

# Brigham and Woman's Hospital – October 17, 2015

## Chronic Kidney Disease – A Patient's Perspective

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### Introduction

I wish to begin by thanking Dr. Li-Li Hsiao for the invitation to speak to you here today at the Boston Kidney Health Series about my experience as a patient with chronic kidney disease. Thanks also to her assistant Allison Wu who helped facilitate my participation.

I am grateful that Allison assured me that there are no psychiatrists here today. I am relieved because, to understand my method of dealing with CKD, you will need to know something about me and from a psychiatrist's perspective, there simply is not enough time.

I would also like to introduce to you my wife Elaine and our 14 year old daughter, Ilana. We adopted Ilana from the Republic of Latvia almost three years ago. It was the most rewarding thing my wife and I have ever done. We love nurturing her especially because she shares our interests in the arts. It took three years to find the right daughter and indeed we love her.

To qualify myself, I am a laymen to the medical profession. I stay informed but have limitations. Now I have become a "Poster Boy" for Chronic Kidney Disease. The last time I was a "Poster Boy" for anything, it was around 1968 when I was Chief of the Ceremonial Section and Bandmaster with the U. S. Coast Guard at a training center in Cape May, New Jersey.

It seemed that there was a U. S. Air Force Radar facility a few miles away. At Christmas time they were broadcasting over the local radio station that Santa's arrival was being monitored by their Air Force radar. Not to be wanting second place, U.S. Coast Guard Group Cape May decided that they were going to bring Santa ashore on the bow of a 95 foot patrol boat.

In planning this feat, they looked around for someone to play Santa. They decided that I wasn't doing anything important so I was commandeered for the "mission". For many children and adults I was the "Poster Boy" for Christmas festivities handing out candy with a mighty "Ho, Ho, and Ho".

I tell this story so you will understand that I like to play. My education is mostly in music and theatre. In that field, we lead and are most comfortable with the "random/abstract" aspects of our thought processes. In the arts, it is mostly "subjective vs. objective", "Illusion vs. reality" and the "willing suspension of disbelief" rather than: it's "either this or that".

Individuals in the field of medicine are most comfortable with a different mental process. It is and requires a “concrete/sequential” approach. Generally, doctors and health care professionals do not speak in metaphors, allegory, simile, and they certainly do not improvise by commandeering things for other than their intended purpose just for a special effect. In the theatre, a bath tub can be a boat and a stick of bamboo can be the Great Wall of China.

I was invited to tell my story about CKD. I cannot speak for others. However, as listeners you must understand that the arts are my playground and life. Of course I can function with a “concrete/sequential” mind set. I have to pay taxes and have run a business and earned degrees in administration as well as music and theatre. I would rather safe guard my proclivity for creativity while keeping great respect for the concrete investigative methods of medicine and those who practice it.

I am 74 years old and not saying I’m in my 75<sup>th</sup> year. When asked in what year I was born, I say proudly: “1941”. Then I usually add: “It was a banner year until December 7<sup>th</sup>.” Even otherwise intelligent looking adults will indicate that they have no idea what I’m talking about. They say: “What?” The fact that folks don’t have at least a sketch of what happened in the 100 years before they were born is a societal or global nuisance.

Contrarily, I have a very personal nuisance with which I deal. It is Chronic Kidney Disease. It is necessary to engage my least favorite “concrete/sequential” mindset in order to deal with it. For this, I have a three pronged response.

### Response: #1 Curiosity

Dorothy Parker, the lyricist, play write, play doctor and stellar author associated with the famous Algonquin Literary Circle in New York said: “The cure for boredom is curiosity and there is no cure for curiosity”. The great American composer, conductor and educator Leonard Bernstein had his fatal heart attack. When it came upon him said: “What was that?” Always curious.

When I was diagnosed with bladder cancer in October, 1989, I was 48 years old. I automatically engaged Curiosity. I probably contracted bladder cancer from having grown up in a loving household with the exception that everyone smoked, my mother, father and maternal grandparents were smokers. I never smoked myself but secondary cigarette smoke most probably was the cause of my ailment.

