

**Make Your Kidney Last
By Putting It First!**



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*Dedicated to kidney
transplant patients everywhere*



“WHY ME? That was the question I asked God and myself over and over again. I knew there would be no quick reply, no simple answer as to why at nineteen years of age my body was being poisoned by the blood running through my veins. With each passing day I became weaker. My eyesight became blurry. The color of my skin was a sickly-yellow. And when I had the courage to look, I could barely recognize myself in the mirror. Oh sure, the doctor told me the name of some long scientific medical term that described my illness but why was this happening to me?

Just a year ago I was graduating from high school looking forward to college and the possibility of becoming a professional athlete. How could this have happened to me? I was young, healthy, and full of life; I was invincible! Or so I thought. I never imagined that in pursuit of a dream, the battle against this deadly virus would come second to the battle against myself. My name is Paul and this is my story.”

What you’ve just read is from the back cover of my autobiography published in 2006 titled “Transplant To Handplant: In pursuit of a dream ...” and I believe it describes perfectly my state of mind and emotions amidst the life and death struggle I was facing. With each passing day I did become sicker and weaker just as I had written. I had no idea what my future held or if I even had a future. One thing was for certain, my life was about to change.

And on September 6, 1989 my life did change. My father gave me one of his kidneys and provided me with a desperately needed and grateful second chance at living. Doctors had told me back then that if all goes well, I might get 10 or even 15 good years out of that transplanted kidney; you may have heard something similar during your transplant experience. While certainly encouraging, in my mind, I was going to make this kidney last a lifetime. Statistically, the odds were not in my favor but I just knew this would be the first and last time I’d need a kidney transplant. I was going to figure this out ... and so far, I have. I want the same for you.

It’s now been 27 years since the transplant and I’ve never felt better! Understand that it hasn’t all been smooth sailing. I’ve had lots of ups and downs since then. In fact literally, ups and downs, mostly on the vert ramp though. Which by the way, has sent me to the emergency room more times than I care to remember, or actually can remember. There were even a few serious close calls but I’ll save that for later. I’ve learned a whole heck of a lot along the way. Though it may sound like a contradiction, especially when I’m flipping and spinning 20 feet above the ground on the big ramps, I’ve always put my kidney first. And for those wondering why I do it in the first place, why I risk life and limb, or in this case life and kidney, then you’ll have to read the book; I promise you won’t be disappointed. I’m publishing this information because I want to share my experience with you so that you can make your kidney last as long as mine has or even longer! I want you to learn from my mistakes and from my successes. If I can make MY dream come true, so



can YOU! And hopefully yours doesn't include the possibility of leaving on a stretcher every time you do it, but if it does, I'm here to tell you – Go For It!

So let me tell you how I did it...

I understand how stressful, challenging, and exhausting it is just getting through the whole transplant process itself. You run the course of emotions. From first getting the word that you're going to receive the gift of life, to waking up groggy, very uncomfortable in recovery and figuring it out as you go can be completely overpowering. You feel helpless; it's out of your hands. Even worse, if like my recovery room experience where I think Nurse Ratched was assigned to me that first day, it was brutal. There was no water, no ice chips, not even a damp washcloth allowed for a dry mouth like I've never experienced before, but maybe it was for my own good. Thinking I was dying while recovering, I somehow I managed to make it through.

If you had a renal transplant at the Cleveland Clinic In 1989, you would have stayed there for 2 weeks after the operation; the first week in the actual hospital and the other in their beautiful rehab facility which was more like a 5 star hotel with great room service. At least that's what I remember... Oh the lobster and hot fudge sundaes!!! And all inclusive too!!! Aside from the life-saving operation taking place, looking back, dad and I actually had a pretty good time together in recovery with some hilarity mixed in (it's in the book). But of course I couldn't wait to get back home and pick up where I left off a year earlier when my kidneys first started to fail.

So once back home in Buffalo the real recovery started. Hunched over like a 100 year old man for what seemed to be an eternity, and where just the site of a flight of stairs left me exhausted, my body started to heal itself and I was on my way. I learned a few tough lessons right away though. **Learn from my first 3 mistakes:**

1. **Never Ever take your transplant meds on an empty stomach!** At least not for a few years until your body acclimates to these powerful drugs, unless you have an iron stomach; I sure didn't. I learned the hard way more than once being doubled over in extreme discomfort 20 minutes after swallowing those life-saving pills. Most likely it was the prednisone causing the stomach problems. I believe I was taking 30mg a day at the time. This usually happened when I was running out of the house in a hurry to hang with friends and didn't bother to eat anything. Always putting my kidney first knowing I needed to take my meds, I would just pop'em with a half glass of water on the way out. My advice is to eat something like a bowl of cereal, cup of soup, waffle, half peanut butter sandwich, something with a little substance to it. Even just 2 slices of bread or a piece of fruit if you're in a rush can lessen the impact on your stomach. Failing to do so might give you nausea, diarrhea,



constipation, and absorption changes. Unless otherwise directed by your physician, always take your transplant meds with food.

- 2. Don't push yourself on recovery time!** In other words, don't overdo it; take your time, a reasonable amount of time to start getting back to your life. Slowdown and be mindful of what you're body just went through. Discuss this with your doctor. Otherwise, like me you might end up on a medevac flight back to the hospital soon thereafter (complete story in the book). Stairs were a killer for me for the first few weeks back home; I was exhausted half way up a flight. You might experience the same but don't worry, things do get easier; be patient. If you've already read my book "Transplant To Handplant" then you know patience is not one of my virtues. Side lesson; Mom knows best! She tried to warn me to take it easy but I pushed myself as I often do and many times I pay the price. So listen to your parents and those who care about you. They only want to see you healthy again and back to 100%. Take your recovery seriously and don't push too hard or you may find yourself back in familiar surroundings; a hospital.
- 3. Truly understand that your immune system is severely compromised!** It may sound cliché to us transplant patients now but it bears repeating and most importantly, understanding. Knowing how your immune system works is vital to extending the life of your new kidney. I had little knowledge of how it worked and underestimated its importance. I really should have been wearing a mask the first few weeks out in public places but at 20 years of age that wasn't the look for me. So I paid the price. Two weeks after the transplant I had a night out with old friends at the club and it kicked my butt, hard. I awoke the next morning about 6:00 am in a cold sweat and shaking uncontrollably. I thought I was in full blown rejection mode and I was definitely worried. After some frantic phone calls by mom, she said we had to go. So off to the Cleveland Clinic we went. It's about a 3 hour drive from Buffalo to Cleveland hugging the Lake Erie shoreline. The long story short is 4 days later, after a smattering of tests and antibiotics, I was feeling healthy again. Oh, did I forget to mention the violent car crash, the shooting, and the emergency helicopter ride to the hospital? I did? Well I won't bore you, it's in the book. 😊

Even 4 years after the transplant I was still highly susceptible to viruses and infections. My immune system was far from normal as proven to myself on a trip back to my new home in Florida from my hometown of Buffalo. I had been running myself down during that week catching up with family and friends and had little sleep throughout. Well it all caught up with me the day after getting back to Florida. I noticed while at work that my upper left arm and my side started to hurt and red spots appeared. The pain became more intense as the day wore on so I left early to see the doctor. I was diagnosed with shingles. "What the heck is



shingles?" I said. For those who don't know, it's a viral infection that causes a painful rash and it comes from the same virus that causes chickenpox. I was told usually older people got it ... but I was only 24! Welcome to the world of immunosuppression. It was times like these that I felt waaay beyond my years. That's why I'm stressing to you to understand just how much of an impact our suppressed immune systems can really have on us. Get educated so that you don't find yourself exposed to all kinds of nasty things like viruses out there.

So as time went on... 5 years, 10 years, 15, 20, 25 years and counting, my life took some wild and unexpected turns. I would overcome each and every obstacle and mountain that stood in my way. I knew if I had made it this far that I was going to make my kidney last a lifetime. But what was it really that got me this far? I took stock of my life and how the transplant had changed me. I reflected on how I was living these past years. **It all came down to 3 core values:**

- 1. Love Yourself:** No one is more important right now than you! Especially immediately after a transplant. It's ok to put yourself first for a while. Yes, you may have other seemingly more important people and things in your life that matter but without your health, you have nothing! Most of you realize that by now. And if you don't have your health, you can't tend to others who rely on you for the love you give them. Remember, if you can't love yourself, you can't love someone else the way they should be loved. No matter what has happened to you in the past there comes a time to forgive or at the very minimum, let go. You may never forget but you need to at least let go and move on. Whether it's forgiving yourself or someone you believe that has done you wrong, keeping it suppressed like the powerful meds do to your immune system will only serve to let bad things slowly creep into your life and keep you in a constant battle with your emotions. I say Let Go and Love Yourself again! It's the right thing to do.
- 2. Love Your Life:** Life is a gift and that gift has been presented to you; unwrap your full potential. It's time to start living again, no matter how many years have passed you by. My favorite all-time quote is from Baseball Hall of Famer, Satchel Paige who stated "*Age is a question of mind over matter. If you don't mind it doesn't matter*". And as one of the oldest competitors in my sport, I find this becoming more meaningful as the years go on. Your dreams, your hopes, your wishes, your passions, your mission, whatever it may be, you can now continue where you left off to reach new milestones in your life, or discover it for the first time. Either way, you have a life worth living! You have been blessed to have a second chance; take full advantage of it! I know that I am.



- 3. Love Your Kidney:** From whomever that new kidney came, it was given to you out of love and sacrifice of another so that you may have a better life, a healthier life and your number one priority from this point on is to take care of it like nothing else. Put it first in everything you do. So what exactly do I mean when I say "...by putting it first"? Well, there's a lot to it. **Start by doing the following:**

Your new kidney is **priority #1** and should never be far from thought. Yes, you can live your life now and get back to doing all the wonderful things you enjoy but always, always, always be aware of the consequences your actions may have on that kidney. Sometimes we just don't understand what can happen and it can lead to near fatal mistakes. We need to educate ourselves. Once you start feeling better and get back into the swing of things it's easy to forget what's really at stake and you can start to take things for granted again. I truly hope that by me my writing to you will help educate and potentially lessen the negative impact certain actions may cause on your kidney health. In other words, learn from my mistakes. I've made plenty of them.

Don't ignore those core values, truly live by them. Your kidney health may depend on it! They can have a direct impact on your mindset and therefore your outlook on life. And when that is affected, it can have significant ramifications whether good or bad to your health.

