

## Chapter 21: The Kidney Connection

One of the things that Ann and I love to do is travel. We have traveled all around the world during the last 30 years, always trying to learn as much as possible about our destination on every trip. We are not the type of people to sail around on large cruise ships and eat 24 hours a day. We are more active physically and, in a constant search for new information, love to learn.

Ann found that the Stanford University Travel Service offered an excursion to Patagonia which looked interesting. Patagonia would be a new destination for us. We had taken

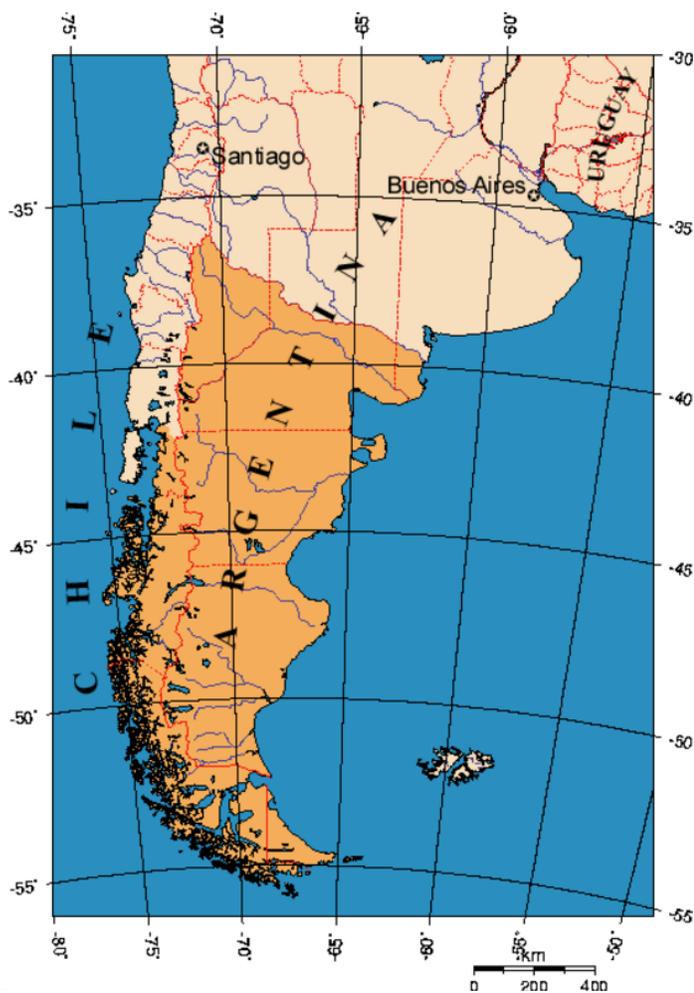
several previous trips with the Stanford Travel organization, and found them to be perfect for our style of travel. They selected interesting places, provided excellent teachers and guides, utilized wonderful hotels in exquisite locations, and handled all of the normally aggravating travel necessities, such as handling suitcases and transportation. So in February 2014, we flew from Los Angeles to Buenos Aires, Argentina where the trip would begin.

Normally, our travel plans are to arrive at our initial destination a few days early. This allows us to recover from jet-lag since it affects Ann greatly. While we were in Buenos Aires, we had an opportunity to meet our old and dear friend, Dr. Bill Laich. Bill and his girlfriend graciously spent time taking us around the city, and helped us sample a variety of the delicious foods. When the time came to leave to Patagonia, we said farewell, with promises to meet again soon.

Patagonia is a sparsely populated region located at the southern end of South America shared by Argentina and Chile. The region comprises the southern section of the Andes mountains as well as the deserts, steppes, and grasslands east of this southern portion of the Andes. Patagonia has two coasts; a western one towards the Pacific Ocean and an eastern one towards the Atlantic Ocean.

From Buenos Aires, we flew to Ushuaia, Argentina. In Ushuaia, we boarded our cruise ship, the “Stella Australis,” which took us, through the Beagle Channel, to Punta Arenas, Chile. The Beagle Channel is named after the ship that carried Charles Darwin on his voyage of discovery from 1831 to 1836. We witnessed some incredible scenery, including Cape Horn, the southernmost tip of South America. We sailed through the Magdalena Channel into the amazing De Agostini Sound, located in the heart of the Darwin Mountain Range, where we went ashore to have a close-up view of the Águila Glacier.

We landed on another island, uninhabited by humans, but home to a colony of adorable Magellanic penguins. We were able to walk on the path, as long as we respected the cross traffic of penguins going to and from the water and their nests. It was extremely cold, at least, for the humans.





*Aguila Glacier, Chile, February 2014*  
<http://arielnet.com/ref/go/1294>



*With Myron at one of the local restaurants*  
<http://arielnet.com/ref/go/2784>



However, the penguins paid little attention to the frozen people watching them as they went about their daily business. They were really cute and it was fun to watch them in their natural environment.

We continued our journey by boat and bus until arriving at our destination in the Torres del Paine National Park. In front of our hotel was a large lake and, in the distance, some beautiful mountains. The spectacular beauty of the location was enhanced by the reflection of the mountains and the sky in the lake. This beautiful tableau evolved as the sun's position changed, yielding new images of the Paine Massif, continuously changing color as the sun traveled across the sky.

Our program spanned three days in the national park, and included numerous hikes, horseback rides, and long walks. Ann and I selected relatively tame activities consisting of walks along the lakes or moderate hiking opportunities. On one of the excursions, which turned out to be longer than we had anticipated, I experienced more difficulty than usual while walking up the hill. My heart was pounding, I was out of breath, and I felt that this was really too difficult for me.

Later in the evening, I was describing my experiences to one of our new friends, Dr. Myron Shapiro. Dr. Shapiro and I had become "trip buddies" since I had difficulty going uphill and he had a problem going downhill. We frequently would sit together while Ann and Myron's wife, Susan, continued the hike. The women would pick us up on the return trip. Dr. Shapiro asked if I had a cardiologist who managed the atrial fibrillation which I had experienced for thirty years. I told him that I did not and he suggested that I visited his cardiologist when we returned to California. Since Myron practiced in Los Angeles, California, he was acquainted with many of the best physicians in various specialties. I agreed that this was a good idea and would contact him after we returned home.

We continued the trip through Patagonia, enjoying the beauty with less vigorous excursions. One excursion was a boat trip around the lake in front of our hotel and another was a walk along the side of a lake.

After we had returned to California, I contacted the cardiologist recommended by Myron. Myron's doctor, Dr. Satinder Bhatia, practiced in a large medical building in Beverly Hills, California with many wealthy and famous people among his clientele. I had an all-day appointment during which Dr. Bhatia administered a series of cardiovascular stress tests. The test results demonstrated that I had excellent cardiovascular performance except for my on-going atrial fibrillation which had been a factor for more than thirty years. Dr. Bhatia discussed the results with me and indicated that I was in good health for a man my age with no cardiac deficiencies. Ann and I returned to Coto feeling relieved with these results.

A few days passed and, as usual, I went to the gym to exercise. While I was running on the treadmill, the phone rang and, since it was Ann, I answered: "Yes, my darling, what is going on?" She responded that Dr. Bhatia had just called and insisted that I had to begin dialysis immediately since my blood creatinine level was 5.6 mg/dL!

Both Ann and I were shocked, surprised, confused, and relatively ignorant about what a blood creatinine level is, and what this value meant to my health. I experienced no difficulties running on the treadmill or with any of my other exercises. If Dr. Myron Shapiro had not suggested going to a cardiologist, I would not have thought to visit any doctor. However, my blood work at Dr. Bhatia office showed a high level of creatinine which indicated kidney failure.

I immediately began to research creatinine and its relationship to kidney function. Creatinine is a chemical waste product in the blood that passes through the kidneys to be filtered and eliminated in urine. The chemical waste is a by-product of normal muscle function. The more muscle mass a person has, the more creatinine they produce. Levels of creatinine in the blood reflect both the amount of muscle a person has and their amount of kidney function.

Most men with normal kidney function have approximately 0.6 to 1.2 milligrams/deciliters (mg/dL) of creatinine. Most women with normal kidney function have between 0.5 to 1.1 mg/dL of creatinine. Women usually have lower creatinine levels than men because women, on average, have less muscle mass than men. Other factors that may affect the level of creatinine in the blood include body size, activity level, and medications.

When there is kidney damage or kidney disease, and the kidneys are not able to filter waste efficiently, there will likely be a rise in creatinine levels in the blood. Dialysis is needed whenever kidney function is too low to maintain health. Some people with no symptoms of illness at all, only discover that they have advanced kidney disease when high creatinine levels are detected in routine blood tests. When signs of too little kidney function do arise, they may include loss of appetite, vomiting, itching, weakness and flu-like symptoms. Swelling in the legs and shortness of breath may occur if water builds up in the body.

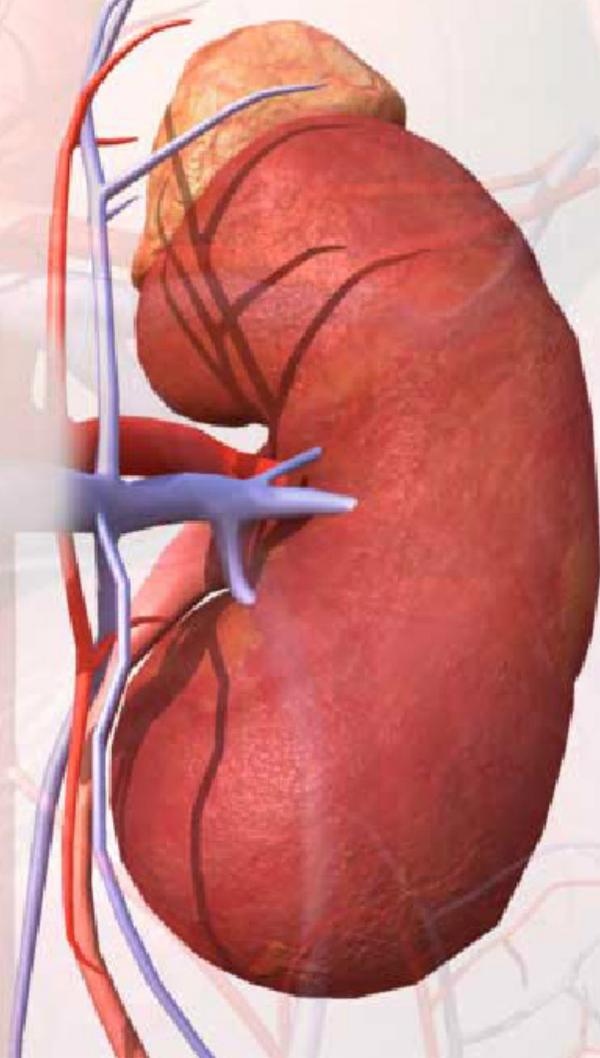
Serum creatinine can be tested in both the blood and in the urine. These tests can help evaluate kidney function. Knowing your serum creatinine allows your doctor to calculate your creatinine level along with your age, gender, and race, to determine your glomerular filtration rate (GFR). GFR is a measure of kidney function. If you know the serum creatinine level, you can determine the stage of Chronic Kidney Disease or CKD.

When I was on the exchange program from Israel in 1963, I was sent to Colorado State University (CSU) in Fort Collins, CO, to work with the track coach there. While I was at CSU, I asked the coach if I could enroll in the anatomy-physiology course being taught in the medical school at that time. He agreed and arranged with the instructor to allow me to attend. I remember that we covered only two organs during the first quarter: the heart and the kidney. At that time, the class concentrated on the details of those organs extensively. Now, in 2014, I began an intensive study on the operation of the kidney from a personal and imperatively necessary point of view.

The kidneys are two bean-shaped organs that extract waste from the blood, balance body fluids, form urine, and aid in other important functions of the body. They reside against the back muscles in the upper abdominal cavity. They sit opposite each other on either side of the spine. The right kidney sits a little bit lower than the left to accommodate the liver.

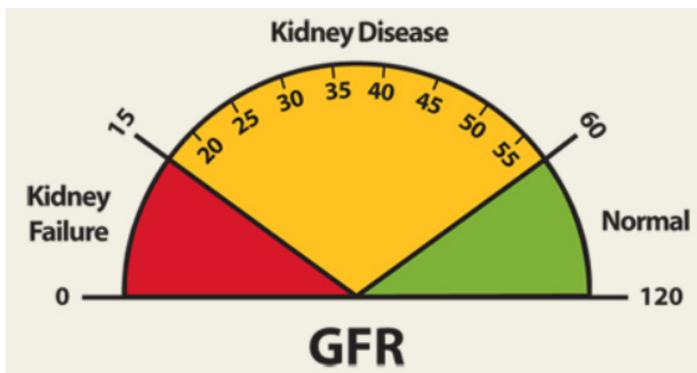
When it comes to components of the urinary system, the kidneys are multi-functional powerhouses of activity. Some of the core actions of the kidneys include:

- **Waste excretion:** There are many things the body does not want. The kidneys filter out toxins, excess salts, and urea, which is a nitrogen-based waste created by cell metabolism. Urea is synthesized in the liver and transported through the blood to the kidneys for removal.
- **Water level balancing:** As the kidneys are key in the chemical breakdown of urine, they react to changes in the body's water level throughout the day. As water intake decreases, the kidneys adjust accordingly and leave water in the body instead of helping excrete it.
- **Blood pressure regulation:** The kidneys need constant pressure to filter the blood. When it drops too low, the kidneys increase the pressure. One way is by producing a blood vessel-constricting protein, angiotensin, that also signals the body to retain sodium and water. Both the constriction and retention help restore normal blood pressure.
- **Red blood cell regulation:** When the kidneys do not get enough oxygen, they send out a distress call in the form of erythropoietin which is a hormone that stimulates the bone marrow to produce more oxygen-carrying red blood cells.
- **Acid regulation:** As cells metabolize, they produce acids. Foods can either increase the acid in the body or neutralize it. If the body is to function properly, it

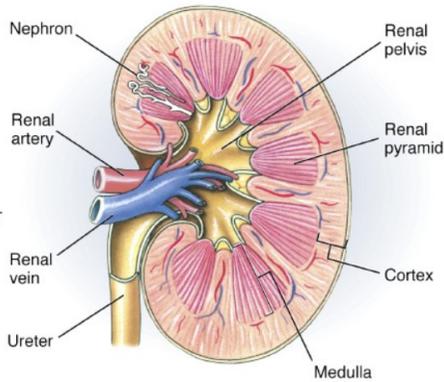


In addition to an elevated creatinine level, my GFR was nearly 12. Imagine what a shock it was for me to be told that I had a terrible disease. I rarely drank alcohol other than an occasional glass of wine or beer, had never smoked, had been exercising since I was about 11 years old, and my diet was focused on eating healthy, organic, low-fat foods. I had lived my life focusing on healthy activities so I was completely dumbfounded how this could have happened to me.

*GFR levels calculated from the creatinine level*



- Structure/Function**
- 1% of body mass
  - 25% of cardiac output
  - Passes total blood volume every 4-5 minutes
  - Filters 180 l per day and reabsorbs 178.5 l of it
  - Produces 1.5 l of acidic (pH=6) urine per day
  - 5% increase in filtration would generate 9 l urine per day!
  - Regulation of kidney ensures that this does not happen.

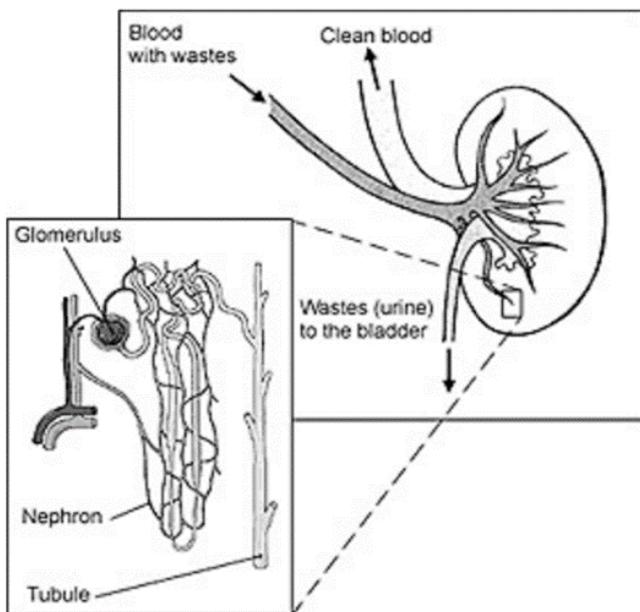


needs to keep a healthy balance of these chemicals. The kidneys do that, too.

Most people are born with two kidneys, but many people live with just one. Because of this ability to live with only one kidney, kidney transplant surgeries with live donors are a common medical procedure today. Because of all of the vital functions which the kidneys perform and the toxins they encounter, however, the kidneys are susceptible to various problems.

