it home as nothing was open. I started feeling myself again.

Beginning mid-January 2021, I went for weekly Procrit (Aranesp) shots at Einstein and my Hgb started improving. I was able to wean down the Prednisone over the next few months. Very slowly. I felt pretty good. Again, the roller coaster. At the end of February, I got my first COVID shot and 3 weeks later my second vaccine. I was tested a few different ways (spike protein test and a special T-cell test) and neither showed that I had built any immunity to COVID. I was still on a relatively high dose of Prednisone at the time.

During 2021, I felt well. Still working at home. Things started opening up. We started to get out more. That helped a lot. I continued to wean down the Prednisone and by the late Fall was on about 7.5 mg per day. My Hgb was pretty stable. My other hemolysis markers were better and stable too.

I had a COVID vaccine booster on 8/14/2021. Still no immunity (spike protein and T-cell tests).

We celebrated Sara's 30th birthday in October sitting outdoors at a restaurant in NYC. Liz and I went on an 8-day trip to Hawaii that was planned in February 2020 before COVID, around a speaking engagement she was going to do with AAP in Phoenix. The conference wound up being made all virtual, but we still went to Kauai. It was a fabulous trip and I felt pretty good. Was able to do everything, including some hiking and climbing (not very strenuous of course, but still had no problems).

I felt about as good as I had over the past 10 years. In October, I saw my urologist for an annual visit. He did the usual KUB and I had a not-small kidney stone in one of my kidneys. We previously discussed undergoing a Lithotripsy to remove it. It was there for a while and was not doing anything but getting it out when I felt well vs. waiting until it became a problem seemed like a good idea. By December, I hit the out-of-pocket max on my IBM benefits for the year, so doing the lithotripsy then made good financial sense.

Had the procedure 12/20/2021. I was feeling pretty good going into it. It turned out to be a "mistake" doing it. I had a couple of days of really bad pain from the procedure, but pain meds helped. That wore off after about 3 or 4 days. But, I probably picked up some virus at the facility – it was not COVID – and I started feeling really crappy pretty quickly. My Hgb again crashed to below 8. It was another Christmas week from hell. Two years in a row. I talked to Dr. Murakhovskaya and we increased my Prednisone back to 60mg.

After a couple of days, without needing a transfusion, my Hgb rebounded back to the 9s and after a couple of weeks back to the 10s. That was the first time I can recall such a quick ride on the roller coaster (usually they were over weeks/months in the past).

In early January 2022, AstraZeneca got approval for Evusheld as a pre-exposure monoclonal antibody for COVID. I had the two shots (simultaneous in both sides of the tush) in mid-January.

I started feeling myself much quicker than I recall. My Hgb level returned to about where it was before the lithotripsy by mid-to-late January. I had a 4th COVID vaccine on 2/18/2022. This time I got the Moderna shot (the first 3 were Pfizer). I got tested for COVID antibodies (spike protein), and lo and behold, I had immunity. Maybe it was the Evusheld and maybe it was the Moderna vaccine (maybe both).

I started feeling pretty well, so we started weaning down the Prednisone slowly again. In early March, my Hgb was 14.2 (the highest I can remember and "normal" range on some ranges). All my other hemolysis markers were as good as they had ever been. I had to undergo another round of primary Evusheld, as the CDC changed its recommendation on the dosage for the primary round.

I feel good now. I started back to work 3 days a week towards the end of March. Did a quick 3 weeks of Breakthrough M2 diet program and went from about 193 lbs. (198 lbs. after the pre-program fat frenzy weekend) to about 178 lbs. (15 lbs.) in 3 weeks. Things are starting to get back to post COVID normal. In April, my Hgb went back down to the low 13s, but still holding strong as are the other hemolysis markers. Fingers crossed that they will stay good. With Passover, I gained back about 5 lbs. but still feeling pretty good.

By the end of April 2022, back down to about 7.5/10 mg of Prednisone per day.