Next, let me break down the 5 main aspects that have made all the difference in extending the longevity of my kidney function.

- I. My Meds** – Your number 1 rule for extending the life of your kidney is to ALWAYS, ALWAYS, ALWAYS take your meds, like clockwork. Never miss a dose. Develop a system that works for you. It took me a few years to figure out mine and refine it but I've been doing it now for so long that it's second nature. It also serves as a great reminder to take your supplements as well; which I'll talk about later in an upcoming section. My "system" has evolved and changed over the years as I gained more confidence in both kidney function and myself, as well as changes in the meds themselves. For example, back in the 80's cyclosporine came in a dark brown light-reducing protective glass bottle with a syringe because it needed to be mixed with another drink like chocolate milk or juice. I chose the chocolate milk. I mean c'mon, who wouldn't want a nice big cold glass of a heavily laced cyclosporine milk to drink, yummy. Then cyclosporine came in hard-to-swallow horse-pill sized caplets in foil along with a strong odor. And finally as a lighter than air small capsule. This finally made things much easier when I needed to take my meds with me out the door. I went from carrying a glass bottle to a plastic bag of meds, to a small foil wrapped pill bundle in my pocket. And now at home I just have 2 bottles that I fill with a



multitude of meds and supplements; 1 for day and 1 for night and I pick out what I need. Do your absolute best to try and take your meds at the same time every day; don't miss a dose. For me, 12 noon and 12 midnight work very well as it coincides with my lunch time at work and around the same time a go to sleep (update - as of 7/23/2016 I no longer take any meds in the day. I have moved everything to night). Always have extra meds on hand; keep a bottle at work, in the car (although heat can affect them – so be aware), keep extra meds just about anywhere you may go on a regular basis. There's nothing worse than being away from home and suddenly realizing you don't have your meds with you.

When it comes to travelling be prepared. My love of vert skating has taken me all over the world. During the competition season I would travel almost every weekend to another city but it wasn't until I planned a trip to Asia where I was very concerned that if I ran out of meds, I'd be stuck and in a very precarious position. So here's what I did. I first had my nephrologist write a note indicating my medical circumstances. I then carried my medical history in a folder with me. I took every prescription I had in the original bottle and added another 2 weeks to that just to be safe. So all in all I think my entire carry-on was full of drugs at that time... lol. And that reminds me, whether you're travelling on a domestic or international flight, always, always, always keep your meds in your carry-on luggage and have an extra supply in your checked luggage. Yes, there have been times where I was very glad I had it with me in my carry-on. Have access to it even on the return flight back home. Don't take it for granted just because your meds are packed in your checked luggage and your flight is non-stop that nothing could go wrong... WRONG! Flights are canceled, layovers take longer than anticipated, and emergency landings do happen. I'm speaking from experience so always have an emergency supply of meds physically on you or within your access at all times.

Know your meds and take your meds! I can't stress that enough. Be aware of onset of side effects and changes with your body. We'll discuss that in more detail coming up. Trust your doctors; feel very good about your nephrologist. I've had mine for 15 years, Dr. Diego Echeverri of South Florida Nephrology Associates. I may not always take his advice but I certainly value his professional opinion and I always discuss every health concern I have with him before making a move. I trust him with my life and especially with my kidney. Should you have any doubt about your physician or his or her actions, don't be afraid, embarrassed, or ashamed to seek a second opinion. I've had to do that myself in a few instances. Put that kidney first and learn to look out for yourself. No one is a better advocate for your health than you. If your doctor objects to it – THAT IS A HUGE RED FLAG! I would never go back to him or her again.



If you've already had your transplant then most of you know what it feels like to get a crash course in pharmaceuticals, as it pertains to your unique situation of course. I remember having to understand what each of the 12 new pills I was being given did for me and to me. A black 3-ring binder was handed to me within a few days of the transplant with different pills tapped inside and the name and purpose of each written next to it. I was put on the standard protocol of immunosuppressant therapy at the time for 1989 – which included the triple play of Cyclosporine, Imuran, and Prednisone. It was 27 years ago but if I remember correctly other meds included a beta blocker like Calan SR, Procardia XL for hypertension, Pravachol for cholesterol, a stool softener, a diuretic, and several more that I can't quite recall. Many of those meds were adjusted and substituted over the next few weeks, months, and even years as my labs had stabilized.

About 8 years after the transplant and for the next 17, I was on a pretty stable concoction of Cyclosporine, Imuran, Prednisone, Simvastatin for cholesterol, and a blood pressure pill like Lisinopril. Along the way other meds were added to the list such as Midrin for migraines, Loratadine for an itch I couldn't get rid of after being in a full leg cast for nearly 9 months, Omeprazole for burning acid reflux, an antibiotic like Amoxicillin before the dentist, Colchicine for gout (I don't tolerate it well), 7 months of Eliquis for a pulmonary embolism, Viagra for ... well, you know what it's for 😊, a one-time 50,000 IU mega-dose of Vitamin D, and something to calm me down here and there for those stressful episodes in life.

As of 2016, things have drastically changed in my transplant medicine regimen and by my choosing. But before I get into that let me discuss the nasty, wicked, pain-in-the-butt, not-so-fun side effects that I endured both directly and indirectly as a result of the transplant related meds. You may have already experienced some of this yourself. Keep in mind that many of these issues didn't arise until 10 years or more after the transplant so just when you think you're out of the woods... BAM! Something creeps in before you know it. Stay vigilante my friends; it's a must! Also, many of these issues took place before there was a Google or at least before it was such a popular and primary resource for researching and gathering information. It surely wasn't as easy as it is now to have the vast medical knowledge base of the world at our fingertips. Many times back then I wasn't sure where to turn or what to do, especially if I experienced a medical issue at 3am on a weekend and didn't want to head to the ER. As many times as I've been there, I'm no fan of the Emergency Room. In fact, I dread it. Let's go through my list starting with the most difficult issues I had to deal with and those that caused me the most suffering (in no particular order).



- **Debilitating Migraines – Started about 4 years post-transplant**

I wasn't sure what was happening to me. In my mind, I thought it was a buildup and release of the transplant meds. I had no clue it was called a migraine. I had never heard of one before let alone experienced the hellish torture ahead of me. In a dark room, wet wash cloth on my forehead, rocking back and forth thriving in incredible discomfort, I was afraid to take any Over-the-Counter (OTC) meds like Tylenol (Acetaminophen) or especially NSAID's like Ibuprofen because of what doctors had told me (filters through the kidney and can affect its function negatively) so I suffered through the excruciating madness. I was experiencing a full-blown, pounding, deep headache from within my skull that included nausea and gastro issues. When I finally threw up I felt some immediate relief but sometimes that wouldn't happen until hours of mind-bending pain. Unfortunately, this was not a one-time occurrence. It happened about 4 times a year back then; sometimes taking 2 days to recover from. I remember one migraine that lasted a whopping 13 hours!!! My gosh! How I needlessly suffered. In fact, it was that episode that I finally made a desperate after-hours call to my nephrologist for some direction on what to do. Thinking it was a possible virus I was becoming nervous. I relayed my symptoms and vitals to him over the phone and he clued me in, I was experiencing a migraine. He put me on a prescription of Midrin caps also known as Duradrin; a combination of acetaminophen, dichloralphenazone, and isometheptene. You can bet I never left the house without those pills; especially after being caught short once or twice. This eventually led me to discover some OTC migraine meds that worked just as well for me. Currently I'm using a local supermarket brand called "Publix Migraine" but I've also taken the Walgreens brand Migraine capsules. If you suffer from migraines, know your triggers. In other words, what causes it to happen? It usually comes down to these 6 things: Lack of food, lack of sleep, dehydration, being in the sun too long, stress (like starting a new job) or a medical condition. As of now I only get them about once every 18 months or so and I always have a bottle of migraine relief tucked away nearby just in case. It usually knocks it out within less than an hour, especially if you catch it early on and know the feeling when it starts.

Here's the key to putting your kidney first: Don't suffer like I did; recognize the signs and symptoms of a migraine, learn your triggers and get the proper meds that work for you. And be VERY aware of the negative impact OTC drugs like Ibuprofen can have on your kidney function.

- **Severe Gout Attacks – Started about 14 years post-transplant**

Here's another debilitating condition that completely caught me off guard. It was 2003 and I was flying back home to Florida from a skate competition in my hometown of Buffalo, NY when my layover flight was cancelled in Philly. Luckily my



good friend and pro skater Chris Guilfoose happened to be in town that weekend visiting family. A quick phone call and an impromptu airport pickup and we were on our way to the X-Games skatepark at the Mills Mall in Philly to make the best of it. I was more than happy to be skating on a great vert ramp with a good friend so far from home as the result of a cancelled flight. As our skate session progressed, I began to feel this strange, out-of-nowhere pain in my left pinky toe. And by the end of the evening I would have sworn it was broken or severely infected somehow but I didn't remember doing anything that would have induced either one. Surely I would have known if I had fallen or hit my foot so hard as to break a toe or somehow punctured it to get an infection.

The next morning I could barely walk. Limping with intense pain, I hopped on the plane (literally) and headed back home to Fort Lauderdale. I went to the ER soon after arriving. Thinking it *was* broke; I believe that I misled the attending physician down the wrong diagnosis path. Many physicians who first encounter severe gout think the same way and often initially misdiagnose it sending you for unnecessary diagnostics and treatments such as x-rays, prescribing antibiotics, or even worse. As in my case I was told it looked like a deep bone infection and powerful intravenous antibiotics were the solution. They even discussed the possibility of having my pinky toe amputated at one point. Wait! What!? My gosh! I'm an athlete, I need all my toes! This can't be right, I thought. Thankfully, mom had me go to a Podiatrist that had a passion for saving limbs and appendages, mostly from diabetic patients. It was Dr. Strauss and Dr. Brietstein that ultimately saved the day or in this case, my pinky toe. Yes, I did require surgery to clean out the gout but this was after 2 months of no improvement. And it was determined that gout was the main cause of this issue. I haven't had a problem with that area since. Now as for the rest of my joints, that's another story. Gout has painfully crept back into my life ever so slowly. You must understand that as transplant recipients, our kidney cannot process and clear the uric acid produced in our bodies fast enough. Hence, the uric acid builds up into needle-like crystals that get lodged in our joints, typically toes, feet, and ankles but can essentially form anywhere. This can result in some excruciating painful and often debilitating gout episodes that may last for weeks or even months! I've been to the ER 2 or 3 times since. Trust me, you don't want this. You may be asking yourself "So why not take meds for it? I know they have them". Here's the problem, medicines like Allopurinol that are most prescribed to gout sufferers contraindicate Azathioprine, aka Imuran. It can actually be a deadly combination. So there goes that option. And for me, the other popular med, Colchicine aka Colcrys plays havoc with my stomach and can lead to a potentially embarrassing situation if not within a very short running distance of a bathroom; trust me on that one. So there goes option #2, literally.