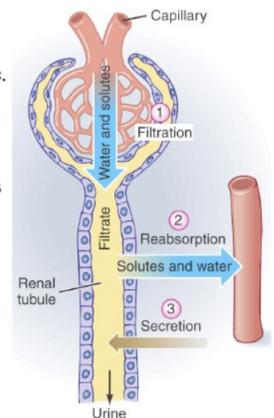
The kidneys are remarkably complex in their structure and functions. The actual filtering occurs in tiny units inside the kidneys called nephrons. Every kidney has about a million nephrons. Within the nephron, tiny blood vessels called capillaries intertwine with tiny urine-carrying tubes called tubules. A complicated chemical exchange takes place, as

*In the nephron (left), tiny blood vessels intertwine with urine-collecting tubes. Each kidney contains about 1 million nephrons.*



## Functional Overview

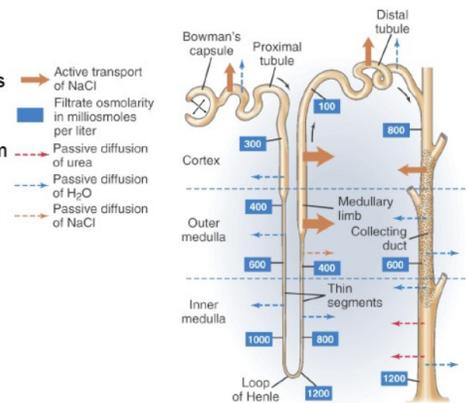
- **Contents:**
  - Water + urea, NaCl, KCL, phosphates, etc.
  - Color and odor product of diet, e.g., asparagus
- **Process:**
  - Filter everything out (and take back what is worth keeping)
  - Reabsorption of water and salts
  - Secretion of additional unwanted substances



## Nephron functional overview

### Nephron Functional Overview

- Most water and minerals taken out of the filtrate
- Each region of tubule has different function
- "Renal clearance"
  - Amount of plasma from which a substance is completely removed from the body [ml/min]
  - Function of filtration, reabsorption, and secretion



waste materials and water leave your blood and enter your urinary system.

Initially, the tubules receive a combination of waste materials and chemicals that the body can still use. The kidneys measure out chemicals like sodium, phosphorus, and potassium and release them into the blood to return to the body. In this way, the kidneys regulate the body's level of these substances. The right balance is necessary for life, but excess levels can be harmful.

In addition to removing wastes, the kidneys release three important hormones:

- Erythropoietin (EPOU): which stimulates the bones to make red blood cells.
- Renin: which regulates blood pressure.
- The active form of vitamin D which helps maintain calcium for bones and for normal chemical balance in the body.

After receiving the unfortunate news from Dr. Bhatia, I contacted my primary care physician, Dr. Fernandez, for an appointment. During my visit with Dr. Fernandez, he felt that this aspect of my health care would be best addressed by a nephrologist and recommended Dr. Nathaniel Ho. I quickly made an appointment to see him.

Dr. Ho was experienced in treating kidney disease and is board certified in Nephrology and Internal medicine. He specializes in all aspects of nephrology, with special interest in treating resistant hypertension and kidney stones. Ann and I arrived for our appointment with all of the results from Dr. Bhatia's stress test and lab results.

We reviewed the findings and compared them to my previous creatinine results for the previous ten years which Ann had gathered from our files. This year, 2014, my level was 5.5. In February 2013, it had been 3.2. Dr. Ho's opinion was that, at my age and with no known reason for my kidney failure, I would most likely need to begin dialysis in the very near future.

Ann asked which would be better: a kidney transplant or dialysis. As a kidney donor to his brother with end-stage kidney failure, Dr. Ho had personal experience with the transplantation process. His immediate response was that a kidney transplant was far superior to dialysis, however, I would have to be realistic about realizing this goal because of my age. He suggested that we proceed along two paths simultaneously. He recommended that we go to the University of California San Diego (UCSD) for the transplantation route since the waiting time for a cadaver kidney is shorter than in the Los Angeles area. At the same time, we should quickly prepare for dialysis when the creatinine levels warranted it.

Ann and I examined in detail which steps are necessary in obtaining a kidney transplant. We learned that kidney transplantation is the treatment of choice for people with kidney failure. This allows patients to stop dialysis, return their fluid and diet restrictions to normal levels, and enjoy a better quality of life. At this point in time, we were pursuing the transplant route, but there might come the time when I would have to begin dialysis.

The first thing that the potential kidney recipient must do is find a hospital that provides this specific type of surgery and then they must successfully complete a series of tests. To qualify for placement on the kidney transplant waiting list, a potential recipient must be relatively healthy and not have cancer, infections, or other diseases.

If the medical evaluation shows that you are a good candidate for a transplant, but you do not have a family member or friend who can donate a kidney, then you will be put on the transplant program's waiting list to receive a kidney from a deceased donor. Everyone on a regional list also is on

a national list kept by the United Network for Organ Sharing (UNOS). This means that when your nephrologist places you on his/her transplant center's list, you also are placed on the national list kept by UNOS. When a kidney becomes available in any area, information is sent to UNOS and a list is generated of individuals who potentially would be recipients for that kidney. If the kidney is a perfect match for someone on the national list, it will be offered to that person no matter where they are located. Those who are on the list are waiting for a non-living donor kidney to become available from a transplant center. According to the National Kidney Foundation, it is difficult to predict how long a person will be on the waiting list, but, on average, waits of two years or more are not uncommon. However, the wait can be longer for older patients.

There are two sources for kidney transplants. One is from a living donor and the other is from a non-living donor (also known as a cadaver donor). Patients who have had kidneys donated from living donors usually enjoy higher success rates than those who receive organs from non-living donors since there is less chance of rejection.

How long an individual has to wait depends on many factors, but is primarily determined by the degree of matching between you and the donor. Some people wait several years for a good match, while others are matched within a few months. The average waiting time for a kidney is three to five years, depending on blood type. However, older individuals frequently fall outside of these time boundaries.

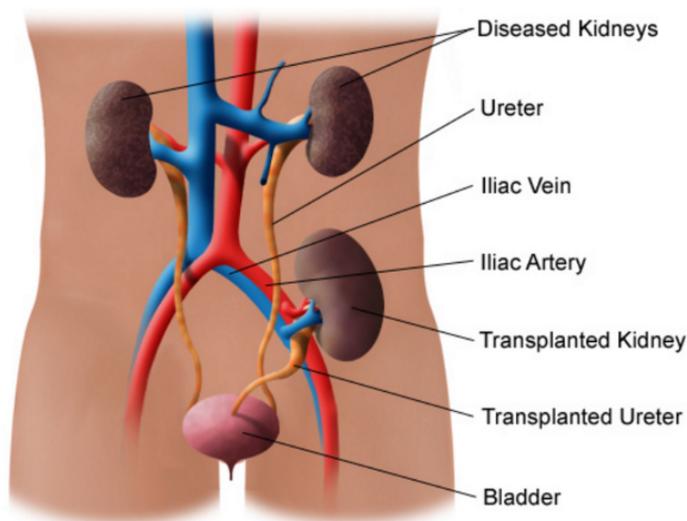
Suitability is initially based primarily on two factors:

1. Blood type: The recipient's blood type (A, B, AB, or O) must be compatible with the donor's blood type.
2. HLA factors: HLA stands for "human leukocyte antigen", a genetic marker located on the surface of your white blood cells. You inherit a set of three antigens from your mother and three from your father. A higher number of matching antigens increases the chance that your kidney will last for a long time.

If you are selected on the basis of the first two factors, a third is evaluated:

3. Antibodies: Your immune system may produce antibodies that act specifically against something in the donor's tissues. To see whether this is the case, a small sample of your blood will be mixed with a small sample of the donor's blood in a tube. If no reaction occurs, you should be able to accept the kidney. Your transplant team might use the term negative cross-match to describe this lack of reaction.

When a person receives a kidney transplant, the donor kidney will be placed in the lower abdomen. The kidney's blood vessels will then be connected to the recipient's iliac



*Transplanted kidney*

artery and vein. The surgeons will then connect the ureter to the bladder. The old kidneys remain intact and are not removed. One reason that the old kidneys are left is that they reside in a well-protected area of the body and there are also structures around it, for example, the adrenal glands, that can be damaged during surgery. Transplanted kidneys are placed in the iliac fossa (in the pelvic area) and attached to a different set of blood vessels. Because of these two reasons, unless the original kidney actively poses a danger to the patient (for instance, if it has a tumor in it), it creates an unnecessary additional risk to the patient to remove them.

After the appointment with Dr. Ho and his recommendation that a transplant would be better than dialysis, Ann contacted the UCSD kidney transplantation center and scheduled our first meeting in June which consisted of an introductory class for interested recipients. We attended the class and were given a long list of tests and procedures that would have to be completed at UCSD prior to any transplant. Following the lecture was a question and answer session, so Ann asked whether there was an age limit. The emphatic answer was “no”.

The UCSD transplant tests included X-rays, blood and tissue typing, urine tests, CT scans, ultrasound scans, electrocardiograms, echo-cardiograms, as well as a nutritional evaluation, and psychosocial and psychological testing. In addition, there were tests to be performed outside of the hospital such as colonoscopy, urological testing, dental clearance, and so on. It was a long list, but we were undaunted since the alternative was far less attractive.

Once again, Ann’s focus on details and task completion was apparent. We began a series of doctor appointments, lab

tests, and diagnostic procedures as well numerous trips to UCSD for their in-house tests. Finally, all the required tests had been performed and we anxiously awaited the committee’s decision whether or not to place me on the transplantation list. It was November by now, and we had been dealing with my problem of renal failure and struggling to solve it. Our nurse coordinator, Dave, was very optimistic since my overall health was quite good, I was continuing to exercise and eat well, and all of my test results looked good. The UCSD cardiologist and surgeon had been very positive with regard to my potential success with a transplant.

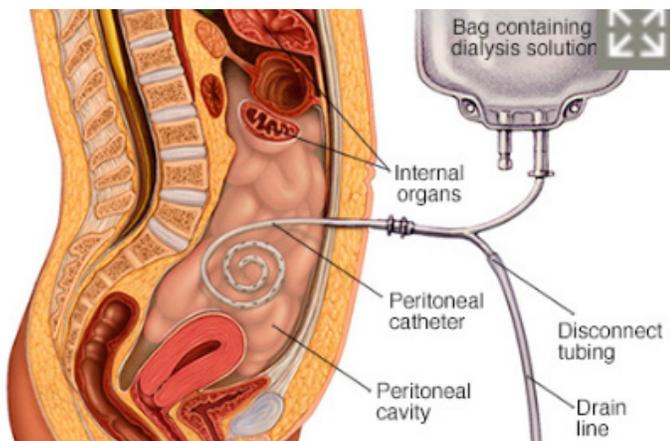
Unfortunately, during this lengthy testing period at UCSD, my kidney function continued to deteriorate. Dr. Ho said that I had reached a level which necessitated dialysis. He told me that there are two types of dialysis: peritoneal dialysis and hemodialysis. In both cases, the purpose is to remove the waste products which are accumulated by being alive and which are normally filtered by the kidneys. When the kidneys are unable to do the job or can only remove some of the waste, dialysis provides an external means to assist or replace the cleansing process.

Peritoneal dialysis (PD) is one way to remove these waste products from the blood when your kidneys can no longer do the job adequately. A cleansing fluid flows through a tube (catheter) into a part of your abdomen, and filters waste products from your blood. After a prescribed period of time, the fluid with filtered waste products flows out of your abdomen and is discarded. A schematic diagram of the procedure is shown on page 550:

Peritoneal dialysis provides a treatment that can be performed at home, at work, or while traveling, and, therefore, can offer greater freedom or mobility than hemodialysis. The process can be done manually by changing the bags or with a machine.

One company, Baxter, makes a machine that automatically circulates the fluids through your body while you are sleeping. This “cycler machine” provides a form of continuous therapy where the solution fills the abdominal cavity, resides there for a prescribed period of time, and is automatically drained. These repeated cycles are performed by the machine while the patient sleeps. Patients have fluid in their peritoneal cavity at all times during the therapy while the patient is attached to the cycler. After the final drain period, some fluid is left in the peritoneal cavity.

The machine is programmed to control how much fluid goes in and out and how often this happens. Initially, the patient prepares him or herself and the machine with lines. These are connected to about 10-15 liters of fluid, usually in 5 or 6 liter bags. The end of the line from the machine is connected to the catheter at bed-time and remains connected all night, averaging 8 hours. The fluid that comes out is collected



*Peritoneal dialysis (PD)*



*The Baxter machine*

in a large drain bag which is disposed of when the patient is disconnected from the machine.

The machine's program controls the fluid movement. It uses a series of clamps and pumps to control when the fluid should be drained out and when to put in new fluid. The machine is programmed for each individual since everyone needs different amounts of dialysis. A picture of the machine without the fluids or fluid lines is shown above.

The idea of peritoneal dialysis seemed like a good choice for me. I could use it at night while I was sleeping and, if we wanted or needed to travel out of town, we could take the equipment with us. Both dialysis choices require surgical intervention. Peritoneal dialysis requires the insertion of a catheter into the abdomen. There is a short waiting period for the surgical site to heal and then dialysis can be started.

I began peritoneal dialysis in September of 2014, and right from the beginning it proved to be a hellacious experience! Ann and I spent at least an hour before bedtime, heating the fluid, cleaning the area, the machine, and me with disinfectants. Then there was a complicated procedure of connecting the tubes and starting the cyclor machine. This portion of the process was the easy part. Hell began when the draining and refilling segments came. I was never able to drain correctly and the machine would set off loud alarms alerting me to correct the situation. I would stand or sit and even tried lying on the floor with my feet up on the bed to drain the fluid. Eventually, I would be able to remove enough fluid to proceed to the next cycle. Unfortunately, this interruption occurred on nearly every cycle all night long. I sometimes was able to sleep for an hour during the time that the fluid resided in my abdomen. But I never slept through the night and could only sleep in the morning after we disconnected the machine. I was always exhausted since I was un-

able to sleep. The fatigue increased as time passed, and every day felt like another day of dragging through life.

The days and months had slowly passed since we had first gone to UCSD seeking a transplant. I continued to fulfill the requirements which UCSD told me that I would have to complete successfully, prior to any transplant. I had a colonoscopy as well as the "green light" laser surgery for prostate reduction. These were normally simple procedures but were made more difficult since I had to undergo the procedures as well as performing my peritoneal dialysis at night. However, they had to be done, and we were quite hopeful that UCSD would place me on the list soon.

In early November, my nurse coordinator at UCSD called to tell us that on the following Thursday, my case was to be presented to the committee to make the determination. He was cautiously optimistic because I was in such good health, but my age could be a factor. Dave assured us that we would know within 10 minutes of the decision. Needless to say, we were both quite anxious and afraid to be optimistic, but we were hopeful since my health was good overall.

Rejected! That was the committee's decision. Imagine the crushing devastation when Dave called to tell us the bad news. He had been in the committee meeting and reported that my rejection was based solely on my age. Dave was equally upset and recommended another hospital in the area where he felt we would find success. He promised to send them my records and would provide us with contact information there.

Ann and I were devastated by this news. Why had they wasted six months of my life? They knew my age in June, why had they not told us then? To date, we have never received an answer to this question.

I continued my daily regimen of waking, breakfast, exercise, and dinner. It sounds less bad than it actually was for

me. I was unable to sleep well at night since the cyclor machine was noisy and set off alarms about every two hours. So in the morning, I would disconnect from the machine and try to sleep at least for a few hours.

Eating was also difficult, since some of the liquid is left in the abdomen even when disconnected. This creates the sensation that you are full, so meal times were less than enjoyable. After only a few bites of food, the sensation is that there is no more room in the stomach. In addition, dialysis patients have very strict nutritional guidelines. You must consume 80 to 100 grams of protein every day, limit potassium and phosphorous, and beware of the salt and sugar amounts in food. This meant that every meal was filled with protein sources in order to attain the daily requirement. Liquids had to be restricted. The dialysis diet is the opposite of a normal diet which reduces protein amounts and increases the quantity of water.

In addition, the liquid in the abdomen not only gave the constant sensation of fullness, but it interfered with other activities. It was impossible to do abdominal exercises. Meal times became a chore rather than a joy. Dinner had to be consumed early in the evening so that there was time for the digestive system to process the food and, hopefully, eliminate some of it. Otherwise, the dialysis was even more restricted since the abdomen was full of waste and had less room for the liquid. I felt truly miserable.

We continued to hope for a kidney transplant. We contacted a second hospital in San Diego which was the one that our nurse coordinator at UCSD had recommended. We waited a month to participate in the mandatory class and when we arrived, were told that it had been canceled. They apologized for not telling us, but it was too late to save us the two-hour drive. They scheduled a meeting with their nephrologist for the following week and, after that appointment, we did not hear from them for three months. It was terribly frustrating to feel so physically miserable with dialysis in addition to having little hope for improvement in the future. It was definitely a low point for both of us. But we aren't quitters, so we continued to face each day as it came.

Despite the difficulties associated with PD, I continued to exercise every day at the gym as well as going to the beach in Newport Beach to walk bare-footed in the sand. Walking in the sand is a wonderful exercise for the feet and legs and demands more energy than walking on a sidewalk. I had loved walking bare-footed in the sand since my boyhood days in Tel Aviv. Now, at the age of 75, it remained an enjoyable exercise, and both Ann and I love the ocean.

