Dit artikel verscheen eerder op http://www.igansupport.org/articles/staniforthsuccessstory.html. De site is echter niet meer bereikbaar dus ik besloot de informatie in een pdf te delen

Jon Staniforth's IgAN Experience: A Success Story

by Jon Staniforth

I want to share my story of the journey I have experienced after being diagnosed with IgA Nephropathy in May, 1997.

A little personal information: I am 51 years old, 6 feet 2 inches tall, and 205 pounds. I have always enjoyed a life filled with athletics, exercise and overall excellent health. I have taken very few prescription medications in my lifetime and, frankly, I have not needed them. I have been a pilot my entire adult life. I entered the Air Force after being commissioned as a second lieutenant and shortly thereafter proceeded to pilot training. Upon completion of pilot training one year later, plus an additional 3 months of ancillary training, I entered the world of flying fighter aircraft, which I had the privilege of enjoying for 20 years. I have been a commercial airline pilot for the past 20 years as well. Thirteen of my 20 years of flying fighters were occupied flying the F-16C in the Air Force Reserves while I was also working for Delta Air Lines, where I am to this day. I retired from the Air Force Reserves in 2001.

In May, 1997, while living in Glendale, Arizona, I noticed there was blood in my urine. Virtually simultaneously, I experienced a 5 mm kidney stone. This kidney stone was a uric acid stone, which was blasted by lithotripsy, resulting in 3 fragments, all of which passed quickly and successfully. Post-operative instructions were to take Urocit K (a potassium-based compound to inhibit the formation of uric acid stones) for the rest of my life.

Some traces of hematuria persisted, which I thought was a consequence of the kidney stone episode. As the hematuria intensified, I became alarmed enough to see a urologist. The urologist suspected – and tested for -- bladder cancer via several cystoscopies. Thankfully, nothing was found to be abnormal. Other possibilities included an AVM or Arterio-venous Malformation, which was ruled out quickly as well. I was then referred to a nephrologist to evaluate if this was a kidney problem.

I went to a young and very bright nephrologist who went through the normal diagnostics and concluded that a kidney biopsy was in order. I was quickly scheduled for this outpatient procedure, which required little more than a topical anesthesia with a plunger-style oversized hypodermic needle to take a core sample of kidney tissue. I was awake during this and was given immediate feedback as the doctor showed me the results, which revealed perfect pink tissue all the way through, thus validating that I still had healthy operating kidneys. There was no evidence of scar tissue.

Feeling good about the results, I was then informed that the real identifier of one?s status is the protein count in the urine. A normal human has about 150 mg or less of protein at any given time in the urine. I had 600 mg. The doctor informed me that was not worrisome and that I would more than likely live to an old age unless the readings were to go acutely higher. I was to have my protein levels tested twice a year.

The odd thing about this disease was that I had gross (macroscopic) hematuria accompanied by blood casts when urinating, which was considered a ' best case' scenario. In my case there was no flank pain -- just a high protein count and gross hematuria. I had absolutely no pain, fatigue or other symptoms that commonly occur with IgA Nephropathy.

When I asked my nephrologists what could be done to cure this condition, he replied 'nothing'. There was no prescription drug or protocol to help this disease. The only treatment he suggested was to take Omega 3 fish oil gel caps to the tune of about 6 grams/day. So with this diagnosis I went off to live my life, still quite clueless about the whole matter. I did my semi-annual tests every six months.

Two years later, I moved to Atlanta, Georgia. I lived in Atlanta for 4 1/2 years and in that time my protein levels escalated to 900 mg, accompanied by the ever-present gross hematuria. In November, 2003, I had a work-related move with my family to Yorba Linda, California. In the 20 months I lived there, I was under the care of a good nephrologist, but my protein levels had risen to 1,300 mg and the hematuria maintained an unrelenting pace. In August, 2005, I moved back to Glendale, Arizona for family reasons. In February 2006, I went to see my new nephrologist after going for a urine test and full blood panel workup.

