For many people, being told that their kidneys are not functioning properly and they will need to undergo hemodialysis on a regular basis is a frightening and unfathomable experience. For me, however, it was a heavily relief when my doctor called me one Tuesday morning and said, “Al, we’ve found a spot for you even sooner than we thought we could. You start tonight.”

During that final predialysis afternoon, I devoured a final farewell banana and washed it down with a quart of ginger ale. The reason I was not severely disturbed about starting dialysis was that for a year and a half I had been wearing a little black bag that collected my urine as it dripped through the exposed ureters on my stomach. I was informed that this ureterostomy was needed to keep me alive and shall we say well until my kidney function deteriorated to the point that hemodialysis was needed.

At age 19, as a college freshman beginning to meet a variety of people including some attractive young females, I found my little black bag a great hindrance to my then nonexistent love life.

Not long after beginning dialysis, I entered the Peter Bent Brigham Hospital (now Brigham and Women’s) to have my kidneys removed because they were believed to be swollen and infected. When my kidneys were removed, the ureterostomy was terminated, and I was informed that I would never again have to wear that bag; that when I received a kidney transplant the ureters would be rerouted inside of my body and I would once again use the normal means of getting rid of my kidneys’ wastes. The week I returned from the hospital I held a bag burning party and officially cremated that LITTLE BLACK BAG!

Being told that I should refrain from indulging in certain beloved foods and dramatically restrict my fluid intake as conditions necessary for successful dialysis were relatively slight discomforts when I knew that I would no longer have to see those ureters staring up at me every few days.

* This article was written many years ago. At that time very few dialysis centers existed.
when I changed that bag. I had a wonderful feeling of personal solidarity once again. Ah!

And how faithful I was to my dietary and fluid restrictions during that first year. I tried very hard not to drink too much or eat foods that would cause my blood chemistries to spiral out of sight. I used to watch longingly at social outings and parties as pieces of pizza and chocolate cake and other such tabooed goodies were consumed before my eyes by my family and friends while I sat quietly with my thimbleful of ginger ale.

However, after about six months of this ascetic living, I began to loosen up a bit and occasionally sneak a bite of chocolate cake or a potato chip. Time, however, proved the old commercial jingle to be true, in my case anyway, for as it turned out I couldn’t eat just one. By the end of that first year on dialysis, I was a full-fledged cheater. Now when my friends and I went out and they consumed cheeseburgers with french fries, mushroom and pepperoni pizzas or chicken chow mein, I not only went along but aided in the consumption of the goods.

I began to put on some weight and regained some of my physical strength and self-confidence. As a result I became much more active physically. I engaged in such activities as handball, basketball, swimming, and bicycle riding, to name just a few. At college, while still on dialysis, I organized and became captain of an intramural gym hockey team that came in second in our division and advanced to the quarterfinals. When the league statistics were released my name was number six on the list of top scorers in our division.

I would frequently go on long bicycle trips or go hill climbing with friends. Although I usually fell behind, I always finished! Of course, there were times when I overstepped my physical capabilities and got sick or, on a few occasions, even passed out. But on such occasions, as soon as I was able to stand I would swear, pound my fist against the nearest inanimate object, and continue on with whatever it was I was doing! Regardless of the obstacle I always and without reservation continued my education and physical exercise.

However, there were not infrequent interruptions in my schooling and physical exploits over my five years on dialysis because of one surgical or medical procedure or another.
The most traumatic operation I underwent during those dialysis days was the unsuccessfully transplanted kidney that my father gave to me. It had taken doctors and my father almost two years to convince me to take that kidney. My father had told me how happy it would make him feel to give me his kidney so I could be free of that machine. When the kidney lasted only five days I felt worse for him than I did for myself. I felt guilty for having subjected him to that painful surgery only to see his loving gesture fail. I vowed never to even consider taking another kidney from a family member even if it meant spending the rest of my life on the machine.

As fate would have it, however, three years later I received an early morning phone call from a doctor, as I had five years earlier. Only this time I was informed that a kidney had been found that might take to me. By midnight, that kidney was part of me and so it remains upon this writing two years later.

I cannot really say that my life style was drastically changed by that transplant, but I think it is safe to say that some notable adjustments of both a physical and psychological nature were made, especially as I began to regain my physical strength.

For the first few months there was that unsightly swelling and puffiness that often comes with fluid build-up in the body because of the still far from perfect functioning of the new kidney. During this period my fluid intake was just as severely restricted as it had been when I was on dialysis; only now I was more mindful of adhering to those restrictions because I now had something definite and immediate to lose by cheating.

In any case, after only a few months the swelling subsided and my fluid ban was lifted. In fact, I was told to flood the kidney, which I now for some strange reason nicknamed "Junior," with water to help keep it functioning properly. Suddenly, for the first time in years, I was drinking as much as I wanted. I turned in my thimble for a stein and made good and frequent use of it! I no longer felt guilty when eating a chocolate bar or a piece of pizza.