One day in early December, we went to the beach to enjoy the ocean and walk in the sand. The beach where we normally walked was near a large "stream" which flowed directly into the Pacific Ocean. It was normally a small stream

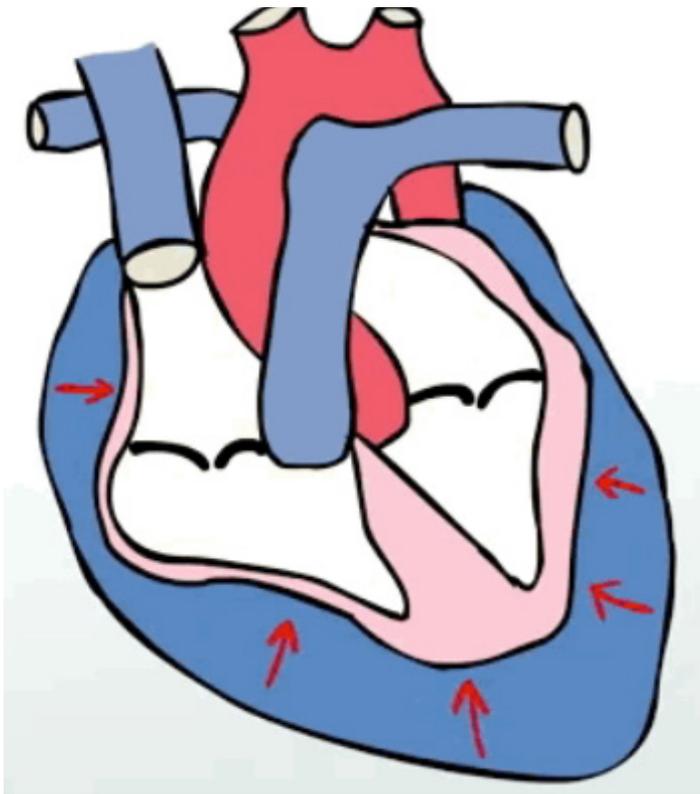
that ran into the ocean and increased or decreased in volume, depending on the amount of rain running off from the land. That day was overcast following several days of rain. A huge storm had dumped so much rain that the stream was flowing vigorously. Surfers and people who live at the beach are told not to go into the water for 3 to 5 days following a rain storm. Since we lived farther inland, we were unaware of this cautionary warning. Unfortunately for me, since I was the one who walked with bare feet, I was unaware that the water was full of materials that had not been processed by any water treatment facility. All types of things are washed off during rain storms, which flow into streams and, eventually, into the ocean. Agricultural fertilizers and sprays, garage oils and solvents, things people dump in drains are just a few of the terrible poisons that flowed into the ocean where we were walking. I was walking barefoot in the sand, oblivious that the water splashing over my feet and up to my knees was filled with filth and pollutants.

The next day I felt pain in my feet and calf muscles that developed to the point where I could hardly stand or walk. I did not want to go to the doctor since I assumed that this problem would pass. I was partially correct about the pain in my feet and legs subsiding, but the pain then moved up higher in my body. I also had some nasal congestion so I thought perhaps it was the flu.

I went to the doctor who shrugged his shoulders and said it seemed to be some kind of virus. They swabbed my throat and did a blood test which turned out to be negative for bacterial infection. In the end, they sent me home, and told me to wait for the "virus" to pass. This "virus" lasted for two months with varying symptoms. I felt terrible, and I probably looked as bad as I felt. At home I could hardly walk. My three daughters visited me for a week after the New Year began in January, but I could hardly keep my eyes open or move around. At least they were old enough to drive to the bagel shop and enjoy Disneyland without me!

The pain progressed through my body with a variety of symptoms which seem to vary as they moved from one body part to another. Ann had to wash me, coax me to eat, and help me to go from the main room in the house to the bedroom to lie down. I was sure that I was going to die soon.

A few weeks later, I felt pressure over my heart. Ann and I decided that we should go to the hospital to determine what was wrong and, perhaps, find something to cure me. When we arrived at the hospital, they checked my heart rate and blood pressure which turned out to be elevated. They could not identify the cause, and attributed my symptoms, again, to a viral infection. The staff cardiologist in the hospital performed an EKG, and decided that I had congestive heart failure. He told me to come to his office as soon as possible because he suspected that I would need open heart surgery.



*Pericardial effect on the heart*

The next day, I left the hospital and went to see my primary care physician. He reviewed the hospital records, and suggested that I make an appointment with a cardiologist that he knew and trusted. Cardiology was not his expertise but he was suspicious that the reason my heart was malfunctioning was probably due to pericarditis rather than something worse. He was sure that the cardiologist whom he was recommending would be able to make a more accurate determination.

Once again, I returned to my search for knowledge to understand my current cardiac situation. I again appreciated my classes in the medical school at Colorado State University as well as my subsequent studies. I began research on the heart and specifically on pericarditis.

The pericardium is a tough, layered sac that wraps around the heart. When the heart beats, it slides easily within the sac. Normally, only 2 to 3 tablespoons of clear-yellow pericardial fluid are present between the two layers which lubricate the heart's movements within the sac. In pericardial effusions, significantly larger amounts of pericardial fluid accumulate. Small pericardial effusions may contain 100 milliliters of fluid while very large pericardial effusions may involve more than two liters of fluid.

Most pericardial effusions are caused by inflammation of the pericardium, a condition called pericarditis. A common symptom of pericarditis is chest pain, caused by the sac's layers becoming inflamed and possibly rubbing against the heart. It may feel like pain from the heart. Pericarditis can be attributed to other factors, including viral, bacterial, fungal, and other infections. Since I had been experiencing other symptoms indicative of a viral infection, perhaps that was the explanation for this apparent heart related symptom. It seemed that my primary care physician had identified the condition of my heart and I was optimistic that the cardiologist would be able to correct the problem.

When a pericardial effusion is caused by pericarditis, the main symptom is chest pain. The chest pain may be made worse by deep breathing and lessened by leaning forward. When pericarditis is causing a pericardial effusion, other symptoms may include fever, fatigue, muscle aches, and shortness of breath. These were exactly the symptoms that I had.

What had caused the cardiologist of this hospital to suggest open heart surgery was a mystery. Maybe it was my good medical insurance. I believe that it is important to be as knowledgeable and informed as possible rather than permitting someone who has known you for only five minutes to make potentially life-altering decisions. They may turn out to be correct in their diagnosis, but it is always good to be as informed and educated as possible since you must be your own advocate.

We visited the cardiologist that my primary care physician had recommended. He performed several tests and came to the conclusion that I did not need open heart surgery. He suggested that we wait for my heart to recover from the pericarditis as well as waiting for the virus to run its course. Ann and I were relieved to learn that my heart condition was not as severe as the hospital personnel had believed. However, we still had the on-going problem of the kidney, dialysis, and trying to find a transplant.

Unfortunately, I still had to deal with the daily effort of dialysis. When I had been in the hospital overnight, they had performed PD there. Not only is it impossible to sleep in a hospital, but now I missed sleep with the PD. After I had returned home, it continued to be very difficult to sleep at night and draining of fluids was a problem. Since dialysis was a requirement for life, I had to persevere.

Shortly after my hospital stay, the liquid that is removed at night during the peritoneal dialysis was cloudy when we examined it in the morning. Ann collected a sample and we went immediately to see my PD nurse. She sent the sample to the lab and, to be on the safe side, added a dose of antibiotics in the fluid which she infused into my abdomen with the normal dialysis liquid. This was on Friday. Monday morning

came with a frightening lab result. The lab had discovered a fungal infection.

I quickly learned that fungal peritonitis (FP) is a rare but potentially fatal complication of chronic peritoneal dialysis (PD), associated with high morbidity and mortality ranging between 20% and 30%. If not leading to death, the inflammatory process usually causes irreversible damage to the peritoneal membrane with subsequent dropout from PD therapy. Fungal peritonitis is a serious complication and should be strongly suspected after recent antibiotic treatment for bacterial peritonitis. Fungal peritonitis accounts for 3%–6% of all peritonitis episodes. The most common cause of the disease is *Candida*, although there are others.

It was a frightening diagnosis but, rather than spend valuable time to determine which specific fungus I had, the doctor decided to use one of the most common and, normally, effective drugs. The main factors associated with the development of FP include previous antibiotic therapy, particularly for bacterial peritonitis, when two important operative mechanisms coincide: fungal overgrowth in the gastrointestinal tract and declining peritoneal defense because of peritonitis.

In general, management of FP poses a difficult challenge. Prompt initiation of therapy is critical but no typical clinical picture has emerged and the infecting organism can be difficult to isolate. The approach to the disease has changed considerably in recent years and the 2005 guidelines from the International Society for Peritoneal Dialysis list FP as a strong indication for immediate catheter removal with temporary hemodialysis. Dr. Ho prescribed the anti-fungal

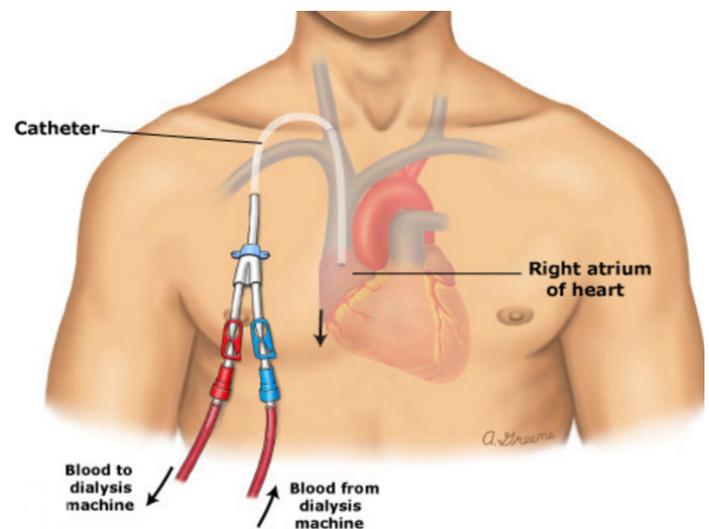
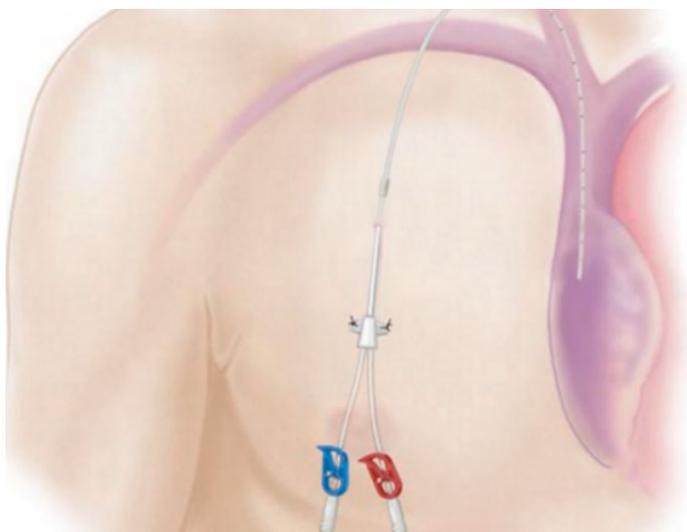
drug, fluconazole, and I was instructed to have the catheter removed as soon as possible.

This required one surgery to remove the abdominal catheter and a second surgery to insert a different type of catheter in my neck. Apparently, the potential source of the fungal infection was frequent use of antibiotics during the various bouts of the two-month disease, which may or may not have been a virus, as well as the use of antibiotics several times when the dialysis fluid had been “cloudy”. It is not abnormal to have a case of excess use of antibiotics wiping out the bad bacteria and leaving the system open to attack from “opportunistic” alternatives. In other words, wiping out the “bad” guys also annihilate the “good” ones as well. This leaves the system vulnerable to other types of infections such as the fungus which I got. No one knew where the fungus had come from but many fingers were pointing at my time in the hospital.

After removing the abdominal catheter, a different system was introduced in order to continue with my dialysis. This alternative technique to cleanse the blood is “hemodialysis”. Normally, hemodialysis employs a fistula, which I will explain later. Since there was insufficient time for the surgery and healing time for the fistula, I had to use a catheter placed directly into a vein in my neck which sends blood directly into the heart. This neck catheter was surgically implanted during the same operation that removed the abdominal one.

During the time I had the neck catheter, I learned about hemodialysis in depth. The dialysis machine filters wastes, salts, and removes extra fluid from the blood because the kidneys are no longer healthy enough to do this work adequately. The machine mixes and monitors the “dialysate”. The

### *Catheter through the neck to the heart*





*Dialysis Machine*

dialysate is the fluid that helps remove the unwanted waste products from the blood. It also helps balance the electrolytes and minerals at their proper levels in the body. The machine monitors the flow of the blood while it is outside of your body.

In hemodialysis, blood is removed from the body and filtered through a man-made membrane called a dialyzer, or artificial kidney, and then the filtered blood is returned to the body. The average person has about 10 to 12 pints of blood. However, during dialysis, only one pint (about two cups) is outside of the body at a time. In order to perform hemodialysis, there needs to be an access created to get the blood from the body to the dialyzer and back to the body. There are three access types for hemodialysis: arteriovenous (AV) fistula, AV graft, and central venous catheter. In my case, I began with the central venous (neck) catheter and then, after surgery and healing, I would be able to have an AV fistula placed in my upper left arm.

When a patient goes to hemodialysis, a nurse or technician will check vital signs and weigh the patient. The weight gain will tell how much excess fluid the patient must remove during the treatment. The patient is then “put on the ma-

chine”. Patients with a central venous catheter will have two tubes connected to the blood tubes that lead to the dialyzer and back to the body. Patient with a vascular access (AV fistula or AV graft) will have two needles. One needle takes blood out of the body, the other needle puts it back. Once the patient is “put on the machine”, the dialysis machine is programmed and then treatment begins. A picture of a typical dialysis machine and patient is shown on the left.

Blood never actually goes through the dialysis machine. The dialysis machine is like a big computer and a pump. It keeps track of blood flow, blood pressure, how much fluid is removed and other vital information. It mixes the dialysate, or dialysis solution, which is the fluid bath that goes into the dialyzer. This fluid helps pull toxins from the blood and then the bath goes down the drain. The dialysis machine has a blood pump that keeps the blood flowing by creating a pumping action on the blood tubes that carry the blood from the body to the dialyzer and back to the body. The dialysis machine also has many safety detection features and warning sounds to alert the staff if anything is amiss.

The dialyzer is the key to hemodialysis. The dialyzer is called the artificial kidney because it filters the blood which is a job the kidneys are supposed to do. The dialyzer is a hollow plastic tube about a foot long and three inches in diameter that contains many tiny filters. There are two sections in the dialyzer: dialysate section and the blood section. The two sections are divided by a semipermeable membrane so that they do not mix. A semipermeable membrane has microscopic holes that allow only some substances to cross the membrane. Because it is semipermeable, the membrane allows water and waste to pass through, but does not allow blood cells to pass.

Dialysate, also called dialysis fluid, dialysis solution or bath, is a solution of pure water, electrolytes, and salts such as bicarbonate and sodium. The purpose of the dialysate is to pull toxins from the blood into the dialysate. The way this works is through a process called diffusion. In the blood of the hemodialysis patient, there is a high concentration of waste while the dialysate has a low concentration of waste. Due to the difference in concentration, the waste will move through the semipermeable membrane to create an equal amount on both sides. The dialysis solution is then flushed down the drain along with the waste. The electrolytes in the dialysis solution are also used to balance the electrolytes in the patient’s blood. The extra fluid is removed through a process called filtration. The fluid is pushed off by higher pressure on the blood side than on the dialysate side.

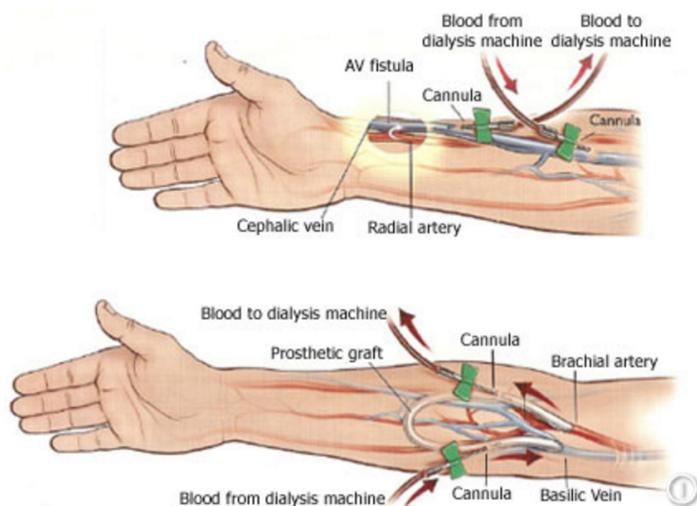
Blood needs to flow through the dialyzer for several hours to adequately clean the blood and rid the body of excess fluid. Traditional, in-center hemodialysis is generally done three times a week, for about four hours per session.