Let me explain my lifestyle in 1989. I was a full-time public school music teacher with many performances both instrumental and choral music. I was a member of the U.S. Coast Guard Reserve meeting one weekend a month, I had a church choir and music directed two Broadway shows annually with community theatre or school groups. I was also a single parent. In those days I would characterize myself as the guy at the carnival with too many balls in the air. (Now, I try to do as little as possible but still I am busy). Also, I owned a full-service retail music store.

After school hours, I was in my music store and I noticed a Rose Wine color in my urine as I completed voiding my bladder. I later learned that when blood appears in the urine for a man at the beginning of the stream, it could be prostate cancer. At the end of the stream it could be bladder cancer.

I had no primary care physician because the U. S. Coast guard gave me an annual physical. If I needed treatment for anything such as the flu or bronchitis, I went into a walk-in clinic. So, I walked in and told the physician I had a bad cold and was run down. I had probably taken too many aspirin because I ran out of Tylenol. My thought was that I had “scorched” something.

The doctor thought that I had a very good “random/abstract” theory and referred me to a local urologist, Dr. John Romano. He scheduled me for a scope procedure that would allow him to look into my bladder. He indicated that he may remove a polyp, or whatever. I could go home the same day or I might be in the hospital three days. He had me see a local cardiologist, Dr. Eric Johnson who became my primary care physician. He indicated I was fit for the procedure under anesthesia.

The result was that I had stage two bladder cancer. I learned more about urology than I wanted to know. A cancerous sack attached to the internal bladder skin will work its way through a layer of fiber and imbed itself growing into eventually three layers of bladder muscle. Clearly, I needed a major operation. I was told that if I did not have the recommended procedure, my cancer would metastasize to my brain and lungs, and soon.

I was directed to see Dr. Robert Krane at what was then Boston University Hospital. He was the professional who developed a procedure called an “incontinent urinary diversion”. Removing diseased bladders was not new. For around fifty years, they simply excised the bladder and hooked the ureters to the lower abdomen with a stoma. The patient used a urostomy bag to externally collect and void urine.

This new procedure involved hooking the ureters up to a section of excised intestine which would work as an internal pouch. This was attached to the lower right abdomen using the ileocecal valve located between the large and small intestine. This is supposed to make the intestine pouch water tight and one would bypass the valve from outside with a catheter to void urine.

I had the seven-and-one-half hour operation on the last day of November, 1989. There was a 21 day hospital internment and a stay at home recovery period until the middle of May when I returned to work. The procedure caused trauma to my kidneys because I came home from the hospital with stints coming out from my kidneys through a secondary temporary stoma to collect urine in a urostomy bag. This allowed the intestine pouch to heal and be ready to be activated as it was finally time to remove the stints from my kidneys.

I got used to my new challenge. I was instructed to catheterize to collect the urine every 4 – 6 hours. I was told that the 16” French Catheters need not be sterile. I simply washed them and kept one in my back pocket (plus extras in my vehicle). I changed them every few days. I found that I held a lot of urine in the new pouch. I could win the “pissing contest” if it did not cover distance, only volume. Draining it goes without feeling or pain. Maintenance also includes changing a wafer and urostomy pouch every three to five days even though most urine stays inside. It is a regimen which got more complex later.

Early on, there was interest in my experience among health care professionals who I might come across. It was a new procedure that most had only read about from text books. I was a curiosity. I was a bit of a

celebrity to take time to explain this new plumbing. Also, my wife had to get used to waiting for me when I would go to a public rest room. Usually it is the man who waits for the female. We deal with it.

## Response: #2 Acceptance

An ascent to realization and recognizing a condition is acceptance. For some, acceptance means giving up. I am not in that category. One should not be like the proverbial ostrich and keep one's head in the sand. There are folks who have a leg amputated because they do not follow strict dietary restrictions that are required of people with diabetes. There is no room for self-delusion.