The nephrologist I saw (who is still my treating physician) is a very well-read and energetic physician with a real passion for medicine. He told me that my protein level had risen to 2,600 mg, with continued gross hematuria; he then informed me that he wanted see me again in three months, when I should 'be prepared to have a 'serious talk.'

The type A fighter pilot in me responded with "Let's cut to the chase and have our talk now!" The doctor began telling me about possible protocols should my protein level escalate above 3,000 mg. The first treatment involved being put on 100 mg of prednisone daily for four months to ?shock? my immune system. I was generally aware of the side effects of prednisone and this prospect did not sit well with me. I asked him what was next if that didn't work. The reply was to run me through a course of chemotherapy. When I asked what if that didn't work, he replied that the next course of treatment was dialysis indefinitely. A kidney transplant would be the final option. I already
knew there were 90,000 people in America awaiting transplants, a figure which the doctor said sounded about right.

I then asked the nephrologist if there were any natural treatments for IgAN, and he replied there were none known to man. He also gave me a script for 20 mg per day of lisinopril, a blood pressure medication [an ACE inhibitor]. The nephrologist aimed to reduce the pressure on my kidneys by reducing my blood pressure. I was to see him again in three months.

I left the doctor's office with the overriding fear that I might not see my kids graduate from high school (at the time my son was 11 and my daughter was 9). Above all, I recognized immediately the seriousness of my condition and the potentially drastic life-changing events that loomed over me. Not only would my kids be affected, but there was the impending reduction in my quality of life, a wonderful life filled with many enjoyable physical activities. Then came the normal family provider-based thoughts as to how was I going to support my family on long-term disability.

For the first time in my life I faced something I could not control ? a reality I never faced before.

Knowing that what I had was quite serious, yet not accepting the doctor's final word on treatment, I realized it was incumbent upon me to find other potentially palatable solutions. This began with an intensive Internet search about what this disease was. I visited chat rooms with other IgAN patients. I read certain websites and a number of JAMA [Journal of the American Medical Association] articles. I researched doctors prominent in this field and any other information I could find that might offer hope. All information pointed to the same few options my doctor presented to me. No relief in sight.

It was now one month before I was due to see the nephrologist again. I continued my research into IgAN, figuring that if nothing else I would go down trying. I Googled every conceivable combination of associated words about this disease, but nothing really promising surfaced. I was
sitting at my desk at midnight and decided to try one more attempt to Google the combination of words 'natural treatment IgA nephropathy.'

This time a website came up I had not seen before that listed my disease by name. I entered that website and read every word on it. The website was owned by two medical doctors who treated very serious life-threatening kidney diseases, including IgA Nephropathy, with natural treatments offered on the site. The next morning I called and spoke to a representative of the company who answered all of my questions and gave me a glimmer of hope. The representative suggested a combination of two of their products made from plants and herbs. I was instructed to grind up the tablets and caplets, put them in a cup, and add hot water, making a tea to be drunk three times per day. Simple enough. I ordered the products thinking that I had nothing to lose by trying.

Three weeks remained before I was to see my nephrologist for my three-month follow up. After five days of drinking this tea concoction, I noticed that the gross hematuria had disappeared and was no longer visible to the eye. This was promising -- and I was hopeful.

The three weeks passed. It was now May, 2006, and I had to return to the doctor and face the possibility that things might have become worse. A definite nervousness gripped me as I waited in the examining room. As the doctor entered, he sat down and got right to business: he started to read my chart, going through the tests. Potassium ? Fine; sodium ? fine; creatinine - fine. I interrupted him and asked "Doc, how about the protein?"

He answered that my protein levels were what really surprised him. All I was hoping for was a 200 - 300 mg decrease from my previous high of 2,600 mg. But the nephrologist told me my protein level was 182 mg! He immediately (and proudly) said, "See, I knew by doubling up on the lisinopril it would really help."

I then had to inform him that I?d never even filled his prescription for that blood pressure medication, much less taken any. After shooting me a look of 'how dare you!' he asked what had happened. I told him the story as recounted above. He immediately replied that there had been no clinical trials performed on my 'tea' and without a double-blind placebo-controlled study this was voodoo medicine with no science behind it.