Despite the various and unpleasant symptoms which I was experiencing, dialysis had to continue using the neck catheter. As soon as I completed the drug regimen to destroy the fungus in my body, it was time to perform the surgery to create a “fistula” for my hemodialysis. A fistula is a surgically-created vein used to remove and return blood during hemodialysis. An “arteriovenous” (AV) fistula connects an artery to a vein. Arteries carry blood from the heart to the body while veins carry blood from the body back to the heart. An AV fistula causes extra pressure and extra blood to flow into the vein, causing it to grow large and strong. The larger vein provides easier and more reliable access to blood vessels. After the patient heals from the surgery, and the vein is strong enough for the dialysis, the fistula is used and the neck catheter is removed. A diagram of a fistula in the lower arm is shown on the right. My fistula was in the arm but above my elbow.

Dialysis patients are all too familiar with the routine of their treatments: go to the clinic, determine pre-treatment body weight, have temperature and blood pressure taken, get stuck with needles (unless the patient has a catheter access), have tubes connected to the dialyzer, and then sit in the chair until it is time to go home. When I first learned about hemodialysis, it did not sound like such a bad system. However, once I began the process of thrice weekly trips to the clinic, I became acquainted with the discomfort, fatigue, and feeling as though I had been kicked and trampled by a herd of horses. I soon changed my mind! It had not taken long for me to realize that neither peritoneal dialysis nor hemodialysis provided quality of life. I could not believe that I, a two-time Olympian who had striven for perfect health for 75 years, had to endure this procedure. This was not life, I thought, and death could hardly be worse.

However, one must continue dialysis to remain in the fight. In addition to having to endure these dialysis sessions, kidney patients must learn a whole new way of eating and drinking. Foods must be low in potassium and phosphorus since the machine cannot remove these molecules. This sounded easy until I discovered that many foods that I love were no longer permitted. Bananas, orange juice, nuts and seeds, pomegranates, and so many other delicious, ordinarily healthy foods are not allowed. The kidney diet includes many “approved” foods which are poor in nutrition, such as popcorn, corn flakes, rice milk, white bread, white rice, crackers, and candies!

Ann was outraged at the diet given to her for me to follow. To our way of thinking, the diet was low in nutrients and extremely high in foods that do not promote healthy bodies. In addition, dialysis patients are the reverse of normal people in that they must consume 80 to 100 mg of protein every day as well as restricting liquids. I had no idea that 2 or 3 eggs



*Fistula*

for breakfast, lunch with turkey, and a dinner with steak or chicken barely reached the required protein level. Ann began to introduce protein drinks whenever she could just to provide additional protein. Surprisingly, many so-called protein drinks were loaded with sugar although attempts were made to conceal this by using many different names to hide the sugar’s identity. The bottom line was it was still sugar. Fortunately, she found a few that had less sugar and good protein amounts. She exerted as much effort as possible to cajole me to eat the required amount of protein in addition to the allowed vegetables and fruits.

Another problem, which was more subtle but persistent, was that tastes change. Food which in the past had tasted delicious, was flavorless now. I had no appetite, and it was a struggle to get sufficient nutrition. I felt terrible, was apathetic, and had no desire to eat.

In the dialysis center, you are not a human, you are a number. Everything functions according to protocols. Once a month, blood is collected and analyzed. The results indicate whether various minerals, hemoglobin and albumin levels, and several other factors are up or down. Regardless of what your blood results indicate, you get the same shots of iron, or Epogen, or Vitamin D as everyone else in the center. There is no differentiation for individual needs, and there are no adjustments to the unique condition of each patient. This non-specific treatment infuriated me and, on several occasions, I refused. I could not understand why I should have an injection of EPO, for example, when my albumin level was good.

I realized that dialysis was essential for staying alive. However, it was depressing and discouraging to wake every morning feeling awful. I felt terrible every day, not just on the



*Connected to the dialysis machine*

treatment days. I began to see the dialysis center as a “torture chamber” and a “cemetery with lights.”

I reached a milestone of sorts when I realized that it was nearly a year since I had first been diagnosed with a kidney problem. My initial diagnosis was in early March of 2014. A year later, there was little progress to show for all of our efforts. I had been rejected by UCSD for my age, not my health. The second hospital had not bothered to contact us after the initial meeting with their nephrologist. But Ann was unwilling to give up.

We had successfully fulfilled all the tests listed on the UCSD form which seemed to be standard for most hospitals. Now that I had been turned down by one hospital and completely ignored by another, we realized that we had to keep looking for a hospital. What we needed was a hospital that would actually agree to give me a kidney transplant. We decided to try one more in Southern California and selected Scripps Hospital in La Jolla, CA, since they were relatively close and had a transplant program.

We made an appointment and drove to La Jolla, which is about 60 miles from our home. We spent the entire day with various staff appointments, blood tests, chest X-rays, and finally we were seen by the transplant nephrologist. He seemed to be impressed with my overall health levels and the results from all of the other tests results which I had undergone. We told him of our previous experience at UCSD. His response was that if we had come to Scripps last June, they would have transplanted me rather than beginning dialysis.

He said that I would have to increase my cardiac output to 50% since it had fallen below that during my bout with the virus. I assured him that I was feeling better and would continue to exercise. I promised him, as a two-time Olympic athlete, that he could count on my recovering and would be ready for a transplant as soon as they were. I also let him know that I had a living donor, my eldest daughter, Tova.

Ann and I felt encouraged by the responses we had received at Scripps Hospital. It was also relatively convenient for us since we could easily jump into the car at a moment’s notice to drive there. While we waited for them to contact us for additional tests and to process my donor, we had to continue the horror of dialysis.

Dialysis continued on a schedule of 3 times per week. Each time I was connected to a machine for 4 hours.

Since I had recovered from the virus and fungus infections, I had been able to return to regular physical exercise and training. I could not work out at all on the days I had dialysis but, on the other four days, I went to the gym regularly. I rode the horizontal stationary bike and was able to increase the time from 5 minutes to 20 minutes within about two months. I began walking on the treadmill, at first very slowly, and worked my way up to 15 minutes per session. I also spent time with flexibility and abdominal work, as well as training with barbells and resistive exercise machines. I was determined to improve my health because it helped me to feel better. It counteracted the depression of dialysis, and it was the only path to a transplant.

By August, my heart health had improved so that the ejection had reached a level of 55 percent. I was scheduled at Scripps Hospital to see the surgeon and the cardiologist for evaluation. I had excellent exam results with each doctor. The surgeon was quite excited to have the opportunity to perform a transplant on a two-time Olympian. He said I would be his first one.

We had one more trip in September of 2015 to Scripps for my last evaluation. After I saw the nephrologist for the second time that year, he was quite impressed by my overall health improvement. The transplant committee met in early October and they placed me on their transplant list. We were overjoyed. At last, we felt like there was hope.

However, in the same conversation with the nurse coordinator from Scripps when she informed me that I was being placed on the list, she said that they had rejected my living donor. At that time, my oldest daughter, Tova, was the one being evaluated to be my donor. When she was disqualified by the donor section of Scripps, it was disappointing for all of us. By rejecting my living donor, this meant we had to find another living donor or wait for a cadaver. Since I was now 76 years old, any cadaver that would be offered to me would be the one that had been rejected by everyone else. No hospital was going to give a newer, younger, good kidney to someone my age. I would be offered the “factory rejects.” It was a relief to be finally “listed” but the prospects of actually getting a kidney seemed bleak.

Our emotions were in turmoil. Ann told me that she was convinced that we would not be getting a transplant at Scripps so we were going to have to find one somewhere else. She was absolutely determined and repeatedly said “I’m not giving up! You are going to get a kidney!” Ann’s mantra became “You are going to get a kidney!” and she repeated this many times every day.

Since I had grown up in Israel, I began to contact my friends there. A friend, Avi Meiri, had a family member who had traveled to Latvia where he lived for three months until a donor became available. Avi arranged for me to discuss the situation with the transplant doctor in Israel. He said that I would have to travel to Israel and have the same series of examinations, blood tests, X-rays, and everything that I had already done in the United States. I could not merely send my previous results.

Another friend, Yosi Tanner, found an organization in Israel but, again, I would have to travel to Israel to meet with various doctors. In addition, I would have to find a compatible donor. Trying to find an avenue through my contacts in Israel demonstrated that it was increasingly more complicated at every turn.

Micha Spira was another Israeli friend who tried to find a route for a kidney transplant there. His results were similar to my other friends and he learned that anyone over the age of 70 was precluded from a transplant in Israel. However, Micha promised to keep looking for another option.

It seemed that our best option, at this point, was with our dear friend, Dr. Bill Laich, in Spain. Bill had moved to Spain from Argentina where we had seen him before we began our trip to Patagonia. Bill had been involved in setting up a new hospital in Madrid but, since it was a private hospital, they were not given permission by the country to perform kidney transplants. All Spanish transplants had to be performed in State hospitals. Arranging for a kidney transplant in Spain would require an enormous amount of preparation and we would have to find a living donor to travel with me for the

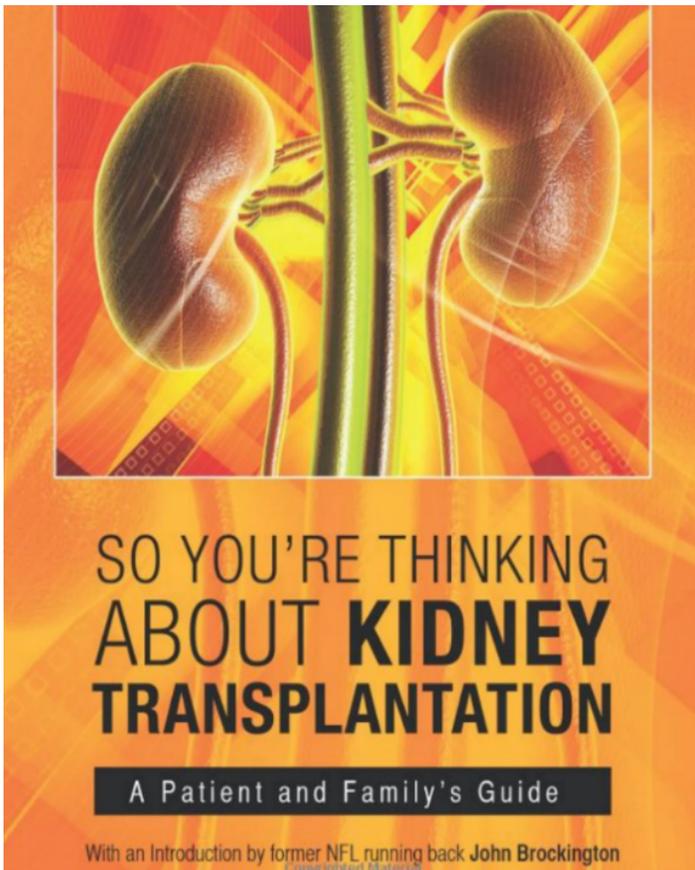
transplant. Bill was confident that everything would be successful, but, as with my attempts in Israel, more complicated and costly.

Ann and I were aware that none of these options was easy or practical. In addition, we would have to pay for everything including my and our donor’s surgical costs, travel expenses, and overseas residence for a period of time. We would also have to arrange for adequate medical follow-up when we returned to the US. But one thing was for sure, regardless of where the surgery occurred, I had to find a kidney, and that meant finding a living donor.

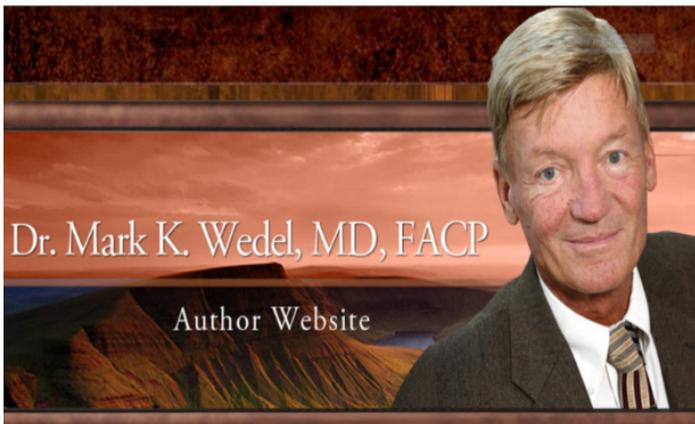
At the dialysis center, I had become friendly with another patient, Rich Hodges. Rich is a wonderful person and we shared interesting stories when his chair was beside mine. We were “dialysis buddies.” During these chats, I told him about my frustration in trying to find a kidney. He suggested that I meet friends of his, Helen and her husband, Bill. Bill was an older fellow who had undergone the same struggles that I was experiencing, but had been lucky enough to have received a kidney. Rich thought that these two people could evaluate what we had done so far, and perhaps suggest what else we might try. I contacted Helen and we arranged a meeting at their home.

During our meeting, Helen nodded her head as we described the long, winding, and, to date, unsuccessful route that we had followed. She and Bill had traveled the same path. Since they had ultimately achieved a successful outcome, she had some advice for us to consider. One important element was to be prepared and provide details whenever we met a physician. Bill showed us his large notebook filled with his lab work, every prescription medicine, professional consultations, and so on. It was an impressive collection of documents, and both of them were convinced that this well-organized information was indirect evidence that they would be equally meticulous with his health care after a transplant. They explained that doctors and hospitals were positively influenced if the potential recipient was prepared for the precision care that followed transplantation. Organized and complete medical records would reinforce this perception.

On her computer system, Helen showed us the large collection of items she had accumulated regarding kidney transplantation. She had organized letters, blogs, photos, and websites that other patients had created in their efforts to find donors. Helen assured us that getting the word out would enhance our opportunity of finding a donor. She suggested that we distribute a blog on the Internet and tell our friends that we were seeking a kidney donor. Helen offered to stay in touch by e-mail, and to provide any additional assistance that she could. We thanked them for all of their help and ideas and promised to stay in touch.



*Book by Dr. Mark Wedel*



Shortly after our visit with Helen and Bill, she sent me an e-mail about Dr. Mark Wedel. She had sent an e-mail to Dr. Wedel asking whether he would be willing to chat with us. Of course, she could not guarantee any miracles but she said that Dr. Wedel had helped a number of people tread the waters while trying to get a transplant. She also told us about his book entitled "So You're Thinking About Kidney Transplantation". She said it was a great help guide for those seeking a transplant. At this time, we were happy to have

some encouragement since it had been a rocky road to this point.

Not long after this e-mail, I received a phone call from Dr. Wedel. He offered to meet us at our home and insisted that he would drive up from his home near San Diego to see us. Of course, we were quite eager to meet him.

On the following Sunday afternoon, Dr. Wedel appeared in our house. He came with his own giant bottle of water and appeared to be in excellent health, which was remarkable since we soon learned that he had received a kidney transplant five years earlier. Dr. Wedel described his saga to obtain a transplant. It was fascinating and complex. As he described the flow of events in his own quest for a kidney, there were peaks and valleys which he said are common for most people. He examined our documents and evaluations and felt that we were on the verge of being placed on the list and receiving a transplant at Scripps. It turned out that the surgeon who had examined me was a golfing buddy of Dr. Wedel, so he said he would put in a good word next time they met on the links. He built up our hopes in the process since he understood the difficulties that we were experiencing. After a three-hour visit, he gave us his book and autographed it. We were very grateful for his time and effort and for the copy of his book.

Dr. Wedel had spent three hours with complete strangers. We had never met him before that afternoon, yet he had gone out of his way, driven more than four hours, and given his entire Sunday to us. Ann and I were amazed that such wonderful persons exist.

During our conversation with Dr. Wedel, he mentioned an organization in Brooklyn, New York, called "Renewal". This organization is composed of Orthodox Jews that have had great success in finding donors. He suggested that we contact them and perhaps they could help us. It turned out that this was one of the most momentous days in our lives, but on that particular afternoon, we did not know it. All we knew then is that the next day would be another agonizing experience at the dialysis center.

Ann was ever the optimist. She sat beside me and told me something that impacted my outlook and gave me the motivation to continue. She said: "Gideon, this is your 3rd Olympics! The first two required long and hard work but you persisted, and did as well as you could do. But this is the Olympics of life. You must work towards this gold medal. You will have to strive and train for this with more effort than for the first two because this one is much more difficult. This Olympics is for more than a gold medal. This one is for your life. Remember: we cannot and will not give up!" That was an awe-inspiring thought for me at this low point in my life. Once I could imagine that I was training and working for my 3rd Olympics, I felt renewed hope.

We decided to contact Renewal in Brooklyn immediately. We found their website on the Internet and read that Renewal is a nonprofit organization dedicated to assisting people suffering from various forms of kidney disease. They are a multi-faceted proactive team that is dedicated to saving lives through kidney donation.

Their website seemed to be especially geared towards us. They described that in a serious medical diagnosis, a patient and his or her family could quickly be overwhelmed by the pronouncement that one is suffering from irreversible kidney failure. With the increased frequency of transplants from non-related donors, they decided to start an organization dedicated to assisting people suffering from various forms of kidney disease. That was how Renewal was born.

Although their aim is to help in any way possible, the ultimate goal is obtaining a kidney for those that would like to undergo a transplant. Their waiting list includes people from all walks of life, of all ages, and from all parts of the world, including the USA, Canada, Israel as well as England and Brazil. Renewal has been successful in helping many of these patients, but the need is still great since each year 8 percent of the patients on the national list die waiting for a kidney.