My first hint of Kidney disease was around 2006. My primary care physician noted to me that my creatinine level was rising to around 1.4. Dr. Johnson focuses upon the health of one's heart and he is very supportive of and encouraging his patients to work with a specialist in other areas. I have always found him to be knowledgeable about concerns in areas other than his specialty. In this case, he told me to find a nephrologist or renal specialist. Immediately, I needed to function as a "concrete/sequential" because of my curiosity and acceptance.

I did not visit the old lady in the swamp for an Acidity Bag (a fowl smelling poultice around one's neck used as protection from evil spirits); I consulted no Horoscopes; I obtained no Voodoo Doll; and I did not use a Wigi board. I mention these rejected options because some of you want to be doctors and inevitably you will run into that kind of mind set with patients.

Instead I asked Dr. Ronald Anderson here at Brigham and Women's Hospital for a recommendation. He is now retired but at that time he was my wife's rheumatoid arthritis doctor. I had accompanied my wife to her visits with him and liked BWH. He suggested nephrologist Dr. Li-Li Hsiao and I secured an appointment.

I first saw her about nine years ago. We have two adorable toy French Poodles and had just acquired the first, the oldest. Pistache was only about a month old and I could not leave her home alone; so, I had her in a carry case. Of course, she needed some attention during my appointment and my tiny contraband was revealed! It must have been a first for Dr. Hsiao but now that our little Princess is nine years old, it helps me to identify my first meeting at the BWH Renal Department. For the record, Pistache's seven month younger brother, Aristide is the goofball. They are named after characters in a Cole Porter Broadway Musical **Can-Can** that Elaine and I directed back then. We are always playing.

Dr. Hsiao has been monitoring me three to four times annually. Particularly, she examines bacteria counts in my internal urine sack from samples. The fact that urine sits there in other than the usual environment leads to a colonization of parasitic bacteria. If a regular physician were to see my bacteria count, they would prescribe an antibiotic before I had symptoms. This happened a few times. The result was that the bacteria got resistant to the usual oral antibiotic taken in pill form. I am not to have an antibiotic unless I have symptoms beyond the urine count. There were extensive testing and consults with specialists (infectious disease doctors and urologists, etc.) As a result, I take vitamins and supplements recommended by Dr. Hsiao. I take a small dose daily of a blood pressure medication more to control the blood pressure in my kidneys than any heart concern. I also use a low dose of a

cholesterol drug. I have a prescription multi-vitamin that does not contain vitamin D. They say that those who take lots of vitamins and supplements have expensive urine. That is just fine with me.

### Response: #3 Diligence

Confucius said: "The expectations of life depend upon Diligence."

Therefore, I am diligent about my health. It takes discipline. We have a very sophisticated water purification system in our home. Regularly, I see lots of physicians. Thank God for my fine health care insurance, Tri-Care for Life for which I am eligible because I am a retired reserve officer of the U. S. Coast Guard.

I see an eye doctor regularly. Do you know they can detect early sign of diabetes from your retina? I see a skin doctor. We check moles for sign of cancer. I get my teeth cleaned every four months. I have a cousin 15 years younger than me waiting for a heart transplant because he did not take care of his teeth. I use the adjustments of a chiropractor when needed and I get a massage every ten days to two weeks. My cardiologist has taken numerous EKGs, heart ultrasounds and a recent nuclear stress test. I had a colonoscopy last summer. We eat healthy. We will very rarely drink an alcohol beverage. In short, I am grateful to be very healthy except for the nuisance of chronic kidney disease.

My kidney disease advanced rapidly in early 2010. Suddenly I had a blood infection that was caused by bacteria laced urine that backed up into my kidneys and entered by blood. Actually, there were four hospitalizations in three months. It was serious because the strain of infection required a rare antibiotic that had to be administered intravenously.

The experience was frightening. I was in my local hospital under the supervision of Dr. Johnson and two physicians who are infectious disease specialists. The result was four 5 – 6 day hospital stays. We were in constant communication with Dr. Hsiao. Visitors were required to wear robes, head gear and masks.

I felt better each time after two days but had to await discharge until the blood tests were cultured. Each of the four times I was sent home with a pic line to infuse myself with an intravenous medication. The prescription was for 10 days beyond what was infused in the hospital. This was for three times a day taking an hour where I self-administered an antibiotic drip. This happened four times in three months. Fortunately, I found **YouTube** while waiting during the infusions and tried to stay entertained.