I simply told him that he couldn't argue with the results in contrast to what he wanted to put me through. Drinking a tea 3 times a day in contrast to chemotherapy? That was a no-brainer to me. I also told the doctor if he had other patients with IgAN, he needed to get them on this treatment. He did tell me that he had about five other guys like me with IgAN. I gave him the website hoping he would at least do a little homework, but unfortunately that never transpired.

Leaving the doctor's office, I felt I had a new lease on life. The grim reaper's noose had been lifted from me, as far as I was concerned never to return. When I got to my car I immediately called the company I purchased the products from. "Obviously you have this disease figured out and my doctor doesn't -- so what was wrong with me?" I asked. The reply was simple but astounding. The representative from the company replied that I had stored toxins in the liver. The tea I was drinking was nothing more than a long-term but powerful liver and kidney cleanse. Once the toxins were purged, the liver came back to full and normal function and the immune system corrected itself, returning all systems to normal levels with healthy function. Imagine that, all without chemotherapy, drugs, or surgery! A simple tea did that.

I returned to my nephrologist in September, 2006 for another follow-up. The doctor got right to the charts again, and when I asked about my protein count, he replied it was 140 mg. I was now under the threshold for normal protein levels in the urine. I did not need to come back for another year.

At my follow-up one year later, the results read simply 'Normal' for all levels in the blood panel and urine tests. Now, feeling pretty confident about what was happening to my restored health, I asked the nephrologist about my protein intake. "You're fine," he replied: I could consume as much protein as I liked. This pleased me because I am still an avid weightlifter and regularly participate in other physically demanding activities.

I completed another regular workup in March, 2009, and all test results came back completely normal. I have been eating a diet with much higher protein levels as well.

It is important to note that after one year of three doses per day of this incredible tea I was able to drop back to one dose per day, which is where I am now. I have taken the tabs and caps for the last 2 years.

This has been an interesting journey for me; I feel incredibly fortunate to have found a cure for my IgA Nephropathy from a small organization that has treated life-threatening diseases with plants

and herbs for the last 28 years. No drugs or surgery was required for me to be restored to perfect health. My doctor told me that this was simply a temporary remission. I disagree. I feel terrible for those who are undergoing barbaric treatments for this disease when something so gentle, yet powerful, exists to cure its cause. That is the key ? to treat the root cause, not to throw drugs at some symptoms, thereby guaranteeing the development of additional compounded symptoms.
Through this journey my eyes have been opened to the health-restoring and life-sustaining power that resides in plants, herbs and spices. The more I read, the more encouraged I am for a robust and healthy life for all who would simply embrace the capabilities that await them.

Jon Staniforth, August 17, 2009

[Ed. Note: Jon wrote about his experience so that it could be shared with the IgA Nephropathy Support Network in hopes it might help others. The company with which he dealt, Goutwell/Fuma Natural, has a website: http://www.goutwell.com. Jon used their product Kidney Well II and a phyto-antioxidant (Red Ganoderma), both of which are part of their kit for treating glomerulonephritis. They also offer products designed to treat diabetic nephropathy, focal segmental glomerulosclerosis, lupus nephropathy, and transplantation rejection, as well as gout.

Kidney Well II contains a number of plants and fungi used in traditional Chinese medicine, including Alisma (water plantain; the root is used in TCM); Astragalus (an immune system booster), Poria cortex (a fungus), Dioscorea (a type of wild yam widely cultivated in Asia) and Rehmannia root (a medicinal herb). Detoxification is a major aspect of traditional Chinese medicine, which has thousands of years? experience behind it.

It is not the policy of the IgA Nephropathy Support Network to endorse particular therapies, but we do report on alternative treatments that patients have found beneficial ? and we rejoice in their success and regained health. If you are interested in trying Goutwell?s products, you should speak with a representative of the company, as Jon did, to tailor a program best suited to your needs.

Neither Jon Staniforth nor the IgA Nephropathy Support Network has anyfinancial or other interest in Goutwell/Fuma Natural.]