I didn’t feel guilty, that is, until upon one of my clinic visits a few months after the transplant. It seemed that my blood pressure had become elevated as a result of the kidney. Since links have been found between blood pressure and the sodium in normal table salt, I was told never to lift a
salt shaker with the intent to shake and to avoid salty types of food and beverages. And since salt in some form and amount is detectable in an infinite number of foods in western man's diet, I was given an extremely difficult if not impossible task.

While on dialysis I knew that even if I cheated excessively on my diet the machine could purify my blood and contain my blood chemistries to within reasonable limits. Now there was no more machine to rely upon to take off the harmful metabolic end products and excesses. I was on my own with Junior. I had to pay more careful attention to my diet and take the prescribed medications or risk the consequences of an out-of-sight blood pressure, which could include the loss of my new found friend.

It was unfortunate that these were not my only post-transplant problems. I had been experiencing slight rejection episodes with the kidney for the first three months. Then during the fourth month, something happened that opened up the kidney and ended my rejection problems permanently. The problem was that it almost ended me as well. You see I had somehow contracted a form of encephalitis called cytomegalovirus. It was touch and go for a few days. No one really knew what was going to happen, including the doctors.

Well, over the years I had had plenty of practice fighting a variety of ailments and the pain that accompanies them. Through it all I had always kept my body in good physical shape, even if it had been at the expense of my diet. Also, I had never stopped my college education. There were some postponements, but I always kept my mind well exercised, as well. If ever I had need of these strengths it was then.

I did survive that incident as I'm sure you realize. Junior is alive and well. I feel great and not long ago I finally got my bachelor's degree, cum laude, I might add!

Well, I hope you'll excuse me now. I'm going to challenge Mount Chocorua in New Hampshire with some friends in the morning, and I really must get a good night's sleep.
Nine years ago, at the age of 46, my somewhat static nephritis took a downward turn. I can, to this day, vividly recall my feelings of fear and desperation when my doctor informed me that within a few months I would be faced with the choice of dialysis or transplantation. I hope that my own experiences and feelings may be of some small assistance to those who have been, or are about to become, members of our most exclusive club. During these past years, I have had two kidney transplants and spent three and one half years on home dialysis. My last transplant took place in June of 1972 and so far has been successful.

Fortunately for my wife and I, a social worker and several doctors at my hospital, the Peter Bent Brigham, took the time and effort to explain and indoctrinate us into this strange and fearful new world we were facing. It appeared as though dialysis was the least risky and most practical route for me to follow. My wife, with absolutely no medical training, and terrified at the prospect, went along with the idea of dialyzing me at home. There were many sleepless nights for both of us as we contemplated the inevitable upcoming problems. At the time our three daughters ranged in ages from 14 to 20. They were of great moral support and eventually also learned to help with the running of the dialysis machine.

Our training period at the hospital and the first year of home treatment were mostly uneventful. My family was wonderful, and we had many pleasant evenings eating dinner, talking, and watching television while I was being dialyzed.

Physically, I fared well on dialysis, but after a year, I began to get the urge to sever the umbilical cord to the machine. Long range, I could see that dialysis would become increasingly wearing and trying for all of us, and as my children grew up, that my responsibilities to them would be lessened. Therefore, I felt that I could assume an additional risk and could consider transplantation.

My sister was willing to give me a kidney and as we were an excellent match, I decided to take a try at transplantation. The operation was sched-
uled for the following year, which was the normal waiting period in those days.

By this time, my second year on the machine had passed and I was totally convinced that transplantation was the route for me to follow. The operation was successful and the transplanted kidney started functioning on the operating table. I went home within two weeks with a normally functioning kidney, and I fully expected that my problem days were behind me.

Unfortunately, this was not to be the case, and I started to reject the transplanted kidney. I returned to the hospital and spent long anxious days and nights that stretched into weeks, getting sicker and sicker as the attempts to reverse the rejection failed. These were indeed dark and sick days. The psychological blow of such a setback was almost unbearable. The depression I felt lasted for a very long time.

However, the short space of time that I did enjoy the transplanted kidney eventually whetted my appetite to try again. The traumatic experience of the past eventually faded away, and I placed myself on the cadaver kidney transplant waiting list. Physically, I seemed to be doing at least as well as before on dialysis. However, the original desire for transplant was still there. My ever patient wife, although she never complained, was beginning to suffer from the tedium and restrictions of my dialysis.