So what do I do? Well, oddly enough, Prednisone is one way to a quick fix, although sometimes it's only temporary (a day or 2). When I feel an attack coming on, and for those that have experienced a severe gout attack, you know exactly what feeling I'm referring to (like the one I'm feeling right now, good gosh, I kid you not), I reach for the Prednisone and pop anywhere from 40 to 80mg depending on the severity. I might need to do it 2 or 3 days in a row but I caution anyone who's thinking of going this route to first consult with their doctor as Prednisone can do some funky things to you before you know it, like mood swings and a rapid increase in appetite = quick weight gain. You MUST be monitored closely by a physician, so please check with your medical professionals first. For me, after taking the Prednisone, 8 out of 10 times it's almost completely subsided within 12 hours and I can walk again without crutches; what relief! Then there is the other 2 out of 10 times that requires something more powerful like a cortisol shot directly into the affected joint. Or even worse, a late night trip to the ER ... ugh, how I hate those. My advice to you is to do your research and you'll find that besides the transplant aspect, diet plays a key role in our suffering. Avoid foods high in purines such as red meat, liver, kidneys (yes, kidneys - sounds cannibalistic doesn't it?), certain seafood like stone crab and mackerel, and also avoid sweetbreads. What the heck are sweetbreads, you ask? It's organ meat from the thymus gland or pancreas, YUCK! Here I thought eating too many sweet rolls was doing to me... lol. Although studies have shown high-fructose sugar can also induce a gout flare-up I can assure you that "sweetbreads" are not the same as "sweet breads", breads that taste sweet. So be aware or you may have an unwelcomed surprise on your plate the next time you order out. I'll include some gout-friendly foods in the diet section of this booklet.

I'm actually going through a fairly severe gout flare up as I write this. This time it hit both feet. It makes for a miserable existence. When gout kicks my butt, I'm disabled. And when I'm disabled, I can't skate, and when I can't skate I'm miserable. *****2020 UPDATE – I was approved for the intravenous gout medicine Krystexxa and have not had a flareup in over 18 months!*****

Here's the key to putting your kidney first: Be aware that as a renal transplant patient you have a higher risk for gout than most; men more than women. Pray that you never experience it but more importantly understand what it is and what causes it so you can avoid it like *The Plague!* When you feel that mysterious pain like a broken toe, foot, or ankle but you don't remember injuring yourself, then there's a good chance that it's a gout flare-up. A higher dose of Prednisone can be your best friend during this time. Always consult your physician before changing your meds though.

- **Multiple Skin Issues Including Cancer – Started about 8 years post-transplant**



Find a dermatologist that you trust and are comfortable with because chances are you'll be taking your clothes off for him or her often. And if you're fair skinned with blue eyes like me, be prepared to have things snipped, clipped, and burned off of you regularly. Although the pain tolerance does build up a bit, it's still no fun. And sometimes healing can take longer than expected.

Remember, most of us have severely compromised immune systems and that can lead to all kinds of funky things growing and appearing on our bodies. Everything from warts, moles, skin tags, bumpy skin, acne, actinic keratosis, enlarged oil glands (sebaceous hyperplasia), and yes, even cancer; It happened to me. You might even be good for years or not realize you have a skin problem until it becomes a big problem. While I'm reminded, here's a tip: keep your razors clean and sterile with rubbing alcohol for wherever you shave. Use an antiseptic to cleanse any cuts or nicks quickly to stop infections or skin disorders from spreading. So heed my advice and see your dermatologist regularly. In the meantime, examine your own body and skin often for any bumps, lumps, and moles that change shape or color. Look closely at your face, fingers, nails, and feet. If you see any discoloration, scabs that won't heal or scaly red spots – SEE YOUR DERMATOLOGISTS ASAP! Do not let it go on – it will not take care of itself.

For me, my biggest dermatological challenge has been the "*Cyclosporine-induced sebaceous hyperplasia*" (enlarged oil glands) – say that 5 times fast. So if you're on Cyclo like I *was* (hint, hint), be aware of this condition. I found the best way to handle and treat it is by having a PDT (Photo Dynamic Therapy) session. It's like the most intense sun lamp or tanning bed for your face that you've ever had. I know that sounds counterintuitive but it works well and your skin will never look better, at least for 6 months to a year because it's only temporary. Don't worry; it only feels like a thousand super-heated needles pricking your skin over and over for about 15 minutes straight... lol. And it leaves you with one helluva sunburn for 2 weeks as your old face slowly peels off and a new one emerges. I've had it done about 4 times already over the years and getting ready to do it again. For maintenance, a few snips with my own scissors keeps those unsightly enlarged oil glands and or skin tags at bay and only takes 2 days to heal. I don't recommend you taking such action before consulting your dermatologist though.

I've also had a number of actinic keratosis (AK's) – little red scaly pre-cancerous spots that seem to pop up out of nowhere. Now me, I'm a little vane and not ashamed to admit that I would use a little cover-up to hide the red spots but they often become numerous and lead to worse things if not treated. So much so, as in my case, that I had to have what's called "Mohs" surgery about 16 years post-transplant on my left cheek. Essentially, a quarter-size hole was cut out of my face



to remove several AK's and stitched back up together leaving a light scar. My advice for you is to ALWAYS seek a second opinion or alternative method to surgery.

Being originally from Buffalo, NY where the sun rarely made an appearance, my pasty white skin did just fine in that environment but having lived in South Florida for over 20 years now has made it more challenging for me, especially as a transplant patient. Sunblock is a must for any outdoor activity in South Florida. I recommend that you always wear a minimum 30 SPF sunblock and a hat when you're outdoors. If you are a sun worshipper like I was briefly after moving to Florida, you're asking for trouble not too far down the road. I mean that is unless you enjoy skin biopsies and liquid nitrogen to remove things on your body. And if you find yourself questioning or wondering what that spot is on your skin, see your dermatologist soon... trust me; you'll be glad you did. Even if it's is a "sensitive" area, don't wait for it to go away on its own.

Here's the key to putting your kidney first: Know every bump, mole, and discoloration on your body. Protect your skin from the sun. See a dermatologist several times a year. Don't ever be embarrassed to discuss your concerns with the doctor. Believe me, they've see it all and It just may save your kidney, not to mention your life.

- **Acid Reflux and Esophagus Scaring – Started about 12 years post-transplant**

Our transplant meds as well as others can wreak havoc on our bodies on the inside too. That was the case when I found myself unable to swallow thick foods like meats and hearty fish like salmon. When I would eat these foods I noticed it felt like something would get stuck in my esophagus and not go down all the way. It was an uneasy feeling to say the least. And when it finally did go down, OMG, what a relief! I was learning to take smaller bites, chew more, or simply avoid those foods all together. But the problem wasn't going away so I made an appointment with my gastro guy who informed me that I had scarring in my esophagus from acid reflux (GERD) and therefore shrinking the opening - Not good. I had an outpatient procedure whereby a small balloon-like device was used to stretch the esophagus wider and then I was put on a proton pump inhibitor like Prilosec/Omeprazole. Just recently I've seen some litigation commercials claiming this medication is harmful to the kidneys. I've been taking it daily for nearly 15 years with no side effects or reduction on kidney function. So I will continue to take it until I see further scientific proof of this claim.

Here's the key to putting your kidney first: If heartburn is waking you up at night or you start to feel like your food gets stuck in your throat or esophagus with a great



sense of relief when it finally goes down, tell your primary doc and see a gastro specialist. It's not going to get better on its own.

- **Depression and Anxiety – Started about 20 years post-transplant**

I had always heard people speak of depression and how it can physically hurt but I never understood what that meant; mostly because I had never experienced it firsthand. I believe my passion for vert skating and being physically active throughout most of my life has kept depression out of my life... that is until 2009. With seemingly one personal crisis after another and skating taking a back seat to life, depression had hit me hard. I found myself afraid to go to sleep one night then sleeping for 12 hours straight during the next. On top of that, anxiety was building daily and I would wake up in the middle of the night unable to catch my breath seemingly gasping for air. It scared the heck out of me and I wasn't sure what was happening. After talking with friends and family about what was going on, I made an appointment to see the appropriate mental health doctor who prescribed antidepressants of course but I really wanted no part of that. My goal was to lessen the meds I was already on, not add to them. So what did I do? I first got myself back on an exercise routine. Not necessarily vert skating but a 30 minute 4 times a week modified P90X-type of routine (I'll discuss that in more detail later on). I'll be honest, it was not easy. I had to force myself to exercise but I knew it would help. The key here was to change my mindset and get the endorphins flowing. I knew from past experience that being physically active was a good way to start. The worst thing for me was when I started to finally feel better and then I would be caught off guard and depression would creep back in. It was like a viscous circle at times. I also forced myself out of the house; even if I had no one to go out with. I'd go to the mall, to the local flea market, a car show, anywhere there were people and I could start building my confidence about myself and change my mindset. There even came a time when I was afraid to drive. This was a first for me and I wasn't about to let depression and anxiety get the best of me. I struggled for 7 months but I finally did it; I was feeling free! Although one who has experienced depression is always aware of how easily it can take over their life and has their guard up for quite a while afterwards. So it wasn't like I woke up one day and knew it had passed. It was more like a gradual painstaking process of battling myself to snap out of it every day.

Here's the key to putting your kidney first: *Should depression hit you – then you need to change your mindset about how you feel and who you are. Force yourself to start an exercise plan (consult your physician first), never stop taking your transplant meds no matter how sad, depressed, or upset you may feel, be sure to supplement with a multi-vitamin and D3 (consult your doctor first), and surround yourself with friends and family until you're ready to move on. And see a therapist if you find*



yourself stuck in a rut and have nowhere to turn. Many employers offer an EAP (Employee Assistance Plan) that you can call and speak with a professional 24 hours a day. I've used it before and found it helpful. And I'm just as prideful as anyone out there.