I sent an e-mail message to Renewal on Sunday night after Dr. Wedel left us. The next morning there was an answer for me to contact Mrs. Rivki Grossman and she would be able to help me. We called immediately after reading the message and left a voice message. Shortly thereafter, Mrs. Grossman called. She explained that Renewal works with only 5 hospitals: three in New York, one in Miami, Florida, and one in Cleveland, Ohio. We felt that the most convenient plan for us to work with Renewal would be to travel to New York. She said we would have to complete the application form and provide three letters recommending me to Renewal. One letter was to be from our rabbi, one from a community leader, and a third from someone who knows me and my character. She gave us the names of the three hospitals and said, when we contacted them, to make sure we specified that we were working with Renewal.

I immediately filled out the application and sent it. Ann contacted our Rabbi Einstein who said he would send the letter immediately. Next I contacted my dear friends, Bob Wainwright, and Mac Wilkins, who said they would write letters as soon as they hung up their phones.

Ann contacted each of the three hospitals and was able to schedule an appointment for me at each of them. It was early November but we were fortunate in making appointments before Thanksgiving. It seemed impractical to have three hospitals, so we called Mrs. Grossman to ask which hospital they would recommend as the most appropriate one for us. We could hear the discussion in the background as we waited on the phone and then the answer was “The

Mount Sinai Hospital” since they have extensive experience in dealing with out-of-town patients. We canceled the other two hospital appointments and began to prepare for our trip to New York.

Ann was even busier than usual. Not only did she have to take care of all of my dialysis responsibilities and other daily needs, which were quite time-consuming, but now she had to prepare for our trip to New York. She arranged our flights, hotel, and made sure that we had our house covered in our absence.

My California dialysis center arranged for my dialysis sessions in New York. This is not something that the casual tourist can do. A dialysis patient cannot walk into a center and ask for treatment. The system is more complex than that, since the new center has to have all of the patient’s records prior to the first visit. Fortunately, we had enough time to have all of this processed before we left. I was extremely stressed about this aspect and had been reluctant to travel to New York. Dialysis saps all of your strength and hope for the future, but Ann reminded me that we had to try this since we were not getting anywhere in California. For inspiration, I received another 3rd Olympic reminder.

As with everything we do, Ann and I had checked into the kidney transplantation program at Mount Sinai. We learned that the Mount Sinai’s Kidney/Pancreas Transplant Program was one of the nation’s leading academic kidney transplant programs. They began in 1967 and had performed more than 3,000 adult and pediatric kidney transplants. We read on their website a description of their philosophy which championed a concept that was especially important to us. The statement was:

*One of the first kidney transplant programs in the Northeast, we have made significant strides in providing more options for patients previously denied access to transplantation due to medical factors.*

#### *Comprehensive, Multidisciplinary Care*

*Located in New York City, the Kidney/Pancreas Transplant Program is part of Mount Sinai’s Recanati/Miller Transplant Institute (RMTI), a comprehensive adult and pediatric abdominal organ transplantation center. Our multidisciplinary team includes experts in nephrology, surgery, anesthesiology, critical care, transplant immunology, and urology. This interdisciplinary approach allows us to provide the best in patient care by taking advantage of the most innovative developments in surgical techniques and transplant medicine. Patients who come to our program have access to the services of The Mount Sinai Hospital, an internationally acclaimed medical institution.*

### *Increasing the Number of Donors*

*Mount Sinai has one of the largest living donor programs in the United States. Half of the yearly transplants performed involve living donors. As part of our commitment to enhancing quality of life for patients before and after transplant, surgeons at our hospital performed the first laparoscopic donor surgery in New York State in 1996. This procedure dramatically reduces recovery time for individuals donating a kidney to a loved one. So far, more than 1,000 laparoscopic donor surgeries have been performed in our transplant institute.*

*Our newly endowed Zweig Family Center for Living Donation focuses on providing the best in medical, surgical, and psychological care to living organ donors. The Zweig Family Center for Living Donation is further developing Altruistic and Donor Exchange programs which will enable all potential recipients to have optimal opportunities to access live donor transplantation.*

*Mount Sinai is one of the first programs in the country to offer “donor exchanges.” This innovative program enables kidney transplant recipients who have willing but incompatible living donors to exchange kidneys with compatible donors. We participate in local and national paired exchange programs and donor chain initiatives.*

### *Increasing Clinical Eligibility*

*Mount Sinai has made great progress in increasing the eligibility of patients previously denied transplantation due to clinical factors. For example, Mount Sinai has an active Paired Kidney Exchange program allowing patients with incompatible donors to receive compatible organs through a process commonly known as a “kidney swap”. We developed and implemented a successful desensitization program to reduce the effects of antibodies that may hinder the ability of many to receive a successful transplant. We can now treat many patients who, due to their high immunologic risk, were previously ineligible for transplantation.*

### *Research Initiatives*

*Mount Sinai researchers are working hard to improve organ preservation, reduce rejection, minimize post-surgical complications and the side effects of immunosuppression, and prevent the recurrence of disease.*

The more that we read, the better we felt about traveling to New York. Although physically I felt terrible most of the time, Ann assured me that this would be good for us and she was confident that we were making progress. “We are going to get a kidney” was her unceasing mantra.

We flew to New York on November 21, 2015. Ann had arranged for us to stay in a nice hotel, The Pierre, on East 61st Street and 5th Avenue which was only a short cab ride away from the hospital, the dialysis center, and Renewal. I arrived exhausted from stress and renal failure. If you have never had kidney disease, there is no way to describe the fatigue and depression that accompanies it. Ann was like the world’s best coach, always encouraging me and trying to divert my attention from the negative to the positive.

The next day, Sunday, our dear friends Bob Wainwright and Jeremy Wise, made the long trip from their homes in New Jersey and Massachusetts to see us. It was very uplifting and helpful for my mood to see these dear people and recognize the effort which had gone into their trips. We had a wonderful afternoon and evening with them and, over a delicious Italian dinner, we laughed about some of our past crazy escapades.

The next morning, Ann and I went to Renewal at their Brooklyn office. Ann and I were apprehensive since our entire trip and future kidney were linked to this organization. Fortunately, the interview went very well. They were impressed by my accomplishments and the letters which they had received from the rabbi and others had extolled my virtues as well. We were relieved when they said they would accept me as a potential recipient.

During the meeting, they explained the process. They would assign me a new “name”, R1013, which was how I would be recognized at Renewal. I could mention myself by name when I wrote my blog or sent e-mails asking for help. But if anyone wanted to help or knew someone else who might be willing to donate a kidney, they must refer to me as “R1013” not as “Gideon Ariel”. All communications and any correspondence with potential donors were to be sent to Renewal, not to me. I was instructed that people should not respond to Gideon Ariel directly, but rather send everything to Renewal. Any references in the communications should be with regard to “R1013”.

Ann and I promised to do everything that Renewal asked. Additional staff members joined our meeting and made many suggestions about how to find donors. Since I was well known around the world in the areas of biomechanics and track and field, they thought I might have the most success in sending out targeted e-mails and posting a blog. They recommended that I prepare the text and they would review it for comments. I promised to work on the blog as

soon as possible and would send it to them via e-mail. We left Renewal with buoyed spirits.

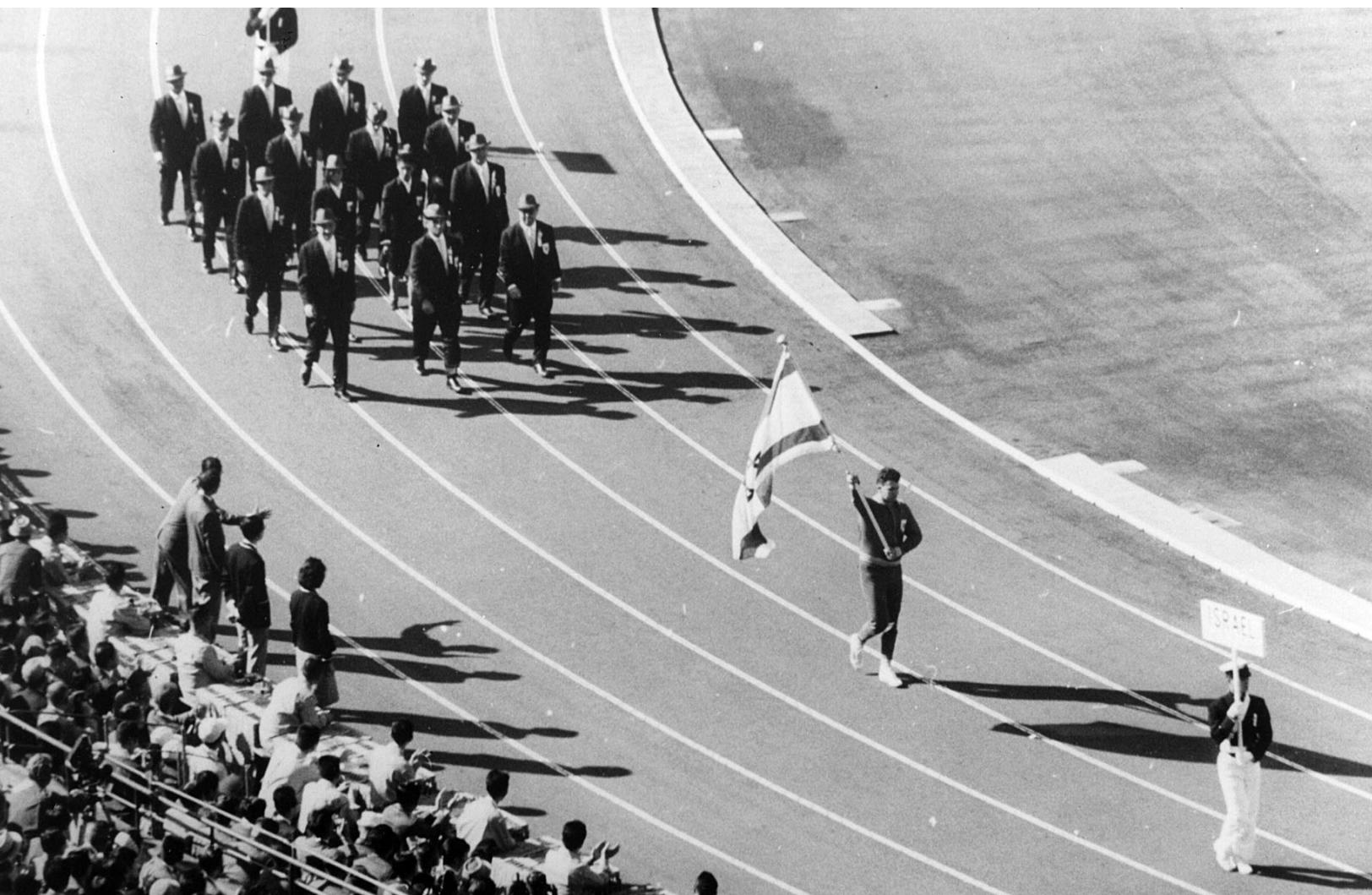
We returned to The Pierre Hotel in Manhattan. I was more exhausted than usual. I had jet lag, was emotionally drained from our trip to Renewal since I had been worried that they would reject me, and I needed dialysis. We had scheduled a dialysis session at the Mount Sinai medical center for 6 pm, so I was able to have a short rest before we left for that.

At that moment, I felt overwhelmed. I recognized the exhaustion that indicated that dialysis was necessary but, at the same time, I was encouraged by the response of the people at Renewal. They had not made any promises but they had a positive outlook which was not an attitude that I had experienced in California. I could not bring myself to have any hope, but Ann reminded me that this was another “training session for my 3rd Olympics”. She unrelentingly reminded me that we were going to be successful. “You are going to get a kidney”.

Wednesday morning, November 25, 2015, dawned crisp and chilly for us, the Californians. But we were oblivious to this as we rode a cab to The Mount Sinai Hospital. As the elevator doors opened on the 11th floor, we were greeted with “Kidney Transplant Center” signs. I silently hoped this

would be as momentous an event for me as when my ancient ancestors, the Israelites, arrived at Mount Sinai in the Judean Desert.

After registering at the desk, there was a flurry of tests: blood, urine, blood pressure, pulse, temperature, and others. Then Jonathan, my nurse coordinator, came in to describe the steps involved in processing me as a kidney transplant candidate. Ann gave him an enormous notebook with the last five years of my medical history. Data sheets were encased in plastic “folders”, front and back, and categorized by topic. The first page was the letter from Scripps Hospital placing me on the transplant list. Each tabbed section presented all of the evaluations and notes of my medical history. These included the examinations and comments from various physicians, laboratory results, the “green light” laser prostate surgery, the colonoscopy, the dental exam and clearance, immunizations including tdap and flu, and other results. Jonathan said he would have the pages scanned and returned to us. Ann immediately responded that the book had been prepared specifically for them to keep. She assured him that we had our own copy. The notebook consisted of about one hundred and fifty pages. On the front of the book, I had put a photo from the 1960 Olympic Games in Rome where I carried the Israeli flag. The photo is shown below:



Jonathan then described the schedule for the rest of the day. We would meet the nutritionist, financial advisor, and nephrologist. He said we would have to come another day to see the surgeon. Ann asked if this meant we would have to fly back from California to see the surgeon. Jonathan responded in typical, help-the-patient-first, fashion. "Oh my gosh, I forgot how far you have come. I'll try to find a surgeon that is still here. Since it is the day before Thanksgiving, many of our staff members will have left. Don't worry, I'll take care of this."

The meetings went as Jonathan had described. Surprisingly, we stayed in one room and the people came to us. Previous experiences had involved our running from room to room. When the nephrologist examined me, he described the tests that would need to be performed and we responded that we had done all of them. They were all cataloged in the notebook that we had brought and given to Jonathan. Immediately, the notebook was located so that the nephrologist could see what had been done, and with which results. His response was quite positive which was a relief for both of us.

Lastly, Jonathan brought us a surgeon, Dr. Antonios Arvelakis, to make his examination. He had a charming personality and an accent. I immediately asked if he was Greek and he responded in the affirmative. I then described how I had competed in the famous, ancient marble stadium in Athens as a member of the Israeli national team. Also, I asked if he knew the Greek champions, Antonios Kounadis, the discus thrower, and Georgios Tsakanikas, the shot putter. I described how I had competed against these men and that they were far better athletes than I was. Dr. Arvelakis was excited and responded that, as a young child, these athletes were among his heroes and that he knew them well. We continued to chat about people we both knew, such as Georgios Dalaras, the singer-musician, and Melina Mercouri, the singer-turned-politician. The deliciousness of Greek food was roundly and enthusiastically proclaimed. It was an amazingly enjoyable conversation with the doctor. Dr. Arvelakis then completed his exam and quickly read through the information in the book which we had provided to Jonathan. We were very pleased that he found me remarkably healthy in spite of the renal failure.

After the exam by Dr. Antonios Arvelakis, Ann and I looked at each other with a sense of relief. Maybe there was hope after all. Jonathan came back to tell us that our day was complete but we had one missing test – a chest X-ray. He gave us the form and directions where to go downstairs to the hospital to complete my evaluation. He explained that it takes two weeks to process the blood tests and then the committee would meet to evaluate my case. We should expect to hear from them shortly after their meetings.

We thanked Jonathan for his help and left to go do the X-ray. As we were leaving the 11th floor kidney transplant section, we met several of the rabbis from Renewal. They kindly asked if everything had gone well and if there was anything they could do to help us. We were amazed that only the day before, we had been strangers, and now they were at the hospital ready and willing to provide any assistance that we might need. We described our day so far and expressed our hopes that all would go well for placing me on the transplant list. Afterwards, we thanked them for their help and made our way down to the radiation department.

After this long but heartening day, I still had to go for dialysis. When I had completed the treatment at ten o'clock in the evening I think I felt the greatest exhaustion that I had ever experienced. We took a cab back to the hotel and I dragged myself back to the room. For the first time in my life, I agreed to let Ann order our dinner from room service! I have never wanted to eat in my hotel room but, at that moment, I only had energy to lie in the bed. It turned out that the food was truly delicious and I was surprised how much better I felt after finally getting some food in my stomach.

The next morning, Thanksgiving Day, we flew back to California. The following day, Friday, I was back in my dialysis chair for another round of being trampled by the herd of horses. At least I knew that we had tried. We would have to wait patiently for a response from Mount Sinai Hospital.

I began work on the blog that Renewal had asked me to prepare. I sent the draft to Rabbi Josh, who quickly responded with some suggested changes. I did as he asked and when he gave his final approval, I sent it out. Until this point in time, I had kept my condition a secret. I was embarrassed that, as a strong, vital, former Olympic athlete, I was such a physical disaster. The people at Renewal and the doctors at Mount Sinai had helped me understand that kidney failure is just a disease. Anyone can be sick at any time. This was a disease that can be helped with a transplant. It is not a cure, but it is possible to save a life and live a long and productive life with this help. However, if no one knows you need help, it is hard to find success. They explained that telling people the situation and asking for help is not a bad thing nor should it be seen as shameful or embarrassing. You are only asking for help, they all told me.