A little more than a year later, I received a call that a kidney was available for me and was a reasonably good match. This time the kidney did not work on the operating table but did start functioning about three weeks later. Cadaver kidneys have the tendency to “go to sleep” and quite often do not function for periods extending to many weeks. I did have two slight rejections during the first few months, but these were easily treated. As with most operations, there is a period of problems that follow, but looking back after several years, they now all do seem minor. Believe me, I never cease to be thankful and also am considerably in awe of what has been my good fortune in this last period of my life.

Some of the thousands who have tried the transplantation route have fared better than I have in that their first attempt was successful. However, unfortunately, many more have not been as fortunate and have never had a successful transplant.
There is no way that I can unconditionally recommend transplantation for everyone. It is a nerve-racking experience. The mental torture that one goes through before the operation, and especially afterward if the kidney does not function immediately, can try the strongest of us. The many long, lonely nights one can spend in the hospital wondering whether it will or will not eventually work is often more than one can endure. There is no track record to follow, as no two transplants act quite the same, except that most go through short periods of usually reversible rejection shortly after surgery.

The physical discomfort from the surgical phase of transplantation is fairly limited. Usually, you are free of all tubes and encumbrances within seventy-two hours and if you are lucky, sitting down to the first “no restriction” breakfast in a long time. Orange juice, bacon, ham, eggs, coffee, and anything you want! For most transplants, there are no eating restrictions, and no physical restrictions, except that contact sports, such as hockey or football are out, as the kidney could be damaged by a sharp blow. Swimming, tennis, golf, etc., are all great!

Prednisone, one of the drugs that is taken daily, does increase one’s appetite, and it may be difficult to keep from getting fat. Also, all of those foods that have been forbidden for so long do taste so good! You are returned to a normal life, a miracle! The two basic drugs that are taken daily are usually Imuran and Prednisone, in pill form. At times these drugs can produce personality changes, such as irritability, particularly in the initial high dosage stage.

There is no guarantee that the transplanted kidney will work, if successful, for one month, six months, or many years. Only time will tell. So much depends upon individual circumstances, age, blood sensitivity, how well one is faring on dialysis, and what quality of life he or she is willing to accept. These factors can make for many months or even years of soul searching before going the transplant route.
I found out about my chronic kidney disease in November of 1987. I had just turned 24 and had also just married in October of that same year. Upon returning from my honeymoon I had to undergo a complete physical for a new job I was starting. This physical exam started a ball rolling which led me to nephrologist Ted Steinman of Boston’s Beth Israel Hospital. That fateful day at the end of November, as I sat in Dr. Steinman’s office with my husband and mother, I felt like a bomb had been dropped, like my whole world was caving in. One of my first thoughts was “Would I ever be able to have a baby?” At first I assumed no. I was devastated with the thought of not being able to have my own child. Soon after, the miracle of a successful kidney transplant was explained to me. I realized that it might be possible for me to have a successful pregnancy.

I spent 2 years on dialysis waiting for a cadaver kidney. After receiving my transplant, it was necessary for me to wait at least a year before trying to become pregnant. Dr Steinman wanted to be sure my kidney was stable and that my medications were at a safe level for the baby.

When I became pregnant, I started seeing Dr. Steinman on a two month interval instead of three. I saw my obstetrician, Dr. Ralph Aserkoff the usual once a month. My pregnancy seemed perfect. I felt great. I didn’t have any morning sickness or excessive tiredness. I exercised almost daily. Everything appeared perfect. Then in my sixth month my blood pressure was a little high. Dr. Aserkoff began seeing me more often: every two weeks. It was comforting to know that both my doctors were in touch with each other throughout my pregnancy. In my seventh month, my creatinine had gone from 1.3 to 1.6. When I had only five weeks to go, Dr. Steinman called me the day after my visit with him to tell me my creatinine had gone up to 2.2. He wanted me admitted to the hospital the next day. I knew there was a possibility of this happening, but I never really thought it would. I suddenly became nervous.

Dr. Steinman decided that my baby was going to have to come out to protect my kidney. My due date was September 25th. On August 21st labor was induced. The next evening, on August 22nd my daughter Elana Beth

11c—Our Miracle Baby
Lauren Marks

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Dr. Steinman decided that my baby was going to have to come out to protect my kidney. My due date was September 25th. On August 21st labor was induced. The next evening, on August 22nd my daughter Elana Beth
was born. We call her our miracle baby. Despite being five weeks early, she was 5 lbs. 3 oz. and perfectly healthy. We couldn’t have asked for more. As for me, I went from being very sick, to being a dialysis patient, to being a transplant patient, and actually having a baby. My kidney function stabilized after Elana’s birth. If it stays at 2.2 forever, I can be perfectly healthy.

But, I am hoping that it will recover so that I can try to have another baby. There isn’t anything in the world like having your own baby with someone you love. It is going to be a very serious consideration though. I wouldn’t want to do anything to risk losing my kidney and the wonderful lifestyle it has allowed me. I am truly grateful that at least I’ll always have Elana Beth.