- **Teeth and Gums – Started about 7 years post-transplant**

It's so important to take very good care of your teeth, gums, and maintain overall oral hygiene as renal transplant patients. And as someone who took 300mg of cyclosporine a day for a few years, I developed overgrowth of the gums. I first thought my gums were separating from my teeth because they started to grow over the tops of each tooth kind of like a flap. Maybe this was some weird side effect from the meds or maybe I was losing my teeth! That's what I thought until the hygienist clued me in. She'd seen this before in transplant patients. So besides the puffiness, redness, flappyness, bad breath, and bleeding gums, you can expect the hygienist to cut away that overgrowth one section at a time, not fun. For a few years I needed to have a regular cleaning every 3 months versus the standard 6. Since then I've taken better care of my teeth and although my meds have changed over the years, my excellent oral hygiene allows for the standard twice a year cleaning for me. And I'm happy to say that I haven't had a cavity or any overgrowth in 15 years.

Here's the key to putting your kidney first: *Brush floss, and scale at home. Get your teeth cleaned at least twice a year and BE SURE TO PRE-MEDICATE if required (Talk to your nephrologist). Save those pearly whites as long as you can! Understand that if you neglect your teeth and gums, BIG, BIG problems are sure to come your way that may affect the function of your transplanted kidney.*

- **Restless Leg Syndrome (RLS) – Started about 15 years post-transplant**

The way I discovered that I had RLS was in about the worst way possible. I was on an 18 hour flight from New York to Hong Kong when it kicked in hard. And if you know anything about RLS, then you know it gets progressively worse when sitting still or lying down.

Within an hour or 2 of taking off I had this strange, uneasy feeling in my legs; sort of like a building-up, creepy-crawly sensation that manifested itself into an intolerant and unbelievably uncomfortable urge to suddenly move my legs. By moving my legs, this would only bring temporary relief; the cycle soon started all over again. And with a booked-solid flight and sitting in coach in the MIDDLE seat, I don't have to tell you how limited my personal space was. With that intolerant sensation occurring every few minutes it was excruciating. I managed to mask my extremely unpleasant experience for the first hour or so through sheer will power and muscle control. But alas, it was futile. There came a point during the flight



where I couldn't tolerate well any further and had to get out of my seat to stand in the aisle. Yup, I was embarrassed but what could I do? So upon returning to the States I started to research why this was happening to me.

Here's what I found. Lack of sleep, lack of exercise, stress, and most importantly nutrient deficiency were all key factors that seemingly contributed to my RLS. I made some immediate adjustments in my lifestyle and noticed a significant difference, as in almost completely gone!

Here's the key to putting your kidney first: *Change your sleep habits. Get plenty of rest- a solid 7 to 8 hours a night. Long-term lack of sleep is very harmful and a definite instigator for RLS. Next, start an exercise plan; even if only 15 minutes every other day; it can make a difference. And last but certainly not least start taking supplements. I recommend a daily multi-vitamin, vitamin D3 (consult your doctor first), and especially the combo of Calcium, Magnesium, and Zinc. With those consistent changes you'll feel a difference. I promise. Left untreated, RLS can leave you restless at night, zap away your energy during the day, and that can negatively impact the health of your kidney.*

- **Pulmonary Embolism (PE) – Started about 25 years post-transplant**

As a former pro extreme athlete and someone who has been physically fit most of their life, it came as a complete and utter shock to me that I would encounter such a condition. But it happened and it almost killed me.

There was a time not that long ago when vert skating had again taken a back seat to life. I was dealing with some stressful and overwhelming personal issues that were weighing heavily on me. I knew from experience that this could trigger depression. So to avoid that from happening I once again forced myself to start exercising regularly at home. As I progressed in my workout from day to day during that first week, I noticed I was becoming short of breath quicker than normal. Even going up a flight of stairs would keep me huffing and puffing midway through but I chalked it up to being out of shape; that made sense to me since I hadn't skated in months. So I tried to increase the intensity of my routine even more but to no avail. It concerned me very much that I seemed to be losing ground but I didn't fully realize what was happening to me until it was almost too late. I mentioned to my mother about the stairs and sure enough not 3 days later did it all come crashing down, literally.

It was about 8pm Saturday night. I was upstairs in my bedroom getting ready to meet some friends for a night out. I bent down to tie my shoe, stood up just as quick as I always have, and suddenly I became light-headed. The room began to spin and I began to slightly panic. I had felt light-headed before during mountain



bike rides where I would get off my bike, kneel down to rest my legs after a grueling trail and stand up quickly but never did I pass out or come close to losing consciousness. Even during the times when I had hit my head pretty hard (wearing a helmet of course) on the vert ramp skating or bmx'ing, I never blacked out. This time, while at home of all places (without wearing a helmet of course), would be different. I felt myself losing it so in my mind I thought if I passed out up in my room, no one would find me. So what did I do? Well, I headed for the stairs... MISTAKE! Just before stepping onto the top landing of the hardwood steps it was lights out for me. Down I went. I later found out even the neighbors had heard the crash through our concrete walls it was so loud.

With my cats looking at me curiously, I woke up 20 minutes later in a pool of blood and sweat. My head was resting on the top step and my body actually on the stairs itself. I was soaked, breathing deeply and had no idea as to what just occurred. Within a few minutes I regained my senses. I realized that I had fallen forward just before the 90 degree angled stairway landing and slammed my head into the sliding door, knocking it off the track, and then hitting the wooden edge where the air conditioning exchange unit was. Yup, I was hurting. I was still dizzy and short of breath so I didn't want to try and stand up, but where was my phone, I thought. It was downstairs in the kitchen. I very slowly made my way down the stairs sliding on my butt one step at a time. I picked up my phone and called my dad who lives 20 minutes from me and then called mom who lives in Arizona to tell her what had just happened. I must have given her a real scare because she was on a plane headed back to Florida to see me the next day.

Upon reaching the hospital, doctor's chalked it up to vertigo and taking my meds on an empty stomach. They stapled my head back together and prescribed the medicine "Anti-vert", of all things. That gave me a chuckle. Well, I had to get a photo of that on Facebook right away for my skate friends around the world to see; a vert skater prescribed the medicine Anti-vert? Now that is irony.

I never did take one "Anti-vert" pill. In fact, the next day I found myself gasping for air while in the shower. I barely made it out and onto the floor on my hands and knees. Desperate for oxygen I reached for the phone and with my last few breaths before the blackness took over I made a choice to call my dad instead of 911. I could barely get the words out "Come over quickly, Dad!" before I had nothing left. Luckily he was just 7 minutes away at Home Depot. Back to the ER I went (for 10 hours mind you!). And this time doctors would schedule the right tests and find out that I had suffered from a pulmonary embolism shower (multiple small blood clots) in my lungs. Now it made sense as to my symptoms but what caused it? Well, they never figured it out. It was an "unprovoked" PE event that seemed to come from my upper left thigh. So with that being said, I was prescribed the blood



thinner Eliquis. Be aware that we as transplant patients should stay away from blood thinners like Coumadin/Warfarin. Talk to your nephrologist for more information. After 4 fun-filled days in the hospital (heavy sarcasm implied) and 7 months later, I was taken off Eliquis and got back on my skates; all was well in the world once again.

Here's the key to putting your kidney first: Take note of every single symptom you are experiencing and have them addressed. Don't be afraid or embarrassed to question your doctor's actions. You want to make absolutely certain to the best of your knowledge that they DO NOT miss something important, like a blood clot for goodness sake (it can kill you). Medical professionals are human and can be thrown off the path leading to a misdiagnosis when multiple issues and more pressing matters are occurring at the same time. I've learned that lesson more than once. Don't put yourself in that ominous position.

- **Other side effects and issues I encountered over the past 27 years post-transplant:**

- **Rapid heartbeat:** Higher dosages of Prednisone would do this to me, as well as other new meds introduced into my daily regimen over the years. Eventually my body became acclimated to them but don't let your guard down, talk to your doctor about what's happening.
- **Night sweats:** This usually came along with the rapid heartbeat and was a possible indicator of high-dose meds. Keep an eye out for possible fever though.
- **Nightmares and weird dreams:** I've had some of the most vivid dreams over the years since the transplant; and in color! So much so that I'm thinking of publishing a book describing my nightly "brain movie" experience.
- **Brittle yellow finger nails:** Try taking the supplement Biotin and also consult your dermatologist.
- **Warts on feet and fingers:** Stay on top of this. See your dermatologist ASAP and don't put it off. It will only spread and get worse.
- **Oily Skin & Acne:** At 40 + years... really? Prednisone and the high dose of Cyclosporine (300 mg/day) I was taking will do that. Sometimes I feel like a teenager again (for the 10th time). A few strategically placed pinpoints of Oxy cream left on overnight seemed to dry that oily skin right up.
- **Hair growth:** Cyclosporine-induced. Why doesn't it grow in the right places?
- **Hair loss:** Also Cyclosporine related – go figure. I encountered this early on after the transplant. My hair would fall out in chunks, as if my scalp became soft-like, scary to say the least at 20 years old. After a month or 2 it subsided and thankfully my hair grew back.



- **Pre-cancerous moles and spots:** I'm like a dermatologist's proving grounds. Staying on top of the skin issues is the key. See a dermatologist often.
- **Stomach cramps from medicines like Prednisone:** never take on empty stomach unless otherwise directed to do so.
- **Trembling hands:** Taking meds like Cyclosporine on an empty stomach will do this to me but sometimes a new medicine or high dose also played a role.
- **Skin tags:** A few precise snips with sterile scissors and I can maintain them.
- **Dizziness:** You should not feel dizzy or light-headed on a regular basis. Discuss this with your doctor if this is occurring.
- **Dry mouth:** Meds related. I chew a lot of sugarless gum these days. FYI - dry mouth can lead to bad breath so be aware.
- **RLS:** Supplement with Calcium, Magnesium, Vitamin D3, (consult your physician first). Get plenty of rest – usually a regular exercise routine will help.
- **Shortness of breath:** This can be a potential indicator for numerous serious health problems including a blood clot (PE). It started for me in 2004 but all pulmonary tests came back negative and medical professionals said I had the best set of lungs they've seen in 25 years. It turned out to be anxiety (in that case), which I did not want to believe but seemed to be true. Although Prednisone has been known to cause this as well. Definitely speak with your medical professionals ASAP should you experience something similar.

