

AN AMYLOID CHRONICLE

By Dan Baker

Introduction and Acknowledgements

It probably seems crazy to have an introductory section and acknowledgements as part of a small paper but I feel I need to set the stage for this and thank some folks and that's that.

Last summer I was a very healthy and athletic sixty year old cruising through life enjoying my professorship at the University, taking good vacations and entertaining the possibility of retirement in a couple of years. Then, as you may read below if you choose, I was diagnosed with amyloidosis and my world changed. Now, almost six months later I realize that I got off easy. It is important for readers to know this. Because of the early diagnosis in which we discovered that none of my organs were seriously involved, I came through all of this easily compared to persons whose disease had progressed or who, additionally, had multiple myeloma. The chemotherapy and recovery were not easy and I would not wish them on anyone. I have just not suffered as some of the friends I've made have. Nevertheless, I was encouraged to write this by several people who thought my insights might actually be useful and somewhat entertaining.

My doctors include John G. Paty, Joe Watlington and Ted Arrowsmith in Chattanooga and Raymond Comenzo and his staff at the Sloan-Kettering Memorial Cancer Center in New York City. They are excellent. I am especially appreciative of Jay Paty and Joe Watlington for the persistence and dedication that led them to diagnose amyloidosis when there was no reason to and very few symptoms to suspect it. I believe they saved my life or, at the very least, may have extended it appreciably. Ted Arrowsmith has been dogged in keeping me on the right path during my recovery and he provided a very quick and caring response during my short relapse. Raymond Comenzo is not only an expert; he is a personable and caring physician. His style has rubbed off on his staff and the nurses on the 11th floor especially Noel, Thea and Trish.

I have included a section about caretakers later in this little epic but I would like to acknowledge the significant role my family, especially my wife, and my friends and colleagues played supporting me during my treatment and recovery.

Oh, this was written in a sort of stream of consciousness format. Sometimes I used first person. Sometimes I seem to have addressed readers directly. At other times it is unclear exactly what I was doing since, I suspect, I was drugged. Sorry. My English teachers were always appalled with my grammar, syntax and punctuation problems. Get out your red pens if you want but don't send me the corrections. You may find a little humor and irreverence in here. I know this is serious business, but I can't deal with this world and my problems without a little fun. I hope this doesn't bother you.

Finally, let me emphasize again that I know full well that people with Amyloidosis, cancer and other serious diseases react differently to treatments and the diseases themselves. This is a chronicle of my experiences, some of which may be common to everyone and some of which will not be. As you will see, I came through the chemotherapy at the hospital pretty easily in comparison to others and my recovery time until I felt normal again was quite short. However, as you will also see, the chemotherapy didn't cure me so the chronicle will also deal with my reaction to the second part of the protocol; a Thalidomide-dexamethasone regimen. So, for what it is worth here's my story which began in the summer of 2004 and I'm first posting in March 2005 with additions to come.

Part I: Too Many Proteins Can be A Problem

This odyssey began when I attempted to shift my life insurance policy from one insurance company whose financial security I had come to question to another company, Northwest Mutual, for which I had much greater confidence. The problem was that the day before my sixtieth birthday, Northwest indicated they didn't want to insure me based on a seemingly routine physical. I had they said, Barrett's disease, a left anterior hemi-block in my heart and too much protein in my urine. OK, thought I, let's see how much

trivial stuff they have been able to dig up to avoid giving a sixty year old a policy. Barrett's disease is a response to acid reflux and involves the chance that some of the cells in your esophagus will be transformed and eventually, cancerous. An endoscopy ruled out those problems. What about this heart thing? Apparently, my ventricles don't fire simultaneously and, judging by old EKGs, haven't for some time. Since there were no apparent effects, especially since I have a history of participation in athletics and for the past four years have averaged a mile per day swimming at a very good pace, the literature suggested that these symptoms should be ignored.

Too much protein in the urine is another matter but it can be caused by a lot of exercise. Another pee in a cup test showed no changes even when I reduced my exercising and got really careful about my diet for a week. A jug test showed the same. There was just too much protein in there.

At this point I should tell you that Dr. Jay Paty had reviewed all of these tests. Jay is a rheumatologist. He deals with arthritis and joint problems. He is also smart and incredibly well versed in many medical idiosyncrasies. He is a diagnostician par excellence. When Jay talks, I listen and Jay said I should go see Joe Watlington, a nephrologist, immediately.

So, I pee'd some more in cups and jugs and got more blood drawn. By this time I was getting upset and I'd researched chronic kidney disease pretty thoroughly. I knew that if I had it there was a possibility that my kidneys could be only twenty per cent efficient because, with kidney disease, symptoms often don't show up until long after the disease has progressed. But I didn't have symptoms except those darned proteins. By my next visit Joe had decided I didn't have CRF. My kidneys seemed to be functioning fine; they were just letting some as yet unidentified proteins through. What's up?

It was kidney biopsy time. Now for those of you who haven't had one of these yet, here's the deal. They strap you on a table because they don't want you to move at all when they do the biopsy. They ask you if you want a sedative and a painkiller in addition to the shot they will give you, which they say will sting like a bee. Now, I'm telling you that if at all possible I want to be alert when you mess with my body so forget the sedative. But, give me just enough pain medicine to dull it, especially since you say the procedure won't hurt, though I might feel as though somebody kidney punched me afterwards (what a surprise). So there you are looking like Jack Nicholson in your hospital gown on a moveable operating table that rolls in and out of a CAT scan donut. Dr. Bessenni says, "You may be feeling a bit of a sting now." Oh, really. Is that what that burning sensation is? This, by the way, is after the folks in the prep room have alerted you to the fact that Dr. Bessenni did really well the first two times he preformed this procedure and stayed in a Holiday Inn Express last night. Why do I seem to attract facetious comments like this?