My own e-mail contacts were extensive since, as a bio-mechanist, I had presented at conferences, sold products, and had friends around the world. My e-mail list had nearly 10,000 contacts of my customers and friends. At this point I could only wait for a response.

One email that I received, shortly after I sent the blog was from one of my customers, Dr. James Hackney. In 2012, Dr. Hackney had downloaded our APAS system for use in

his research at his university. Subsequently, Dr. Hackney sent me some interesting questions:

*Dear Dr. Ariel,*

*I hope that this message finds you doing well. I am in the process of revising an manuscript describing a study with which I used the APAS as the instrumentation for data collection, and I am embarrassed to admit that there are some issues regarding filtering which I am not sure that I can answer, despite reading some sources including MODIFIED SEGMENT LENGTH NORMALIZATION by Stivers K A. Wise J., Ariel G., Vorobiev A. G. , and Probe J. D. (which I accessed through the Ariel Dynamics website).*

*One of my questions is very direct. In the filtering program, when if one advances the display to the acceleration data curves and then applies a digital filter (with a low pass frequency cut-off of 10 Hz in my case), is one actually filtering the acceleration data, or filtering the displacement data and observing the changes resulting in the acceleration curves which result from the filtering of the displacement data?*

*The second question I have is actually from one of the reviewers. "What are the characteristics of digital filter, and what is equivalent cut-off frequency and decay rate in the displacement domain of the filter which was applied in the acceleration domain?" Could you please direct me to literature which answers the previous question regarding filtering in APAS?*

*Thank you so much for your generosity with your time and effort!*

*James Hackney PT, PhD,*

*Department of Physical Therapy*

We had exchanged similar e-mails during the intervening years. After I had sent the blog about my need for a living kidney donor, I received the most surprising e-mail from James:

*Dear Gideon,*

*I actually would consider donating a kidney to you. Twelve or thirteen years ago, when I was a PhD student at University of Minnesota, and was considering doing it for a friend's husband, and had my blood antigen matched. I don't know if these records are still available, or would be helpful if they are. What is the*

*first step I should take to see if I am a possible donor for you?*

*Best,*

*James Hackney PT, PhD*

*Department of Physical Therapy*

Needless to say, I was shocked and joyful at the same time. My answer was immediate:

*Dear Dr. Hackney:*

*Wow!!!! Thank you so much. I am speechless at your wonderful offer.*

*Please contact the organization who will help and guide you through the entire process.*

*They are wonderful and kind people and will keep everything confidential.*

*You can learn about Renewal and see them on their Web at:*

[www.renewal.org](http://www.renewal.org)

*Make sure you watch the video at:*

<http://www.life-renewal.org/>

*If you call or write to Renewal, please use my code: R1013. This identification code will enable the wonderful people at Renewal to know that someone is contacting them about Gideon Ariel. Thank you so much for your assistance in saving my life.*

I wanted to make sure that James contacted Renewal and, although we had been in communication with each other for quite a number of years, I did not want to break Renewal's strict rules. They had explained the rationale for maintaining distance and silence between donors and recipients. Renewal had been actively involved in more than 100 kidney transplants in just two of the New York hospitals. Although their success rate was phenomenal, some donors changed their minds before surgery. Therefore, rather than put undue pressure on the donors or cause anxiety in the recipients, Renewal kept them isolated from each other. They told me of instances when potential donors had changed their minds on the day before the operation was scheduled. It was an infrequent occurrence, but they felt better at keeping information private until the transplantation proceeded. This strategy eliminated the stress for donors and recipients.

Another individual with whom I was in contact on a regular basis was Lucia Tristao, whom I discussed in a previous chapter. When Ann and I had initially traveled to New York in November, we had shared lunch with Lucia, Bob Wainwright, and Jeremy Wise. During that luncheon, Lucia learned of my problem and said she was blood type “O” and was willing to be a donor. After thanking her profusely, I had given her the phone number for Renewal and explained how they worked. Lucia promised to call them. She had called me periodically to tell me about which tests she had taken and the kindness of the people at Renewal. When Renewal personnel told her not to talk to me, she explained that we had been friends for more than 30 years and it was hard not to speak to each other. However, the folks at Renewal were very emphatic about this point, so she kept most of her information to herself from that point.

Two weeks after our trip to New York, I received a call from Mount Sinai telling me that I had passed all of their blood tests, and that they had reviewed all of my previous test results and comments from the physicians. At their committee meeting, they had placed me on their transplant list. In addition, they were in the process of evaluating my donors. I was overjoyed to have been placed on their transplant list and surprised to learn that things were happening so quickly since in my previous experience everything proceeded extremely slowly.

Later that same day, I had a call from my friend, Lucia Tristao. She was calling to let me know that she had passed all of her tests so far. She only had two more days of testing and then she would know whether she was qualified to give me one of her kidneys. Again, I was shocked at the speed which the various New York groups were moving in the transplantation process.

December rolled into January. My Mount Sinai recipient coordinator, Eileen, called to say that several donors had been identified and things looked promising. She directed me to get clearance for surgery from my cardiologist. Ann and I jumped on this task and sent the positive results to Eileen a week later.

Eileen called to say everything was ready for the transplant and she hoped it would be scheduled for the middle of February. Ann and I were overjoyed, but afraid to get too excited. There were too many things that could go wrong.

As things transpired, Renewal and the Mount Sinai Hospital staff determined that James Hackney would be the best candidate, since he was only 52 years old, and the other donors were older. However, the situation was that James was teaching at the university and would not be available until April 1st. For Ann and I, this was the longest month and a half in either of our lives. Days seemed to be 72 hours long rather than 24, but we could only wait and hope for the best.

Finally, the date for the surgery was set for April 14th. I was instructed by Eileen to come to NYC on April 3rd, have dialysis on April 4th, and arrive at Mount Sinai at 9 o'clock on April 5th for blood tests and examination by my surgeon.

Ann now began the enormous job of preparing for our trip. Not only did she have to arrange air travel to New York, housing, and dialysis for the time between April 3 and April 14, but she had to prepare for the three months that we would be living there following the transplant. She gathered clothes, shoes, soaps, and all of the other items that she was sure that we would need. You would have thought we were traveling to Outer Mongolia and would never see a store to purchase our supplies. Eventually, she packed eight boxes and shipped them to our friend Bob Wainwright in New Jersey since he could drive them up to us once we were in our “permanent” apartment.

Finally, the long-anticipated day arrived, and we flew to New York. By this time, my energy level was quite low so every physical activity drained the remaining strength out of me. Walking from the jetport gate to the luggage arrival site felt to me like I was climbing to the top of Mt. Everest. However, Ann was always there, cheering me on, and reminding me that we were arriving at my 3rd Olympic city for the games to begin soon.

I had the dialysis on Monday at a wonderfully friendly center located only 2 city blocks from our apartment. Ann had found a residential hotel which was more home-like than a regular hotel room and where she could prepare our food. We had learned months before that dialysis patients can rarely find proper food at restaurants. Therefore, Ann shopped carefully and prepared our food. She is a health nut and insists on purchasing organic fruits, vegetables, and meats. Also, she strove to provide the “healthiest” diets possible, so we had quite a lot of fish as well.

On the morning of Tuesday, April 5th, we arrived early at Mount Sinai for our appointments. Eager, excited, but afraid to be too optimistic would best describe our emotions. After the blood tests, which seemed to comprise so many vials I felt there would be nothing left in me, we were taken to the examination room to meet my surgeon. We had been informed that my surgeon was the Greek doctor, Dr. Arvelakis, who had examined me the previous November. We were happy to learn this news since he had been quite charming and we were confident in his abilities.

The appointment was set for 9:30 am. We waited and waited and checked our watches and kept waiting. Finally, at 10:30 am, the door opened and someone we had never seen before walked in and sat down. He said that he was Dr. Arvelakis' boss and that our surgeon was still operating on a patient so he hoped we would not mind if he performed the examination. We were shocked that the head of the depart-

ment was taking his time to examine me. The doctor was Dr. Ron Shapiro and we chatted about his background and the circumstances that brought him to Mount Sinai. He reviewed my records and, at one point, looked at me quite quizzically, and said “Are you really 76 years old? Because you look better and fitter than I would have expected.” As Dr. Shapiro proceeded with the physical exam and updating the relevant records, we discussed what had brought us to New York. We described how two hospitals had turned me down solely due to my age and that the third hospital had not contacted us in 6 months. He looked me directly in the eyes and said, “Any hospital that fails to perform a transplant on a recipient who has a living donor is committing murder.” Dr. Shapiro told us that Mount Sinai had transplanted a patient the previous year who was 82 years old at the time and had not only survived, but was playing golf every day, weather permitting. He concluded his examination and proclaimed me fit and healthy enough for the transplant.

We also discussed with Dr. Shapiro our concerns about finding a transplant nephrologist near our home in California. We asked if he would be able to recommend a hospital, staff, and transplant nephrologist, in Southern California where we could receive care. We told him that there was no way that it would be as good as Mount Sinai but we needed help closer to our home. He promised to take care of this situation before we returned to California which would be some time in the next three months.

When we returned to our apartment, we read about Dr. Shapiro, the head of the Transplant Center at Mount Sinai.

Ron Shapiro, MD, is the new surgical director of the Kidney and Pancreas Transplant Program at Mount Sinai’s Recanati/Miller Transplantation Institute. Dr. Shapiro, a leading surgeon with more than 30 years of experience in the field of transplantation, trained at the University of Pittsburgh under Dr. Thomas E. Starzl, a transplant pioneer. Before coming to Mount Sinai, Dr. Shapiro was a Professor of Surgery at the University of Pittsburgh and the Robert J. Corry Chair in Transplantation Surgery at the Thomas E. Starzl Transplantation Institute. After 26 years with the University of Pittsburgh, Dr. Shapiro is leaving his endowed chair in Pittsburgh to return to The Icahn School of Medicine at Mount Sinai, where he completed his internship and residency.

In his new position at the Recanati/Miller Transplantation Institute, Dr. Shapiro will oversee the abdominal organ transplantation programs and services specific to adult and pediatric kidney transplantation, as well as adult pancreas transplantation. RMTI is among the most comprehensive transplantation centers in the world, and includes one of the largest living donor programs in the United States.



*Dr. Ron Shapiro, head of the transplant center*

Dr. Shapiro has co-authored four books: Atlas of Organ Transplantation, Renal Transplantation, Pancreatic Transplantation and Living Donor Organ Transplantation. He has published more than 380 articles, 65 book chapters, and has given more than 520 lectures. Dr. Shapiro has been repeatedly named by Castle Connolly, Ltd. as one of “America’s Top Doctors.”

Ann and I were amazed that such a gifted and obviously important staff member had examined me. Dr. Shapiro mentioned, in addition to being head of the department, that he had performed two transplants during the weekend. We learned later that he devotes time to research as well as his clinical, professional, and educational duties. In addition to his stellar skills and reputation in his medical field, he was kind and charming. He calmed our fears and apprehensions with his cheery smile and pleasant demeanor. Our spirits were lifted every time we met another staff member at Mount Sinai. Everyone we met was kind and sympathetic. Every experience from drawing the blood, having vital statistics mea-

sured, and interacting with the doctors was another lesson in caring and optimism.

Dr. Shapiro assured us that my surgeon was, indeed, going to be Dr. Arvelakis. Dr. Shapiro told us that I would be in excellent hands for the surgery. When we returned to our apartment, we quickly began our research and discovered that he had amazing credentials.

Antonios Arvelakis, MD is a practicing surgeon in New York, NY, specializing in Transplant Surgery. He currently practices at Mount Sinai School of Medicine and is affiliated with MidState Medical Center, Mount Sinai Medical Center, and Yale-New Haven Hospital. Dr. Arvelakis also practices at Yale Transplant Surgery Department in New Haven, CT. In addition to English, Dr. Arvelakis's practice supports these languages: French, Spanish, Arabic, Korean, Polish, Vietnamese, Russian, Italian and German. We knew he was an amazing surgeon and had been fun to talk with during our previous meeting, but we had no idea that he knew so many languages as well. We felt quite confident with Dr. Arvelakis as my surgeon.

*Dr. Antonios Arvelakis*



At this point, we were waiting on pins and needles until April 14th. Our friend Bob Wainwright drove up from his home in New Jersey every other day just to see me. My friend Lucia walked across Central Park nearly every day to see if she could help in any way. It was gratifying to know that I had such good friends in my life.

On Saturday, April 9th, we moved from our apartment to the Mount Sinai Transplant Living Center (TLC). This facility is just a few blocks from the hospital and is designed for patients and family members to live in an environment that is more like a home rather than an impersonal or strange hotel room. My donor, James, would arrive the next day and we wanted to be there to greet him and assist in any way that we could. He arrived at about 6 pm so all three of us three enjoyed one of Ann's home-cooked meals.

Renewal had made all of the arrangement for James, met him at the airport, and driven him to the TLC. Our room was in a different section of the TLC from James' but we met every morning for breakfast. Our routine was quickly established. James would wake very early in the morning, buy a cup of coffee from the corner shop, and walk up to Central Park to enjoy the scenery. He would be back for breakfast and tell us where he planned to walk that afternoon. Other than his one day at the hospital, I think James walked at least 6 miles around the various boroughs of New York every day. Ann prepared dinner for all of us every evening during which we enjoyed interesting conversations about biomechanics. James' field is physical therapy so his biomechanical applications were different from those I had concentrated on in sports. We soon discovered that he was extremely knowledgeable in many related areas so our evenings were lively and informative.

We eagerly waited for James' wife, Polly, to arrive on Monday. James decided to surprise her and meet her at the airport. I was relieved that he decided not to walk all the way to LaGuardia to meet her. We were instant friends when Polly arrived. She took off her coat, kicked off her shoes, and was happy to enjoy some of the vegetable beef soup that Ann had made for all of us. We became great friends during those days that we spent together before and after the surgery.

Another group at the TLC were the Crespi family. The father, Paul, had received a kidney from his son, Andrew, on the Tuesday before we arrived. Paul and Andrew had been discharged on the same day that Ann and I had arrived. It was extremely helpful for Ann to meet this patient and his donor since it was "on-the-job" training for her. Paul's wife, Beverly, was a fountain of useful hints, details about medications, and the many other aspects that transplant patients experience.

By Tuesday, Ann, Polly, and Bev had become like sorority sisters with so many newly shared experiences. They helped



*Before surgery with James, my donor, and Ann*

each other with all manner of things such as where to get double extra-large pajama bottoms. Neither Ann nor Polly had realized that post-transplant patients are full of gas and have unnaturally distended abdomens. Normal pants cannot close so they were off to the store to find these sizes. One night, I arranged for my friend, Lucia, to accompany Polly to a Broadway play and we promised to be good “baby sitters” for James. We were all happy and, perhaps, a little apprehensive, but finally Thursday arrived.

Two men from Renewal came to the TLC at 5 o'clock in the morning to take us to the hospital. They guided us to the reception desk and waited with us until it was time to go to the preparation room. With so much experience, they knew exactly where to go and guided us at every turn. When the time came for James and me to take the elevator to the operating floor, the gentlemen from Renewal took Ann and Polly to the appropriate waiting room. After they had been sure that the two wives were settled and secure, they explained that they needed to leave them in order to check on two patients at a different hospital.

While our wives were waiting for James and for me, the procedures for the kidney transplant were set into motion. They actually consist of two separate operations: one for the donor and the second for the recipient. These operations are actually very complex and require a team of medical profes-

sionals and, of course, a kidney. The process of kidney transplantation is a precise sequence between donor and recipient. James' surgery began first. He was anesthetized and his left kidney was surgically removed by his surgeon, Dr. Chin. After the kidney had been deemed healthy, it was prepared for transplantation. As soon as my doctors were advised that my “new” kidney was coming, my transplant surgeon, Dr. Arvelakis, made an incision on my lower, right abdomen just above the groin.

As soon as James' kidney arrived, Dr. Arvelakis connected it to my vessels and reported that my “new” kidney began working immediately. He then placed it in the lower abdomen. My “new” kidney's blood vessels were connected to my iliac artery and vein. He then connected my ureter to my bladder.

After the surgery, I was taken to the recovery care unit where I was monitored by medical personnel until the anesthesia wore off and I woke up. During the recovery period I had been told about some things that I could expect: some pain; an ultrasound procedure to verify that the new kidney was functioning correctly; and a catheter to drain urine from the bladder would have been inserted but would be removed as soon as possible. One important reason for the catheter was so that the urine could be monitored for color and quantity.



*My first breakfast with my new kidney, April 15, 2016*

About 9 hours after she had seen me get into the elevator with James to go to the operating room, Ann was called to the waiting room desk to meet Dr. Arvelakis. He described how well the surgery had gone, and that my new kidney was functioning perfectly. He told her that I would soon be sent to the recovery room, have an ultrasound to make sure that the new kidney was functioning correctly, and that after about four hours I would be transferred to a normal patient hospital room. He then asked her if she had any questions. Ann later told me that she was so happy and relieved that, probably for the first time in her life, she was speechless. “Numb” was how she described herself. She wanted to laugh and cry for joy at the same time but, finally, she managed to ask if I was alright. Dr. Arvelakis smiled and assured her that I was perfectly fine. He said she could go up to recovery in about half an hour and see for herself.