Here's the key to putting your kidney first: Don't ignore changes in your health; not even the smallest ones or what you deem to be "insignificant". They CAN make a difference in extending the life of your kidney. Keep a documented record of what's occurring so you can thoroughly discuss it with your doctor.

For the majority of the time since I've had the transplant, my meds have consisted of the following:

- ✓ Cyclosporine/Sandimmune (non-modified): 125mg 2x a day
- ✓ Azathioprine/Imuran: 75mg 1x day
- ✓ Prednisone 7.5mg 1x a day (Unless gout kicks in, then 50mg for 1 or 2 days)
- ✓ Lisinopril 5mg 1x a day
- ✓ Simvastatin 10mg 1x a day
- ✓ *Omeprazole: 20mg 1x a day

*As I mentioned earlier, you may have seen a recent commercial where a lawyer or spokesperson links Nexium, Prilosec, Prevacid or just about any Proton Pump Inhibitor (PPI) to kidney failure including transplants. I can tell you that I've been taking Omeprazole every single day for 15 years without any issues that I'm aware of. Talk to your nephrologist with any concerns.



And when it comes to my Labs – regular blood work is very, very important. We should all know our numbers, especially the blood serum creatinine level. Creatinine levels vary based on the size of a person and muscle mass. Normal range for men is between 0.7 to 1.3 mg/dL and for women it's 0.6 to 1.1mg/dL. Most of us are not normal though and I clearly fall into that category. 😊

Historically, my creatinine has ranged between 1.6 and 2.4. For the past 15 years it's been holding steady for the most part with a slight decrease to where it is now at about 1.7. Not bad for 27 years post-transplant.

With that being said, what I'm about to tell you is extremely controversial and incredibly risky. Some even say foolish and should NEVER EVER be attempted without the knowledge and consultation of your nephrologist and other medical professionals that provide medical care for you. Are you ready? Here it is. Over the past 3 years I have been slowly reducing the amount of transplant-related meds that I've been taking by nearly 80%. As of writing this (July 2016), I have managed to take my original Cyclosporine dosage of 300 mg a day down to ZERO! That's right, for the past 3 months I have been completely off of Cyclosporine. For my Prednisone of 7.5 mg, I've weaned myself down to 2.5mg a year ago and as of 1 month ago I have completely stopped taking it as part of my transplant regimen. Only during gout flare-ups do I take it for a day or 2. And as far as Imuran goes, I'm down to only 25mg 1x a day.

This has been against my nephrologists' wishes but he is monitoring the transition closely. I've had my labs done about every 4 weeks for the past 3 months to monitor any significant changes and I will continue to do so over the next 6 months as I attempt to come off all of my transplant meds.

DO NOT ATTEMPT THE SAME; OTHERWISE, YOU MAY RISK LOSING YOUR KIDNEY AND YOUR LIFE!!!

Again, this may sound contradictory but I believe that I'm still putting my kidney first, even though I'm attempting to stop taking all immunosuppressive meds. History has shown us that our immunosuppressive meds have had a high probability of eventually turning toxic against the kidney as well as negatively impacting our health in many other aspects. I'm not the first to attempt this. Although still considered extremely risky, there have been other successfully documented cases of this nature out there such as Robert Phillips, who



had his transplant performed by Dr. Thomas E. Starzl at the University of Colorado in 1963. Mr. Phillips was the world's longest surviving living-related kidney transplant survivor at the time of his passing in 2015 at the age of 88; an astounding 52 years with the same transplanted kidney! And the last 20 years of his life were immunosuppressant free! That's the part I'm most interested in knowing more about. I'm continuing to do more research.

Here's some promising news for future kidney transplant recipients: In the last few years scientists at Stanford University have conducted clinical studies with positive results for stopping immunosuppressive therapy within months after the transplant by infusing donor bone marrow cells into transplant recipients.

But as for me in the here and now, after 27 years of rarely missing a dose, I've decided to gradually wean myself off all immunosuppressants. In my eyes it's a calculated risk that I'm willing to take. I'm getting my labs done often and my nephrologist is closely monitoring the situation while I'm coming off each of the meds. I believe that I'm still putting my kidney first by trying to extend the life of it and reducing the chances of diminished functionality from the toxicity of the meds.

I wish that I could discuss my thoughts with my original Transplant Surgeon, Dr. Andrew Novick of the Cleveland Clinic in Ohio but sadly, he passed away from cancer in 2008 at just 60 years old. I'm so grateful that I had the chance to reconnect with him and say thank you in person when I returned to the Cleveland Clinic as a guest speaker in 2003.

Here's the beginning of a great article about the incredible dedication and difference Dr. Novick made in this world.

*By Kathy Siemon, The Plain Dealer
October 18, 2008*

"In the delicate world of kidney transplant surgery, Dr. Andrew Novick was a pacesetter pioneer. The world-renowned urologist helped design one of the most prestigious facilities in the world -- the Glickman Urological and Kidney Institute at the Cleveland Clinic. But he never had the chance to practice there. Novick, 60, died from complications of lymphoma today, two weeks before patients entered the new facility."

You can read the full article here if you like:

http://blog.cleveland.com/metro/2008/10/dr_andrew_novick_dies_was_reno.html



So once I figured out my med schedule I stuck with it for nearly 27 years, meds at 12 noon and 12 midnight. That's what worked for me. As mentioned earlier, I recently made some adjustments to my daytime med schedule but no matter what, consistency is the key! Do all you can to NOT miss a single dose. It will most likely happen a few times over the years but just don't make it a habit and then become careless about taking your meds at the same time every day. For me, it seemed whenever my normal routine was thrown off, I'd either forget to take my meds or couldn't remember if I actually did or not. That's why I used to wrap my meds in a bit of foil each day and carry it in my pocket. I was never big on the M - S pill box but if it helps you, by all means do what you need to do! You'll get to a point where you'll know every shape, size, color, and purpose of each pill; that is until the pharmacy throws you a curve ball and sends you a generic or the manufacturer decides to change something. So always, always, always question your meds if something doesn't look quite right and you're not absolutely 100% sure it is what you think it is. And if possible, use a mail order pharmacy where you typically get a 3 month supply for 2 month co-pay. Also, if your employer offers a Flexible Spending Account (FSA) or Health Savings Account (HAS) take advantage of it. Not only does it save you money because it's based on pre-tax dollars but typically they send you a Visa or MasterCard debit card specifically for eligible medical expenses with 100% of your funds available to you immediately. This comes in handy when finances are tight and you suddenly remember that you need refills or have a co-pay to shell out. Having that card for those expenses can help ease the pain in the wallet.

II. My Diet - It's all about the right food and the right drink for transplant patients – Let's start with the right drink: **WATER, WATER, and WATER!** Did I mention drink lots of water? Beyond the recommended 6 to 8 glasses a day, get into the habit of also drinking a FULL glass or more with your meds whether in the day or at night; I know waking up in the middle of the night to use the bathroom once or twice is an inconvenience but trust me, it's worth it and your kidney will thank you by continuing to function optimally for a long time. This is a BIG part of Putting Your Kidney First! **KEEP YOUR KIDNEY HYDRATED!** I can't stress that enough. A dehydrated kidney has to work harder. A dehydrated kidney increases your risk of rejection. A dehydrated kidney will not last as long as it could. And by the way, if you're drinking enough water your urine should be practically clear, darker could indicate dehydration.



For me, I only drink Publix brand Purified water; that's our local Florida Supermarket. I prefer either purified or distilled. You'll need to stay hydrated like never before. It's best to drink it consistently throughout the day rather than chugging it down in one or 2 shots when you're really thirsty. Buy a decent water bottle that you can take with you no matter where, work, school, the gym, in the car, the park, wherever. And if you live in a hot or tropical environment, you'll need it even more as your body will dehydrate quicker than you realize and that can be dangerous no matter how good your health is. When exercising and burning big calories, I specifically like to drink Gatorade G2 because it works well for us transplant patients. It's both low calorie and low sugar and it still replenishes our bodies after a good sweaty workout. But don't get into the habit of drinking it as a substitute for good ole fashioned H₂O. G2 is great for replenishing vitamins and nutrients lost when perspiring profusely, so only consume it during or after those high-energy activities. Mix it in with your workout water if that works for you. And here's a tip: Have you ever been woken up in the middle of the night by a crazy painful cramp in your toe, foot, calf, or leg? Guess what's causing that? YOU'RE DEHYDRATED! Drink a glass of water or mix it with some Gatorade G2 and in 30 minutes, problem solved.

Now let's talk about the wrong drink. Cut out the sugary high-fructose beverages. Start looking at every label. Ever take a look at the sugar content in a 20 oz. bottle of Mountain Dew? You know the ones, conveniently placed near the checkout counter in the small fridge; a whopping 77 grams of sugar! Stop the sodas, even the diet sodas are problematic, the juices, the energy drinks ... GOOD GOSH, the energy drinks!!! Chock full of chemicals that are not so good for our hearts let alone our 1 and only kidney, we should stay away. Funny thing, I had never even tried a Red Bull until about the last year I was wrapping up my competitive days back in 2004. I wasn't a fan back then but a few years later I got hooked. 3 a day was the norm for me. Then the next size up, then it was Monster. 3 Hour Energy did nothing for me. Since I never messed around with any type of illegal substances, I guess this was my experimental phase...lol. Can you imagine a punk skater not drinking, smoking or having any tattoos? Yup, that was me, the conservative rebel. But I digress. I knew I was headed for trouble if I kept up the energy drinks much longer. It lasted about 4 months and I was finally able to break it. Mind you that I never even had a cup of coffee until I was 40 years old. I wasn't a big fan of caffeine to begin with. Plus growing up in a house where people drank coffee all the time and left those coffee stain rings on the counter really turned me off from the hot beverage.



If you enjoy that fizzy carbonated experience in your beverage but don't want all that bad stuff that comes with them, I found a decent carbonated calorie free drink at Walmart from *Clear American Sparkling Water* (Google it). Comes in lots of delicious flavors and doesn't have that nasty diet after-taste like so many other zero drinks. And it's only \$.68 for 33.8 ounces at my local Walmart.