The end result was that my creatinine count bounded up to the low and mid 2's. For the record, a creatinine level reaching 2.0 makes one uninsurable for long term health care. My count settled into 2.4 to around 2.6 which brought my disease officially to a critical stage.

I creatively reasoned that the problem was  $\frac{3}{4}$  of an inch away, just inside that connecting ileocecal valve. I remembered when first I was released from the hospital in 1989. I used to irrigate the pouch after the operation with the assistance of a visiting nurse. Why can't we simply do that? Urologist Dr. Romano and Dr. Hsiao were reluctant to infuse saline water at this stage due to the capacity of pouch, possible back-up into the kidneys and a possible introduction of more infection.

I remembered Dr. Robert Oates, now of the Boston Medical Center (formally Boston University Medical Center Hospital). As a young urologist, he attended my original operation. I posed the question to him about mechanically irrigating the artificial bladder much as was done to rinse our blood and mucus after

the operation while it was healing. He said: "We do that for patients with spina bifida." He suggested to be conservative and infuse less than half capacity once daily of saline solution with a syringe (1.25 ML). It's like rinsing your mouth. It was out of the question to use an antibiotic in this manner because of the resistance the bacteria would develop.

So, this daily irrigation became a regimen to cut down numbers in the bacteria colony. Recently, Dr. Hsiao has increased the irrigation to every twelve hours (or, to 2 times daily) 1.25 ML each time. This was because we noticed a lower protean count in a urine sample after irrigation. Ever since the four hospitalizations in 2010, I now use a brand new sterile catheter every time I syphon off urine. Instead of every 4 – 6 hours, it is now every two-and-one-half to four hours. It is a relatively simple protocol except it is time consuming and such a personal nuisance. The alternative is worse.

Think of it: every time I go on a vacation, I need a 2.5 ML bottle of saline solution for each day. I need my syringe to infuse the solution. I need wafers and urine bags for every three to five days and I need 7 – 8 catheters a day! I am fortunate that my health insurance pays for all this paraphernalia.

The average person loses one percent of kidney function annually. I lose around two percent a year. My present kidney function is at 24%. This sounds horrendous; however, Dr. Hsiao indicates that even a function of 7 % is not yet sick enough for a transplant. My current situation translates to 10 to 12 good years remaining, barring infections. Kidney disease is symptom free as it approaches. This is extremely dangerous for those who are not curious, accepting and diligent.

## The Coda

In the performing arts, Aristotle identified that everything should have a beginning, a middle, and an end. In musical works, the ending is commonly called the coda. In closing, I defer to Yogi Berra the famed New York Yankees catcher and manager who was known for brilliant and whimsical quotes. He said: "The future ain't what it used to be."

When and if the time comes for me to have a kidney transplant, perhaps there will be artificial kidneys available (or, one can be conjured up by a 3-D computer printer – whatever that is – I was born too soon to understand). Then there is the possibility of a genetically altered pig's kidney that could be transferable.

I have a 91 year old uncle who had a pig's valve placed in his heart when he was 70. Earlier this year it leaked. He came here to Brigham and Woman's Hospital where cardiologists went up an artery in his groin and installed a new valve which they inflated inside the pig valve. That was on a Monday. My wife visited him on Tuesday and he was walking! That was not a conceivable "future" when he was younger.

Back to the big picture. Let's go to the year 2075 when our daughter Ilana will be 74 (or, she may say she is in her 75<sup>th</sup> year). She will be what my age is now. When asked her year of birth, she will say: "2001, a banner year until September eleventh." Hopefully the culture will not have forgotten its history to its own detriment and folks won't say: "What?"

Hopefully by then, there will be no more kidney disease. In the meantime we have curiosity, acceptance and diligence to get us through whether we are "random/abstract" or "concrete/sequential". I regret that I cannot stay to meet and speak with any of you personally. We have a wedding to attend. Allison has my email if you need any clarification. Thank You for this opportunity to speak with you about my chronic kidney disease.