Of course, I was unaware of all of these activities. I remember riding the elevator up to the operating room floor. James and I parted with thumbs up and I was taken to a preparation room. The staff had me lie on a bed where they proceeded with all of the regular pre-surgical activities. My abdomen was shaved and “painted” orange. The nurse inserted an IV in my arm while the anesthesiologist told me what he was going to do and when. Dr. Arvelakis came to tell me that James’ surgery was proceeding nicely and that my operation would begin soon. He also smiled and told me not to worry because everything would be fine. The last thing I remember was being wheeled into the operating room as I dozed off.

I do not remember anything else until I awoke in the recovery room. When I woke up, I felt no pain, and I asked the nurse if everything had gone well and if I had a new kidney. She assured me that everything was perfect and that my new

kidney was producing quite a lot of urine. Since the nurse was emptying and measuring the urine output, she showed me the full container. I had not seen that amount of urine from my body for years and was ecstatic to know that James' kidney was working so well for me!

At that point, I saw Ann and I greeted her by asking "Who are you?" Every time that I had been anesthetized, I had asked her the same question so she was appreciative of the joke since she knew I was awake and aware. Ann stayed by my side for the next four hours, until I was transferred out of the recovery room to my hospital bed.

I was unaware of my hilarious behavior during my time in the recovery room. Ann is still laughing about it every time she has describes the situation. I certainly do not remember pressing the "pain medication" button but apparently I pushed it frequently. This contributed to me not having pain, but added an extra dimension to my humor. Ann told me that I asked the nurse to have dinner with me as soon as I got out of the recovery room. Ann assured me that the nurse agreed with every one of my proposals! I continually told my other nurse that his country produced great sportsmen and women but I referred to his country as Russia, Ukraine, Georgia, and several others but he was not actually from any of them.

One of the gentlemen from Renewal visited later in the evening. Ann said he listened attentively as I babbled about my father traveling from Poland to Israel in 1917; how my grandparents had lived in Jerusalem; what I had done as a child; how I had come to America. It seems that I talked at great length while he nodded and smiled in agreement. I have absolutely no recollection of this conversation, but Ann told me that it was something unusual, to say the least.

Finally, at about 8 o'clock in the evening, they wheeled me up to my hospital room. I shared my room with another transplant patient. James' room was next door to mine. Donors are given private rooms to reflect their honored status as life givers. Ann checked on Polly and James. James was sitting up and eating his dinner while Polly beamed at his side. All was well with both of them which was a great relief to us.

Ann helped me eat the Jello and other bland things that arrived on the meal tray. I was astonished that I had an appetite and was even more surprised that I ate everything in front of me. That was a phenomenon that pre-dated dialysis. Ann stayed with me until 10 o'clock and reluctantly left so she could have some dinner and sleep.

When Ann arrived the next morning, I was having breakfast. She had brought a camera to take my picture and it is shown on the left.

For the first time in years, my skin actually had some color as opposed to my previous pale white completion. My hemoglobin level had been 8 the night before but, by morning, it was higher so I had not needed a blood transfusion. My appetite was good so I ate nearly everything they sent on the tray. My blood levels were excellent. In the afternoon, I was able to get out of bed and walk around.

My first walk was to go next door to see James. He had been walking around earlier with his wife and was now resting. We were both happy to see each other and that everything had gone so well. I told him what a fantastic kidney he had given me and he said it was an "industrial strength" model.

Ann and I had discussed for several months what we could do to thank someone who saved my life. Money was not the answer because, as James had said, he had given me a kidney, not sold me one. So, what could we possibly do to say "thank you" for such a profound and lifesaving gift. Finally, we decided that education for his sons would be a way.

We sat in James' hospital room and described our idea of saying thanks. We would pay for the college education for their sons at any school they wanted. The parents and boys would make the choices, they would guide them as parents do, and we would provide all of the resources that would be needed including travel and living expenses. Both James and Polly were overwhelmed but agreed at last.

We left their room and continued my walk. Since it did not seem prudent to overdo the first exercise day, we returned to my room. This schedule continued for three more days and then I was discharged.

The discharge procedure was conducted by Dr. Rafael Khaim who sat with us as he patiently explained the procedures that we had to follow every day. We were instructed thoroughly on which medications to take, how much, and when. These routines were very specific and there could be no deviations or exceptions. The medicine had to be administered on time, every time. Any deviation could result in the kidney being "discovered" by the immune system. Should that occur, the normal body immune response would seek out and destroy my "new" kidney since it would be perceived as a foreign invader which needed to be annihilated. Dr. Khaim was kind and gentle in his approach. Everything was now in our hands. The details might seem excessive and overwhelming, but Dr. Khaim assured us that it would be straightforward and we would have no trouble following the directions. However, he told us to call him any time, day or night, if we needed his help.

We promised to follow the rules precisely and Ann, ever the person with great attention to details, made copious notes. We left the hospital with an enormous bag of medication. We returned to the TLC and were greeted with



*James Hackney, Ann, and I at the TLC after our surgeries; the Seder table; The Matzot with James in the background; James reading from the Haggadah*



cheers and congratulations by the staff and current residents. Although I felt good, I was quite tired, so I immediately went to our room to take a nap.

Alyson was the young administrator at the TLC. She had Lupus, which had damaged her own kidney, and had received her transplant about nine years earlier. She was still at the center when I arrived and joined the group in welcoming me “home”. Alyson worked hard to help all of the donors, recipients and their families, to have a peaceful, calm, home-like atmosphere.

Alyson also gave us an excellent suggestion which was to have alarms set on our cell phones which would alert us twice per day that I had to take my medicines. What a fantastically helpful hint that was and one which we continue using. No matter where we are, what we are doing, when those alarms sound, there is no delay in taking the pills. We have been watching a movie, in the doctor’s office, and riding in a cab when the alarms have gone off. Ann always carries the medicine and some water to drink. We are meticulous about the schedule and hope it will serve me well.

Everyone settled into the recovery mode at the TLC. James was incredibly healthy and begun his walks around New York shortly after his discharge from the hospital. It seemed that Central Park was his favorite place since he made many trips up there to walk around, eat from the food trucks, and sit to watch the people. Polly went with him and, fortunately, they had lovely weather for their weekend strolls. Polly had to return to Missouri on Tuesday, but James would be staying until Friday since he had to be evaluated and released by his own transplant surgeon.

Ann was our “administrator”. She arranged for James to have his granola for his early morning jaunts. She took care of me and fixed dinner for all of us each evening. We were supposed to take care of James, but he was well beyond the need for our care. We mostly enjoyed meals and conversations together each day.

At this point, the plan was for James to see his surgeon on Thursday and fly back to Missouri early Friday morning. I realized that Friday night was the evening that we celebrate the Jewish holiday of Passover with the meal known as the “Seder”. I wanted James to share this Seder with us but he could not change his trip schedule.

I decided that we would celebrate the Seder on the evening of the 21st, since it would be the 22nd in Israel. This was a real challenge. Usually, Seder plans are weeks in the making: cleaning the house, shopping for and preparing things in advance, setting the table, and cooking. We had two days in which to cram two weeks of work. I contacted the people at Renewal for their help. Ann managed to buy all of the kosher food necessary, but we were missing a few items. We

had to have the Haggadah which is read by everyone during the Seder. “Seder” means “order” and the Haggadah presents the entire evening sequence of events of prayers, readings, and instructions “in order”. We had to have this for things to go smoothly. We invited Lucia to join us and, as it turned out, she had a white tablecloth which we could use for the holiday meal.

The wonderful people at Renewal were able to bring copies of the Haggadah, a pre-made Seder plate, yamakahs for the men, and the gefilte fish. Now, we had all of the basic requirements for our Seder.

We had fun spending our Passover Seder with two dear friends. The next morning, we arose at 5 o’clock to say our thanks and safe trip to James. We obviously would stay in contact since we now shared our DNA with each other.

Later on Friday, Bob Wainwright drove up in his big SUV to help us move to our new apartment at the Bristol Plaza. Our apartment was quite spacious, with a large living room, dining area, fully equipped kitchen, huge bedroom, 1½ bathrooms, and extensive storage space. Another handy advantage was the daily maid service to change all of the linens and clean the kitchen.

When we arrived, I realized that I was tired. It reminded me that it was just over a week since I had undergone major surgery. However, with the help of the hotel staff, Ann and Bob were able to move everything into our apartment.

Now, Ann and I could live more normally than we had in some time. We settled into a steady routine. There was a full laundry facility just outside our door so Ann could keep everything clean. Cleanliness is an important factor in maintaining the health of kidney transplant patients. She could shop daily at several local stores and acquire fresh organic fruits, vegetables, as well as meats and fish. The doctors had impressed upon us that we needed to avoid crowds, that I should not shake hands or kiss people, and focus on germ-free living. Therefore, Ann prepared our food for each meal.

Initially, I was still prohibited from eating some of the same foods that had been part of the dialysis diet. However, within a few weeks, my kidney was able to process everything. Imagine my joy the day Ann gave me orange juice which she had just squeezed and a banana. I had not been able to enjoy these for nearly two years.

Our routine included going to the hospital twice a week for blood tests and seeing the physicians. Blood was drawn as soon as we arrived at the hospital since the doctors needed to know the blood levels before I took the next dosage of drugs. Afterwards, I could take my medicine when our telephone alarms sounded. Frequently, these alarms would go off in the middle of a physician’s exam. But they were unperturbed and, in addition, pleased that we were so responsibly compli-

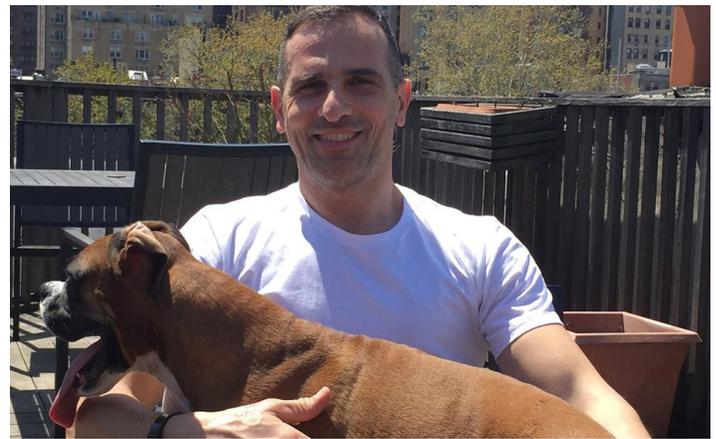
ant with taking the medication exactly on time. Each week, I met members of the fantastic medical staff.

My first visit after surgery was with Dr. Arvelakis. When Dr. Arvelakis enters a room, he brings sunshine with him. He exudes such happiness with his demeanor that you find yourself smiling. I was wearing one of my normal animal T-shirts since that is what Ann selected for me to wear, and the first thing Dr. Arvelakis mentioned was the lion on my chest. This launched the conversation into animals and pets and how much all of us loved animals. Dr. Arvelakis told us about his boxer and how obsessed he is with her. Ann asked, since he had a cell phone, if he had any pictures. Oh my goodness, his entire phone was filled with pictures of his adorable dog from puppy-hood up until the day before.

After we had finished our animal discussion, Dr. Arvelakis examined me and answered all of our questions. The incision site looked good and he pronounced me in good health. He reiterated the instructions not to do abdominal exercises, but walking, walking on the treadmill, and carefully controlled resistive weight lifting was approved.

On the cab ride back to our apartment, we were again discussing the excellence in quality and caring staff members at Mount Sinai Hospital. It seemed to be the focus of our con-

*Dr. Veronica Delaney*



*Dr. Arvelakis at home with his boxer*

versations each and every time we interacted with someone there.

This was our routine for the next month and a half. Mondays and Thursdays we went to the hospital for blood tests and to see a doctor. Each week, I was examined by a different physician, either Dr. Arvelakis or my transplant nephrologist, Dr. Delaney.

Dr. Delaney had first visited me when I was still in the hospital. Now she examined me every other week, alternating with Dr. Arvelakis. Dr. Delaney had been educated in London, receiving both MD and Ph.D. degrees, and had additional studies and training at Montefiore Hospital in New York. Not only was she smart and personable, but she had a charming Irish accent. She was very thorough in her examinations, but Ann and I sometimes forgot to listen to the details since we would be caught up in her lilting accent.

Every day, we exercised. I was surprised to see and feel the improvement in my strength levels so soon after we had begun this daily routine. I had a nice long nap every afternoon. We watched movies on our system every night after dinner. Our friends, Bob Wainwright, Lucia Tristao, and Jeremy Wise, would frequently visit which helped the recovery process.

The gentlemen from Renewal also visited quite often now that the transplantation had occurred. Prior to that, they had maintained distance since there should be no contact between recipient and donor prior to the transplant. Now they called and visited regularly to inquire about my health and to see if they could do anything to help us. As time passed, we realized that they are an amazing, generous, and caring group of people. Their focus is to find kidneys for people who need them and make sure that the transplants happen.

The more we learned about the thinking and actions of Renewal, the more we came to appreciate the devotion and

dedication that these people have for individuals in need. They were always positive and happy in their demeanors and did everything to help with the mundane details of life, such as making sure the donor and his or her family were supported in every way. For example, relieving the anxiety of getting to the hospital on time for surgery, guiding us step-by-step through the initial in-take procedures, and staying with us until the last moment, provided a sense of comfort and reduced the fears and trepidations that can accompany pre-surgical events. After the surgeries, they provided many additional tasks to help the donor and his wife through all of the steps of recovery. They visited him in the hospital every day, picked up James and his wife when he was discharged from the hospital, and drove them to the TLC. They made sure that they had food and offered to assist in any way that would hasten and enhance his recovery.

Now that the transplantation had taken place and James had returned to Missouri, they continued to give attention to me and our needs. Since there were no more impediments to discussing financial matters, I asked David Schischa whether we could reimburse them for all of the expenses they had made in supporting James and his wife. His answer, surprisingly, was “no”. All of their finances are covered with donations since they are a tax-exempt philanthropic organization. David explained that all costs of the actual procedure are covered by the recipient’s insurance. Transportation for the testing, if needed, is taken care of by Renewal, as is food and lodging for a family member wishing to be with the donor during the hospital stay. Renewal’s goal is to assist each and every patient and donor with any help and support they may need. He further explained that all of the testing, housing, and transportation for each donor costs Renewal approximately \$20,000. They raise monies to pay for this kidney donor through donations to Renewal.

My next question was what was the amount of their largest donation? David described how a family had pooled their money and give \$300,000. Ann and I had already discussed the subject, so I told David that we wanted to give \$100,000 which would help five other people to live a new life like I was. Needless to say, this donation was accepted by Renewal as you can see in the photograph on the right:

The people from Renewal became regular visitors to our apartment. In early May, they asked if I could give a presentation at one of their fund-raising events, which I quickly and willingly agreed to do. Ann and I arrived at the site and saw approximately 75 people chatting. A.J. Gindi was conducting this particular fund-raising event. He had told us previously, that he had donated his kidney several years before and that life-saving event became his inspiration to try to help other people receive transplants. A.J. introduced me to the group and I explained my situation from kidney failure to



*Donation of \$100,000 to Renewal,  
accepted by David Schischa*

transplantation. I told them that as a recipient, I had given \$100,000 to help Renewal give life to other patients in need and that every individual in the room had to give money to help others. My plea must have been persuasive since they raised \$250,000 that evening.

I was happy to receive the following letter from A.J. Gindi on behalf of Renewal:

*Dear Friend of Renewal,  
Kidney Transplant NOW  
Please pray for:*

*Donor: Avigayil Mechsa bat Batya Itta*

*Recipient: Mordechai David ben Aliza Freida*



*Ann and I with A.J. Gindi, David Schischa, and Menachem Friedman*

*Today's donor, Avigayil, decided to donate her kidney immediately when her husband the recipient found out he would need a kidney transplant. Because of her selflessness Mordechai will B'H not need to undergo dialysis as most kidney transplant recipients need to until they find a donor. He surely will be indebted to his wife for the rest of his life.*

*Today's Transplant is dedicated to the speedy Recovery of Gideon Ariel. Gideon Received his new lease on life last month with his Kidney Transplant. Gideon is Renewal's first former Olympian to receive a kidney. He played in the 1960 & 1964 Olympics on the Israeli team.*

*B"H, kidney transplants have a great success rate. However, there needs to be Siyata Dishmaya that they be successful. Please take a moment to say tehillim for the success of the transplant.*

*Thank you,*

*A.J. Gindi, Community Advocate, Renewal*

The day before our departure to California, some of the Renewal members came to say goodbye and wish us con-

tinued good health. While we were chatting, Mechachen Friedman told me that I had at least five donors in addition to the ones we knew. We knew about Lucia and Ann's brother, Marshall, but there had been others as well. Although we did not know these people, we were grateful that they had been willing to help save my life. Before the Renewal members departed, we took the photograph shown above.