Let's quickly talk about alcohol. I like to boast a little about the fact that I had never gotten drunk until I was 45 years old. I've only met 1 or 2 other people that have told me the same; we're becoming a rare breed indeed. My reasoning for that was because I saw my friends get into fights, crash their cars, look like fools, and do some things they surely regretted. I was usually the designated driver anyway so I didn't mind. Here are my thoughts now. If you drink, always do it in moderation. Have someone you trust with you, and NEVER, NEVER, EVER DRINK AND DRIVE! Oh, and if you suffer from gout, sorry but alcohol is a BIG NO, NO for us, sigh.

And speaking of gout ... there's a ton of information out there in Google Land about which foods are safe and which are not; much of it confusing and contradicting from one source to another. It's not as easy as just stopping drinking or cutting back on the red meat and shellfish (oh how I wish!) The bottom line is that gout is a complex form of arthritis. And once you add in the kidney transplant factor and all that goes with it, the contraindications between our meds and gout meds, and it even gets more complicated. So what do you do? Well it's important to talk to an arthritis/gout specialist, not just your nephrologist. You do not want long-term chronic gout. It can damage your joints and deteriorate your bones. It's been an especially tough battle for me these past 18 months. But that's an ongoing battle I'm still fighting. I encourage you to do your own research. It's important to learn about this potential pain in the foot affliction for us but here's a basic list of the food and drinks you want to stay away from to get you started. This is by no means a complete list so I encourage you to do your own research.

Stay Away from foods with a high purine content such as:

- Red meat (That includes steaks & burgers!)
- Fatty poultry
- Anchovies
- Sardines
- Gravy
- Goose
- Kidneys, yes kidneys
- Heart
- Brains



- Herring
- Mackerel
- Tuna
- Mussels
- Consommé
- Meat Extracts
- Shrimp
- Lobster
- Stone Crab – No! My favorite! ☹
- Processed foods (frozen dinners, packaged deli meats)
- Saturated fats
- Any food containing high-fructose sugar
- *Possibly dried beans, legumes and rice – there's conflicting info out there*

Avoid these drinks:

- Sugary beverages - Any drink containing high-fructose sugar
- Alcohol – especially beer
- High-fat dairy

Foods and beverages deemed to be safe:

- ✓ Cherries
- ✓ Whole grain Products
- ✓ Low-fat Dairy products (yogurt, cheese, cottage cheese)
- ✓ Plant oils like Olive, Sunflower, Canola
- ✓ Cereals with little or no sugar. I like Multigrain Cheerios or Product 19 with fruit (raspberries, blue berries, strawberries, black berries or bananas
- ✓ *Most vegetables – conflicting info on Mushrooms, beans, and spinach*
- ✓ Water
- ✓ Skim milk
- ✓ *Possibly Coffee – there's conflicting information out there*

Factors that contribute to gout

- High uric acid (aka hyperuricemia)
- Obesity
- Kidney Disease
- Certain Prescription Medicines
- Family History of Gout
- Age/Sex – Occurs more in men between ages 30 and 50 than in women
- Recent Trauma



Supplements

There's a lot to be said about supplements but we must be aware of which ones can interfere with our meds. For instance if you take cyclosporine you'll want to stay away from St. John's Wort and any supplements containing Licorice. Here is a short list of what I think are the supplements that have helped me the most in maintaining a healthy and functional kidney over the past 17 years:

- Multivitamin (without niacin) - I take Life Extension 2-per-day tablets or the LEF Mix
- Vitamin D3 - I take Life Extension Vitamin D3 1000 i.u. 2x per day
- Vitamin C - I take a Walgreens brand 1000mg 1x per day
- *Calcium, Magnesium, Zinc - I take Nature Made brand containing all 3 in one 1x per day
- CoQ10 (Ubiquinone) – I take Life Extension 25mg or 50mg 1x per day

*Take your Calcium and D3 together for the best absorption.

If you take Cyclosporine you should also avoid the following supplements and foods due to potential harmful interactions:

- ❖ St. John's Wort
- ❖ Licorice
- ❖ Grapefruit
- ❖ Ginger
- ❖ Chamomile
- ❖ Quercetin
- ❖ Resveratrol
- ❖ Echinacea

Always tell your doctor about which supplements you are taking – they may interfere with your prescription meds!

Before I started to supplement I would get 2 or 3 colds a year and they would last about 3 weeks or more; it sucked! But not anymore; I haven't had a cold in at least 5 years and when one did catch up to me, it only lasted about 4 days. I believe there are a lot of good things to say about supplementation but I encourage you to do your own research on those you are considering to add as part of your diet.

Now about the right foods: Kidney transplant nutrition regimens are not exactly the most exciting. Low sodium, low sugar, low calorie, low alcohol, and full of fiber diets don't



exactly sound delicious do they? Unfortunately, for most of us this will be the norm. The potential to develop diabetes, high blood pressure, and high cholesterol increases significantly with our transplant medicine regimen. So we must always be on guard to protect our health I'll be the first to admit it ain't easy. I've fallen into some bad eating habits over the years but we should all strive to make that kidney last by putting it first! Here's just an example of my daily diet:

Breakfast

Multigrain Cheerios with sliced bananas or blue berries in fat-free milk, or 2 hardboiled eggs, 1/3 cup of coffee black if needed to wake up, lots of water.

Lunch

Whole grain pasta with skinless chicken breast or cold chicken wrap from Chick-fil-A, fresh fruit of choice (mostly dark berries), lots of water.

Snack 1

Sweet potato chips, or no salt pretzels, or sugar free chocolate cookies, lots of water, 1/3 cup of coffee - black if I need a boost to get through the rest of the work day.

Dinner

Pan grilled salmon/tilapia with veggies (sometimes brown rice) or baked chicken (season to taste but watch the sodium) with roasted red potatoes and carrots or whole grain pasta in olive oil & garlic or Chipotle chicken burrito/bowl, lots of water

Snack 2

Sugar free ice cream, frozen yogurt, or chips & guacamole, lots of water

Always consult a renal dietician for a meal plan best suited for you.

III. My Mind – Have a positive, uplifting attitude/mindset. I didn't get to where I'm at, 27 years post-transplant by having a bad attitude. Well, at least not *always* having a bad attitude... lol. Sure, I've had really bad days and some incredibly trying times but my core values have always persevered, which in turn allowed me to succeed. When times are tough regardless of what it may be that's causing you distress, think about the incredible gift that you have received; a second chance at life! Maybe this is even your third or fourth! Are you going to allow anything to get in the way from making that kidney last as long as possible?! Especially something in your control like your attitude? No way! Of course not. Yourself, Your Life, and Your Kidney are all worth loving, I promise you. And no matter how dark and clouded the future may seem to you at that moment, you will shine through. I still like the old saying "Where's there's a will there's a way". And you've already proven that you have the will.



Case in point: In 1999 when I was lying at the bottom of a steel vert ramp outside of Atlanta, GA on a 98 degree day with a broken tibia, fibula, and fractured knee, I truly believed my skating days were over. You want to talk about the darkest of days... well this was this epitome for me. 6 months in a full leg cast and 3 more in a short cast and you can bet I had plenty of time to contemplate my future. Heck, I didn't even know if my leg would be straight enough to wear skates again. The mind games that persisted in my head were endless torture. I had become bitter and angry about my dreams being cut short and started to take it out on others around me; one point yelling at a stranger at the super market about who knows what. It was my mother that pointed out how I had lost site of the big picture and how my anger and bitterness had only served to make me and potentially others around me miserable. Thankfully, this low point in my life was only temporary but in the midst of it all it can sometimes be very difficult to see the light. From that day forward I began to visualize myself skating again, back on the ramp and back on top of my game. I had always been inspired and motivated by what was to come, what the future held: a competition, a demonstration, a special event, whatever the occasion, I visualized myself into that future event and knew that it was only a matter of time before it became reality. And that's what brought me out of this darkness, future visualization. My mindset began to change from negative to positive. There was a reason why I was given that second chance at life. Maybe I've yet to discover it but I wasn't about to let this unfortunate incident stop me from realizing my full potential.

Like all of us, I had high hopes for my newly transplanted kidney but little did I know that 27 years later I would still have that same great kidney functioning better than ever, let alone still able to skate on the big vert ramps just as well as I did some 30 years earlier. My gosh, so many people had told me 20 years earlier to stop skating and tried to convince me that I was already too old at 26! Thank The Lord that I did not listen to them! And that leads me to another reason why I wrote this booklet. I want you to know that you are NOT limited by anyone! Not the negativity of others, not the doctors telling you what your limitations are; if there's a will in you then you will find a way. What's YOUR motivation?! DO NOT LET ANYONE NEGATIVELY INFLUENCE YOU! STAY POSITIVE THROUGH THICK AND THIN BECAUSE OF THE POTENTIAL THAT LIES WITHIN YOU AND YOUR VERY BRIGHT FUTURE!

When I faced uncertain times regarding my kidney function, especially after seeing a dramatic rise in my creatinine or levels in my blood that pointed to signs of potential trouble, I DID NOT STAND IDLY BY LEAVING IT UP TO FATE OR DESTINY. I KNOW THAT ONLY I AM IN CONTROL OF MY DESTINY HERE ON EARTH SO I TOOK IMMEDIATE ACTION.



If you're anything like me and still get excited to receive your lab results before your appointment, call your doctor to discuss your concerns should you see something that has changed for the worse, especially if your appointment is not within a day or 2. Listen to your nephrologists' medical advice. Don't mess around with that. Think about what has changed with your diet or lifestyle that may have caused the increase or decrease in numbers. Seek the advice of your transplant team or other medical professionals if necessary. When I saw almost a full point rise in my creatinine back in 2002, it worried me greatly. I made arrangements to be seen by Kidney Transplant Specialists at Jackson Memorial Hospital in Miami for further tests and evaluation. They got me back on the road to a lower creatinine and I was relieved. I have never let my guard down since. There were times before that when I went 6 months or more without having labs done... MISTAKE! That's waaay too long! What was I thinking? I wasn't, that's what. Yes, life gets in the way. For me, skating was my life and I got caught up in the feeling like I was almost "normal", as in feeling good and at the top of my game. I had almost forgotten that I was a kidney transplant patient during that time. I WON'T LET THAT HAPPEN AGAIN!

Something very important to be aware of though, watch out for signs of depression. Those who don't recognize the signs can be taken into a deep, dark, scary place that can be incredibly difficult to get out from. You already know that it happened to me. Only by the grace of God was I able to snap out of it and change my mindset. I never knew what it meant when I heard the phrase "depression hurts". Now I can completely relate. There's a physical hurt inside, a pain that you cannot easily escape. Now I understand. So keep that positive attitude NO MATTER WHAT THE CIRCUMSTANCES ARE. YOU CAN OVERCOME ALL. I want you to have the same great experience that I have had of making that kidney last as long as possible by always putting it first!

- IV. My Body** – I know that I mentioned this earlier but it bears repeating: Be very aware of the changes in, on, or around your body. After 27 years of immune suppression, let me tell you about what you can expect if you're not watching closely: multiple skin issues like acne, warts, irregular moles, actinic keratosis, and even cancer, for which I've been treated for multiple times; including Mohs surgery on my face. All of this leads to lots of cutting, burning, freezing, stitching, and snipping. Oh and don't forget plenty of biopsies. Not fun folks. Most of these issues never even arose until about 10 years out. My advice to you: SEE A DERMATOLOGIST REGULARLY!

Another area that I mentioned earlier to be very mindful of is your teeth. As transplant patients we have to pay extra care to our dental hygiene. Bad breath, bleeding gums, overgrowth of the gums, plaque buildup are ALL issues that can sneak up on us and before you know it, BAM! You have a potentially serious, not to



mention expensive medical crisis on your hands, or rather mouth in this instance. Depending on which immunosuppressants you're taking, you may experience different dental concerns. For me, overgrowth of the gums (puffy gums) and plaque build-up brought on by Cyclosporine seemed to affect me most. My hygienists, and close friend, Sonia had made me aware of what was happening. She recommended a regular cleaning every 3 months versus 6. That, along with my own personal dental care, has allowed me to be cavity free for 15 years. I would highly recommend buying your own tooth scaler and stock up on floss picks along with brushing very well (get waaay back there) 2 to 3 times daily will certainly do your body and your kidney good!

You already know my battle with gout. I hated the word from the first time I heard it. It's an ugly word to me and I was embarrassed to admit that I had it. I had no idea what it really was, how you got it, or what to do when it hit. And the pain associated with a really severe attack is even more distressing than you can imagine. It's a debilitating form of arthritis. You can't wear any shoes because of the pain and swelling, certainly not any Rollerblades, you're on crutches sometimes, you can't go to work, and sometimes you can't even put a sheet over your feet it hurts so bad. My point here is to have your Uric Acid level checked. We as renal transplant patients should be at or below 7mg/dL. I've not been able to maintain that level regardless of my diet. I've been as high as 10.2 which is not good at all. It's an ongoing battle for me this past year. Trust me; you DO NOT want this affliction. Ask your rheumatologist for more information.

And while we're on the subject of trying to avoid the not-so-fun stuff, if you truly want to stay out of the hospital for any nasty viruses that should come your way, then you're going to need to be a germaphobe; not the full-on "crazy" kind but the sensible kind ... with a kidney transplant on the side and a severely impacted immune system. Taking preventative measures and steering clear of contagions is your mission from now on. Wash your hands often, be aware of what you're touching and where you then put your hands; don't touch or rub your eyes or mouth if you can help it. Carry hand sanitizer or disposable wipes. If you have pets, take precautions when playing or cleaning up after them. A small scratch or nip from an animal can become a major health issue for the immunosuppressed. I personally have cats and my family has had dogs and while playing with them or breaking up a cat or dog fight, I've encountered the occasional bloodletting. Treat that as something very serious. Cat scratch fever is a real condition. We love our pets dearly but bacteria from a scratch or bite can lead to a serious infection and it can go quickly downhill from there. Make sure you wash, clean and load up on the anti-bacterial ointment should this occur. And be aware of any change or worsening condition near the affected area. This goes the same for cuts, scrapes, punctures or any type of wound



you might incur whether at play on the field or milling around the house. Note that live-virus vaccines should be avoided. Be sure to talk to your transplant team or nephrologist about anti-virus medications.

Regular exercise is a HUGE factor in making your kidney last as long as possible and keeping it functioning optimally. Besides taking your meds and drinking lots of water, being physically active is next on the list for me. Always, always, always, **CONSULT YOUR PHYSICIAN AND OR DOCTOR BEFORE STARTING ANY FITNESS REGIMEN.**

When it comes to exercise and fitness I have my "extreme" side, which you already know, and my down-time side in which I'm still active just at a lower-risk level. I certainly don't expect you to strap on a pair of inline skates or jump on your bike and head to the nearest skatepark, leave that to me ☺. But you can ensure that you're getting that blood flowing by coming up with a fitness routine appropriate to your level. Most people when they first get motivated to burn some major calories go waaay overboard and then feel so sore for the next 3 to 5 days they never go back, at least not for a while. Don't fall into that trap. **TAKE IT SLOW AND INCREASE GRADUALLY FOR THE FIRST WEEK OR 2.** There's no shame in prepping your body for what's to come. Don't throw your body into shock. I mean you wouldn't just enter a marathon without training first, would you? I hope not.

So when I'm not skating vert or riding my mountain bike due to injury, travelling, or just taking some time off, I like to do a modified version of the P90X workout to the best of my ability. I call it "Paul40X". Here's a general overview of what it includes:

- Stretching (but not bouncing) for about 7-10 minutes
- Abs – upper (crunches) & lower (leg lifts) 3 sets of 25
- Cardio for 12 - 15 minutes including jumping/squat jacks and running in place for bursts of 45 to 60 seconds with up to 1 minute of rest in between
- Pushups – 2 sets (as many as I can do)
- Jump squats – 2 sets (as many as I can do)
- 20 LB free weight chest press (2 variations) - 3 sets of 18-20 reps
- 20 LB free weight fly's – 3 sets of 15-20 reps
- Optional exercise (medium impact)
- Repeat if necessary until I hit 40 minutes

Now I'm not saying this is what you should be doing to keep that kidney going. Not by any means. Each one of us has to come up with a fitness routine that is right for him or herself based on many factors so please consult a professional and speak with your nephrologist about it. Once you're cleared to start sweatin' to the oldies you'll



want to keep track of your routine but perhaps you're not sure where or how to begin? I recommend spending a little time on YouTube where you can find thousands of stretching, cardio, weight training, you name it, fitness videos out there at every level. I'm on there often looking for new ways to keep it fresh. And again, TAKE IT SLOW. Maybe only do 5 or 10 minutes the first few days and go from there. If you start to feel dizzy, short of breath, or ill, STOP IMMEDIATELY and sit or lie down. Always have your water bottle and phone close by.

Be sure to buy a blood pressure cuff; preferably a manual one, not the electronic. I believe you get a more accurate reading by watching and listening yourself. Know how to use it and recognize the signs of hypertension – a real killer of kidneys. I don't want to see you coming anywhere close to breaking my resting BP record of nearly 300 over 200 pre-transplant. Good gosh, when I think of that... It's a miracle I survived!

REMEMBER, I AM A PROFESSIONAL EXTREME ATHLETE WITH OVER 30 YEARS OF EXPERIENCE – DO NOT ATTEMPT ANY HIGH-RISK, HIGH-IMPACT ACTIVITIES SUCH AS VERT SKATING, SKATEBOARDING, ROLLERBLADING, MOUNTAIN BIKING, CONTACT SPORTS OF ANY KIND, ETC. WITHOUT PERSONALLY CONSULTING A FITNESS PROFESSIONAL OR YOU MAY RISK GREAT BODILY HARM AND OR INJURY TO YOU AND YOUR KIDNEY WHICH MAY RESULT IN DEATH.

Throughout those 30 years I estimate that I've fallen on the ramp approximately 7,000 times, most without incident because I wear the proper safety gear but I did manage to rack up some pretty good ER/Hospital time throughout. Have a look at my list of issues & injuries that I overcame to skate another day:

- ✓ Broken ribs
- ✓ Broken tibia
- ✓ Broken fibula
- ✓ Broken toes
- ✓ Dislocated fingers
- ✓ Fractured knee
- ✓ Fractured elbow
- ✓ Torn MCL (multiple times)
- ✓ Torn ACL (multiple times)
- ✓ Torn PCL
- ✓ Torn Patellar tendon
- ✓ Torn groin (multiple times)
- ✓ 20 stitches above left eyebrow



- ✓ 12 stitches in the chin
- ✓ 100's of skin burns from the ramp surface
- ✓ Hip injuries (Multiple times)
- ✓ Fluid on the knee (Multiple times)
- ✓ Facial wounds (Multiple times)
- ✓ Multiple cuts, gashes, and lacerations to the rest of my body
- ✓ Staples to the head (Multiple times)
- ✓ A concussion or 2 - I can't really remember 😊
- ✓ Severely bruised tailbone (multiple times)
- ✓ Multiple shoulder injuries
- ✓ Severe whiplash
- ✓ Plantar Fasciitis
- ✓ You name it, I've sprained it

And that's what I can remember. At one point, my closet looked like an annex for a medical devices company. Filled with crutches, canes, supports, braces, wraps, straps, and other disability equipment, I almost had enough to start my own franchise!

So don't try this at home, kids!

V. My Faith – My faith is the last but certainly not the least of what I believe to be 5 key aspects that have allowed my transplanted kidney to function optimally for the past 27 years. I've accomplished more than I thought ever possible post-transplant. My faith has only made me stronger, made me resilient. By no means am I implying that I'm not susceptible to trying times and a life without adversity or even despair, as you've read. But by now you can see how I've managed to get through it by putting my kidney first and living by my 3 core values: Love Yourself, Love Your Life, and Love Your Kidney. Like this chronicle, I'm an open book and I will hold nothing back to help you succeed in making your kidney last and I believe having faith in a higher power will do just that.

Understand that this section is not written to offend but to offer an inside look into my deep and personal kidney transplant experience which includes my relationship with Jesus Christ. Regardless of what faith you may consider yourself to be, you must reach deep down inside to overcome whatever life will throw at you. And for me, it also means reaching out and up to The Lord. I could NOT have persevered without Him in my life.

I was raised Catholic but found myself at a crossroads about 8 years ago and decided to do some soul searching. What I came to discover through my own historical



research and a brief but powerful supernatural experience was that there IS a living God and He knows every single thing there ever was, is, or yet to come. And He's waiting for us. And guess who else is waiting for us, our pets! Yes! God loves animals and they are a part of Heaven awaiting our arrival; I promise you!