In the time following the transplant, my normal weekly routine continued. The sequence for kidney transplant patients are blood tests and physician exams twice a week for the first month. The second month, these tests are reduced to once a week. The third month, testing is done every other week. On testing days, Ann and I would try to go outside in the beautiful sunny May days each time we went to Mount Sinai. We went outside when the weather was sunny and warm, but several times, we enjoyed museums instead. Although my stamina was improving, it was still limited so these excursions tended to be short.

One day in May, Drs. Delaney and Arvelakis informed me that I could go home to California. My health, the kidney, all the blood work indicated that I was ready to return to my own home to continue the recovery process. I knew that Ann was worried that it was too soon for me to leave Mount Sinai, but I wanted to go home. It was such a strong urge that Ann relented and began the process of moving.

Since I knew that we were leaving the excellent care of Mount Sinai, I sent an e-mail to Dr. Ron Shapiro to ask about where he suggested we go for care once we returned to California. Since I had only met Dr. Shapiro once, nearly two months earlier, I was not sure whether he would even remember me. I was surprised to receive an answer to my e-mail within 2 hours as follows:

*Shapiro, Ron (Transplant)*

*To Gideon, Rafael*

*Dear Dr. Ariel,*

*This is already organized. Cedars has agreed to follow you—I got this sorted out either just prior or just after your transplant. Rafael will explain it all before you leave New York.*

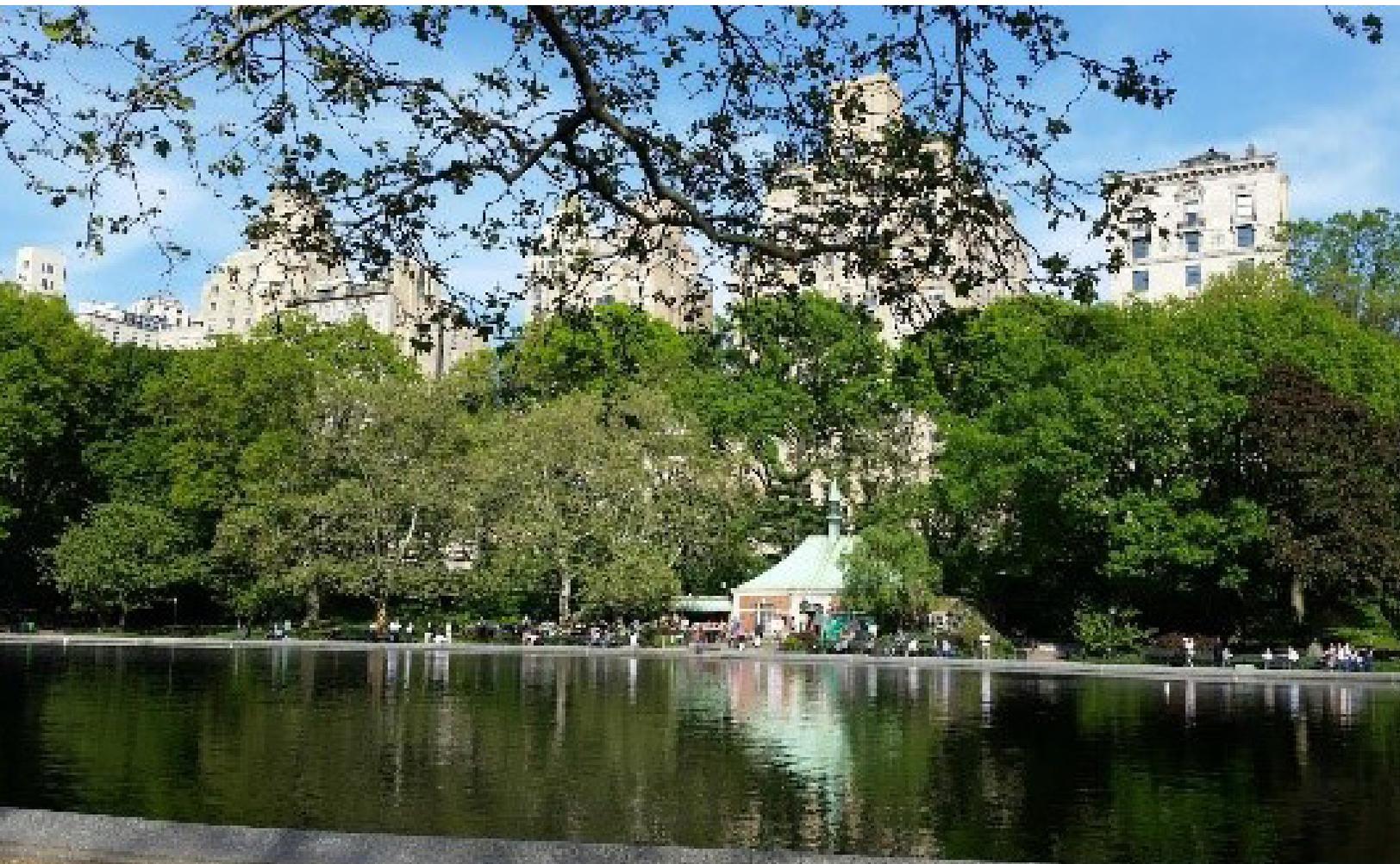
Ann and I could not believe it. It had happened again. The most unbelievable attention from caring people and this was the head of the transplant department. He had so many things to do that were very important and life-saving, but he had taken personal time and effort to respond to me. We

were and have remained in awe at the fantastic people at this hospital.

Our trip back to California was the same process, in reverse, as traveling to New York City. This time, however, I was so much healthier. Ann packed boxes for shipping, cleaned all of our things out of the apartment, arranged for air and ground transportation, and took care of the other things involved with moving home. My “job” was to concentrate on packing up our electronic gadgets, and, at Ann’s insistence, to take care of myself and not overdo anything. I had to organize our computers, movie system, the new printer we had acquired, as well as the numerous collection of wires and connectors. Ann had an entire box just for these things. She made sure that one of my jobs was taking a long nap in the afternoon.

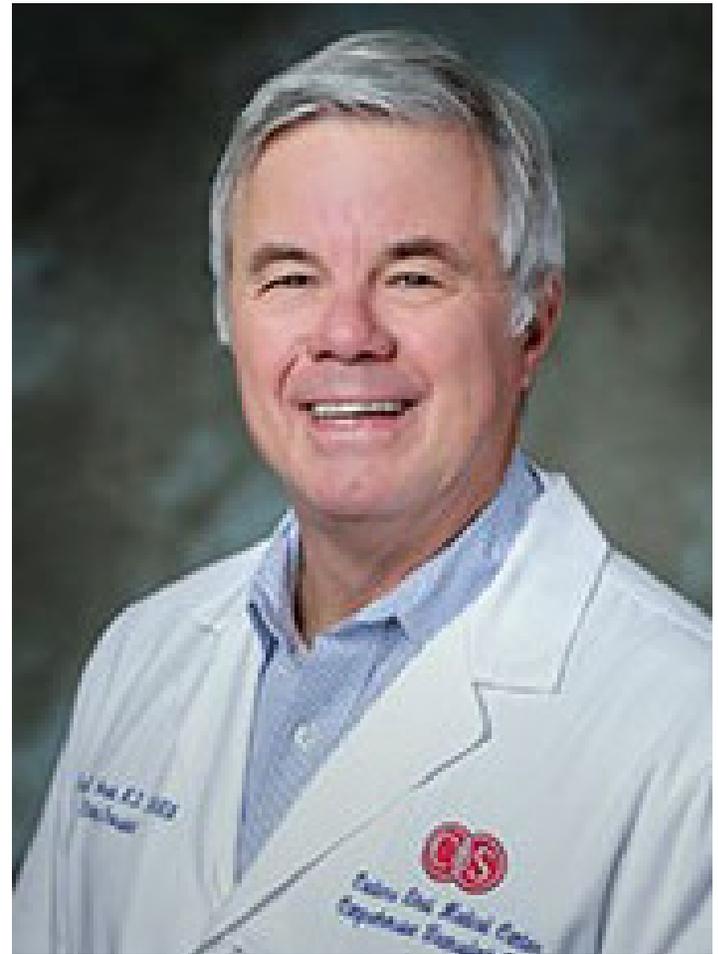
My last examination at Mount Sinai for blood tests and the final doctor exam included a meeting with Dr. Rafael Khaim. Dr. Khaim is the clinical operations manager for the kidney and pancreas transplants. He had been the one who discharged me from the hospital and now he needed to explain all of the details of life in California vis a vis my

### *Outside in Central Park*





*Dr. Rafael Khaim*



*Stanley C. Jordan, MD*

new kidney. He explained that my care had been arranged through personal contacts between Dr. Ron Shapiro and his colleague, Dr. Stanley Jordan, at Cedars Sinai Hospital in Los Angeles. These two doctors were old friends and had on-going research projects together. Dr. Khaim had contacted and arranged for my care to be transferred to Cedars Sinai, and had transmitted all the necessary records regarding my surgery and post-surgical care. It was a relief to know that we had a doctor in California that Dr. Shapiro knew personally. Because this connection was essential for me, a kidney transplant recipient, we felt more confidence in leaving.

Dr. Khaim gave us a large notebook with all the necessary data we might need at Cedars Sinai as well as contact information. He was able to answer all of Ann's questions and calm her with assurances that we could contact him if there were any problems. We were sad to leave Mount Sinai but we were happy to be going home. We thanked Dr. Khaim profusely for the help and kindness he had shown us.

Finally, May 21st was our departure day from New York City. What a fantastic day it was to be traveling home with

my "industrial strength" kidney and a new lease on life. I had spent only forty-nine days in New York City, but my future life had evolved from a horrible existence in renal failure to a healthy promising future of good health. It was more than a dream come true. I truly had won a gold medal at my Third Olympics.

We contacted Cedars Sinai Transplant Center the day after our return to California and scheduled an appointment with Dr. Stanley Jordan. A week later we had our first appointment there and discovered a West Coast version of Mount Sinai. Dr. Jordan smiled and was quite happy about my successful transplant. We discussed the many people he knew at Mount Sinai, especially his friend and colleague, Dr. Shapiro. He reported that my blood test results that morning indicated that my path to good health was continuing. We left our new California hospital and staff with relief knowing that I was in good hands.

When we returned to our home, we researched Dr. Jordan. He had an amazing profile and we pleased to learn that he continues to be involved in research projects. Everyone,

including doctors, who continually immerse themselves in new explorations, are learning how to bring these discoveries into their lives and improve their professional skills.

Stanley C. Jordan, MD

Director, Division of Nephrology

Medical Director, Kidney Transplant Program

Medical Director, Human Leukocyte Antigen and Transplant Immunology Laboratory

#### Summary

Outstanding Clinical Investigator Award, Western Society for Clinical Investigation, 2016

Pioneer in Medicine Award, 2015

Prize for Research In Scientific Medicine (PRISM), 2015

UCLA Alumni Association Medical Science Award, 2006

Now that I have a healthy, properly functioning kidney, I have asked myself what I learned from this experience. There are three categories of thought: my own individual health experiences, the medical professionals I encountered, and advice for other people with kidney disease.

In retrospect, I realize the many mistakes and missteps I made between the first evidence of kidney failure and the transplant. I was informed at the beginning that transplantation was better than dialysis. For this reason, Ann immediately contacted the suggested hospital, UCSD, and made an appointment for us to attend the initial, mandatory class. This class is required before they would begin the testing to determine whether or not I would be accepted as a transplant candidate. At the end of the two-hour class, Ann had raised her hand and asked whether age was a factor. The answer had been that they have no age restriction.

We proceeded under the assumption that, other than failing kidneys, I was in good health and would be approved for transplantation. To that end, I had the “green light” laser surgery to ensure that my new kidney would have no back pressure from an enlarged prostate; I had a colonoscopy to verify that there was no cancer; and I had numerous other medical examinations during the nearly six months while we waited for me to be placed on the “list”. It was, therefore, a crushing event when I was rejected in November due to my age. They knew my age in June and they could have told me at that time that I should consider looking for alternative transplant hospitals. This process of being accepted by a hospital, spending six months of testing and waiting, and then being rejected due to age was repeated twice before we traveled to New York and received a kidney.

What I understand now and wish I had learned at the beginning rather than at the end of the process is the importance of finding the right hospital. If the hospital does

not provide timely information about you and your current status, if they are not forthcoming about your prospects for transplantation, then keep looking until you find a hospital that will. It is your life. Do not let a hospital delay the process and steal time from your life. Ask at the beginning and keep the pressure on them. You are your only advocate.

In retrospect, I believe that I started dialysis too early. I certainly did not feel good when my creatinine reached 6. I started the procedure with peritoneal dialysis but soon learned that it did not provide the freedom of life that had been promised. I was unable to sleep, I always felt so full of liquid so it was difficult to eat, and then I acquired a potentially deadly fungal infection. Hemodialysis was equally horrifying. Not only was it time consuming, but I felt terrible all day and night. It kept me alive, but there were many days that life did not seem worth living.

I believe, however, if I had found a hospital like Mount Sinai, which approached the situation with a sense of urgency, I might have been able to skip the agony of dialysis or delayed the onset. My message is to wait as long as you can before beginning dialysis. If you have found the right hospital and the best staff, they will help you with this decision.

Another mistake was that I did not recognize nor accept kidney failure as just a disease. I was ashamed and embarrassed to ask for help. This was a dreadful mistake. I should have begun actively and, with real urgency, looking for a living donor. If this is your situation, you must aggressively search for a donor. You might need more than one potential donor since frequently donors and recipients have incompatibilities of blood types, antigens, or other issues. Keep looking. Make sure your hospital processes your potential donors quickly. Never forget that this is your life and you must maintain as much pressure as you can to save it. If you have found the right hospital and doctors, they will be as involved and concerned as you are. They want to give you life as much as you want to have it.

Another mistake we made was not realizing the need to aggressively search for living donors. In general, a kidney from a living donor is healthier and will last longer than one from a cadaver. There are wonderful, generous people who are willing to help you. Sometimes you just have to ask. That was how I was able to find my wonderful donor, James. I asked for help. Do not stop asking for help, send blogs, put up posters in coffee shops or company notice boards, and spread the word. Do not be shy about asking for help. Remember, it is your life you are saving.

Be sure that the potential donors are connected to your transplant hospital or support group. Since distance is to be maintained between donor and recipient, find a way to keep checking on the progress in identifying a donor match. This step will be quite difficult because of the separation between



*Last Week Tonight with John Oliver*  
<http://arielnet.com/ref/go/2791>

donors and recipients but it is the most important aspect. You must have a donor and I suspect that the expression “the squeaky wheel gets the oil” is probably appropriate in this area as well.

Between the discovery of kidney failure and transplantation is a giant, dark maze of mystery, lost time, and ignorance. Even when you acquire copies of your own medical history, it is virtually impossible to know what the doctors and the hospitals are actually thinking about your individual situation. The desperate recipient is kept in the dark about the chance of transplantation. Even if living donors are being processed on your behalf, you are not allowed to learn anything about their progress or failure. The recipient is essentially blind and gropes about in the dark at each and every step, all the while hoping for a donor and a successful transplant.

While we were in New York, we met another recipient who had spent the previous two years as I had... waiting in vain. He had a living donor but one month before his transplant at a hospital in Connecticut, his doctor detected a spot on one of his kidneys. He was told that the kidney would have to be removed and he would have to wait two years before he could be transplanted. However, since he was 68 years old, two years later would put him over their limit of 70 years for transplantation. He asked what this meant for him. The answer was that he was going to die. The end of the story for this man is much happier. He contacted a doctor at Mount Sinai. His kidney was removed, found not to be malignant,

and he received a kidney from his living donor the following month at Mount Sinai Hospital.

Ann and I spent two miserable years stumbling around making one mistake after another. But my wife would not give up. Every patient with a kidney problem must have someone to help them in their struggle. You must have someone who will encourage you, and who will search, dig, question, harass, and never quit. You feel terrible every day but you must have an ally who feels better and can continue to search on your behalf.

We compliantly waited for the system to work for us. The system failed us until we found Renewal and Mount Sinai. These two organizations believe in life and work to give each person, donor and recipient, the ability to live. Without them, I probably would not be here today.

Keep trying. Search relentlessly for donors. There are wonderful people out there who will selflessly, lovingly, give you a kidney. Keep looking for them. Find a hospital that is committed to saving your life not just extending it with tests and exams. Keep looking for that institution and those doctors that are committed to you. They are out there. Never go outside of the legal system. There are legal ways to find a kidney but you have to keep looking for one.

### **Never, never, never give up!**

So, this is the end of the amazing story that revived my life from the horrible existence of dialysis and renal failure. I am recovering my health and my life. I hope to be able to travel again with my loving wife, Ann. I would never have made it without her. She never gave up for one moment and always encouraged me. How lucky I was to find the amazing organization, Renewal, and the best hospital and doctors in the world, Mount Sinai in New York City.

Most of all, I owe my life to Dr. James Hackney.

James, very nearly a complete stranger, gave me one of his kidneys. He gave me life just because I asked him for help and he believed that he must help people. I still cannot believe that such saintly persons actually exist in this world, but James does. Every morning when I wake up, in good health, I appreciate and thank this wonderful man for giving me life. I am so happy to be alive. I owe my life and happiness to James Hackney.