But I digress; oh how I can digress within this realm of my faith because there are so many poignant aspects to it. In the end what ultimately opened my eyes was something both truly spectacular and supernatural. It wasn't some logical conclusion or overwhelming documented historical evidence, although all of that did play some role but it was something much, much more. Let me explain. On an otherwise uneventful evening, alone at home, following the conclusion of a movie I was watching titled "The Gospel of John", I had asked The Lord Jesus into my heart telling Him how much I loved Him. I was on my knees with tears in my eyes repeating again and again how much I loved Him. Then from out of thin air came a firm yet gentle voice that boomed and commanded attention. Within the room, all around the room, from within me, from what seemed all around me, the voice permeated all that there was, and the voice simply said 2 words to me, "I know". It was nothing more and nothing less than what I needed to hear. The Lord had just told me that He knew everything that I felt and was going through and it was going to be ok; I need not worry. I froze in place. I looked around to see if anyone else was in the room; no one. I was completely overwhelmed with emotion knowing who had just directly spoken to me and what He had just said. I gave thanks and never have I had something similar happen to me again. It was an encounter I will never forget and has impacted me deeply to this day.

There was a time when I was unemployed for about 6 months and found myself staying up later and later as each week passed by. During that time while on YouTube one night I came across the NDE (Near Death Experience) phenomenon. If you want a true glimpse into what I call "the door step to Heaven", then watch some of these incredible testimonies. I promise it will give you a new perspective from people who were there and came back, most against their wishes. It will change your feelings about death and what is yet to come for us. There are literally hundreds, if not thousands of NDE testimonies out there from people all over the world from all walks of faith; you have to decide for yourself which have credibility. Just go to YouTube and start to search "NDE" or "NDE Testimony". Some of my favorites include the following:

- Dr. Eben Alexander
- Nancy Rynes
- Captain Dale Black
- Jayne Smith



- Dean Braxton
- Reinee Parasow

With my love of animals, especially cats I had mentioned earlier about breaking up a cat fight or 2 in my day. Well, I actually had 2 very deep cat bites in the meaty part of my hand between the index finger and thumb. I'm talking deep gashes and torn flesh from sharp teeth sinking and tearing into my skin in the heat of battle between 2 aggressive animals. Long story short, one of my cats was on his last days and another sensed his weakness and attacked him fiercely! My instinct was to break up that cat fight with my bare hands – MISTAKE! Now covered in flowing blood and potentially bacteria laced, I knew what this could mean for me and my kidney – INFECTION! For my own personal reasons I did not want to go to the ER at that time. Instead, I placed my hand in the New Testament and prayed hard, packed the wounds with antibiotic and bandaged it up for weeks. Incredibly, I healed up with no sign of scarring or trauma. And this happened twice on 2 separate occasions! Blood stained crumpled pages in my Good Book serve as a reminder of my faith; a true miracle that no infection occurred. It sits on my nightstand 'til this day. Now, I DO NOT recommend that you treat your medical emergencies the same way, certainly not (Go to the Emergency Room) but this was a real experience that happened to me and I believe relevant to this narrative. I have more supernatural stories that I could tell but I'll save that for another time my friends.

So whether you're God-fearing, consider yourself a spiritual being, or believe this life is all you have, it still means that you believe in something. And at the very least, if you want that kidney to last then you better believe in yourself. In my personal experience it takes a helluva lot of moving pieces coming together to make this work and solely relying on yourself is an unnecessarily heavy burden. Reach out to a higher power. This incredibly complex Universe and all that goes with it (including us) was not set in motion by mistake; it has purpose, meaning, hope and truth. I can promise you that we ARE eternal beings, as in forever, and this is just one step along the way of an incredible journey that does not end.

In closing, let me stress that these are not just 5 "independent of one another" random elements, but rather they coalesce for the purpose of extending the life of your kidney. Don't neglect any part of them if you want that kidney to last as long as possible. Let my actions, my mistakes, and my successes be a shining example for you proving that we, as kidney transplant patients, can overcome anything. I mean just look what I've put my body through and I'm still going! We can achieve our goals, live our dreams, and enjoy our lives until we transition into the next realm. I'm telling you the truth; what awaits us after this life is nothing short of pure love, bliss, and harmony. Are you ready?



Let's recap it all

AVOID THESE 5 "KIDNEY KILERS" AT ALL COSTS:

1. Not taking your meds as prescribed.
2. Not staying hydrated.
3. Not getting regular labs done.
4. Not keeping your blood pressure under control.
5. Ignoring the warning signs of infection, illness, or rejection.

Here's the bad news...

Fail to avoid those "kidney killers" and you will almost certainly diminish the life expectancy of your transplanted kidney and potentially lose your own life as a consequence.

And here's the good news...

You CAN make your kidney last by putting it first! Below are 50 factors that have worked for me and can work for you. What I've learned over the past 27 years of being a renal transplant recipient and patient has given me the insight to significantly extend the life of my kidney with no end in sight. If you follow these factors faithfully, you too may achieve the same. *These are not necessarily in an order that may work best for you and always consult your nephrologist before-hand.*

50 FACTORS TO MAKE YOUR KIDNEY LAST:

1. Always, always, always take your transplant meds – Never stop or miss a dose!
2. Never let yourself run out of meds – Call refills in as early as possible.
3. Know your meds - What they look like and what they do for you.
4. Stay away from anyone with a cold, flu, infection, virus or that is contagious - Live-virus vaccines should be avoided.
5. Truly understand how severely your immune system is compromised – Wear a mask if advised.
6. Take your meds at the same time every day (within the hour).
7. Drink lots of water - Stay hydrated throughout the day. Always carry water with you.



8. Stay active. If your doctor agrees, put together a sensible exercise plan – 3 days a week. And start slow for a few weeks – Don't overdo it. Trust me on this one.
9. Get labs done regularly – Especially within your first 5 years, and then continue as instructed by your nephrologist.
10. Give thanks to God and Pray, Pray, Pray. If you don't believe then meditate and thank your donor whether alive or deceased.
11. Keep a list of your meds and dosage on you, in your wallet or purse.
12. Be a germaphobe – Carry hand-sanitizer, wipes, and wash your hands often.
13. Create a system to remind you to take your meds.
14. Live by my 3 core values: Love Yourself, Love Your Life, and Love Your Kidney!
15. Bring your meds wherever you go – Use whatever container works for you.
16. Have extra meds at places where you spend lots of time: work, school, friends, car, etc.
17. Always eat something with your meds unless directed otherwise.
18. Drink a full glass or more of water with your meds – Even at night.
19. Be mindful of your medicine's side effects - Research your meds (Google it).
20. Get plenty of sleep (6-8 hours). Lack of sufficient rest will run your immune system down even further and make you more susceptible to bad things creeping in like colds, flus and other viruses... remember my shingles story?
21. Avoid Long-term use or altogether usage of OTC drugs like Acetaminophen and especially NSAID's like Ibuprofen (I've taken it maybe 5 times in 27 years).
22. Stay in close touch with your transplant team – Especially the first year.
23. When travelling, keep your meds in your carry-on luggage both coming and going, as well as enough for 10 extra days or more in your checked luggage.
24. Take your medical history, doctor's notes, and prescriptions with you if travelling internationally.
25. Use a mail order pharmacy if possible - Get a 90 day supply.
26. Enroll in an FSA or HSA for meds and copays if your job offers it.
27. Don't hasten your recovery – Take your time in getting back to your daily routines and extracurricular activities.
28. Keep a rock-solid positive attitude – Be thankful for your second chance at life and make the most of it, no matter what.
29. Attend to every cut, scratch, bite, wound, scrap, and nick. - Watch for signs of infection and seek immediate treatment – Have anti-biotic cream close at hand.



30. If you're a pet owner like me and love animals, be extra careful with scratches, bites, and cleaning their little messes – Wear gloves if you can. We're incredibly susceptible to infections.
31. If you smoke, PLEASE STOP! Easier said than done I know, but if my mom can do it after 35 years you can too! Just ask yourself what's more important: the health of your new kidney or cigarettes?
32. Find a trusted nephrologists & dermatologist – Be comfortable with him or her.
33. Ask your nephrologist lots of questions.
34. Seek second opinions for your medical concerns, even if the diagnosis sounds right – Don't be afraid or embarrassed. No one will be in more control of your health than you are right now.
35. Don't let multiple health issues stack up untreated. Even the smallest things can turn into BIG problems before you know it and that is a recipe for disaster. Address them immediately.
36. Keep your teeth and gums healthy – See a dentist 3 times or more per year.
37. Buy a blood pressure cuff and thermometer. Learn how to take your own BP and pulse - Monitor your vitals daily/weekly.
38. Know what you're eating - Read the label for sugars, protein, calories, fat, etc.
39. Limit your red meat intake, including pork. High-protein diets can make the kidney work harder and we are also at a higher risk for heart disease than most.
40. If you take Cyclosporine, no grapefruit, pomegranate or licorice for you.
41. Avoid high-fructose sugar in food and beverages as much as possible.
42. Avoid high sodium food & beverages.
43. Stay away from Energy Drinks – They will dehydrate you. Instead, drink water and Gatorade G2 to replenish during workouts.
44. Limit your caffeine intake – Be very aware of your coffee consumption.
45. Maintain a healthy weight for your body type – Check your BMI (Body Mass Index).
46. Join an online kidney transplant group to compare stories and learn what others have experienced - I've been booted out of 1 or 2 over the years for speaking my mind on a few subjects... lol. Compare war stories and battle scars. It can be very therapeutic.
47. Avoid stress whenever possible or find a therapeutic activity to help release it.
48. When outdoors, always wear sun-protection - SPF 30 or higher.
49. Sign up for online access to lab results and keep a record (I use Quest).
50. Do your research on any and all health issues that are affecting you – Understand the processes occurring in your body and speak with your doctor about them.



Follow these GOLDEN RULES to extend the life of your kidney by putting it first!

That's exactly what I'm doing.

And to that, I would affirm is the truth as I have experienced it. For I believe within my heart and soul that without following the above discussed guidelines, my kidney wouldn't have lasted as long as it has. Here's to another 27 years! Thank you, Lord. And I wish ALL of you great health and wealth in mind, body, and spirit. God Bless.

Your kidney transplant brother,

Paul Noworyta



*For exclusive content about my kidney transplant experience go to
<http://kidneysaresexy.com/exclusive/>*