On with the procedure. Here's the fun part. They go into your kidney from the side since they don't want to hit a renal artery. This is a good thing. But since kidneys move around even when you breathe they slowly insert a guide needle bit by bit as they slide you in and out of the CAT scan donut for look sees. They ask you to hold your breath and you feel a bit a pressure as the needle goes deeper and deeper. Sometimes they ask you to hold your breathe for quite a while-maybe 30 or 40 seconds. No problem with me but what if some old geezer has asthma? The good part is that when they slide you out of the donut you can look up and see where the needle is and, if you are curious and your doctor is the talkative type, he'll converse with you about the fun he's

having. After they have found their spot with the guide needle, they insert one the size of a knitting needle and core out a bit of tissue. You don't even know it.

Following the procedure they want you to lie on your back to compress a bandage to make sure you aren't bleeding. There's no incision, just a little hole. After they are satisfied and especially if you say that the procedure was a breeze and that you want to go home, they inform you that you are spending the night. With people like me who find the procedure painless, fascinating and easy, they are certain that we'll mow the lawn, tote forty pound sacks of birdseed or do equally stupid tasks, so they show their wisdom and force us to stay. I was told not to worry if my urine was a bit pink that evening since they had obviously been messing with a very vascular area. It wasn't. Too much information? Sorry. So, following a boring and uneventful night I was allowed to go home with instructions to take it easy and, in the event that I had blood clots in my urine or sudden extreme abdominal pain, to hot foot it to the emergency room. Didn't need to.

So, several days later I was in Nashville working on a research center project with my friends from the State Department of Education. Sitting at the Farmer's Market, chowing down on too much very good Chinese food with Vance Rugaard and Matthew Pepper, I got a call from Joe Watlington who indicated that when I had time I should look up the word amyloidosis. He informed me that it is a rare and very bad disease and that the proteins we've found are amyloids. They attack several organs and, in a sense, gum them up until they don't work anymore. This is serious business and not the kind of news you want at lunch when you are discussing cruises you've been on and fine beers you like to occasionally imbibe. The good news is that he said we'd caught this thing very, very early and it appeared to be localized in my kidneys though they were working just fine. Still, I was aware that I had a killer in my body. The drive home to Chattanooga was interesting. I was more aware of the beauty of the hills and valleys than ever before. I started to struggle with how to break the news to my wife, Emily, but knew that even though I would have a chance to look some of this up before I saw her and would be factual and hopeful as Joe has instructed me to be, I'd be emotional and scared. And we did have a very emotional evening focusing on hope and the best outcomes but acknowledging the possibility for the worst. I called the kids and in my candor, scared them too much. At least it was out in the open and I tried to tell them that subsequent visits to Joe Watlington would nail this thing down and tell us how to treat it. It is hard, even with grown children, to determine how much to say or how they will react.

A bit about Joe Watlington. Emily and I had met Joe and his family at the Flagstone Meadows B & B (super place!) in Mancos, Colorado about five months before all this started. There we were in rural Colorado with our innkeeper friends Harris and Wendy Court and the Watlington family showed up. So, based upon Jay Paty's recommendation that Joe was a very fine doctor and my knowledge that he was a good fellow who liked Colorado and shared my fascination with the American West, I went to see him. What an incredible set of coincidences. What a godsend. Had it not been for the fact that both Jay Paty and Joe Watlington are incredible diagnosticians there is a very good chance that nobody would have known that I had amyloidosis until it was far too late since, I learned, the symptoms of the disease often do not manifest themselves until the disease has progressed dramatically. Watlington, like Paty, was kind, thorough and took the time to explain the disease in detail. Jay and Joe are model physicians. My dad, who had been a small town physician, would have liked these guys. There is no higher praise.

Joe next referred me to Dr. Edward (Ted) Arrowsmith, an oncologist. What wonderful news. I had to see a CANCER doctor. Apparently, amyloidosis can be associated with another disease called multiple myeloma; bone marrow cancer of some sort. Ted, it turns out, pulled no punches either and he too is very good at his specialty. I learned that I am very much the exception not the rule. I'm sixty. Often amyloidosis patients are considerably older. I'm in excellent shape and many others are not. Other than the protein in my urine, I had no symptoms at all. No swollen tongue or joints, no shortness of breathes, no heart problems, no nephrotic syndrome. Nothing. So, we were way early on this. But what about that multiple myeloma thing?

So, the next thing in store for me was the bone marrow biopsy that would inform us about multiple myeloma. I had been told that bone marrow biopsies were invented during the Inquisition when torturers felt burning people at the stake was too easy. My understanding was that a large, probably sweaty person with a maniacal assistant would strap me down and insert a hollow 5/8 inch Black and Decker drill bit into my femur and suck out a quart or two of marrow while I screamed, even though “bones don’t have feeling.” Enter Dr. Sandy Sharp (as in sharp needle he said) and his assistant Ginger. Ginger was not fiendish. Dr. Sharp was not huge and sweaty. Neither admitted to staying in a Holiday Inn Express but wished they had said so.

The procedure began with Sandy saying; “You’ll probably feel a sting now.” Why do they all say that? I guess because they are correct. The next ten minutes were a journey through unbelievable pain. Not! I felt slight tinges as the needle numbed its way down to the iliac crest of my hipbone where they got the marrow. I vaguely felt the extraction needle going in, felt a lot of pressure when it was pushed through the layer of bone, felt a tug when the marrow was extracted, felt a little more pressure when some bone was excised and the needle was removed and that was it. They had me lie on my back while the slides were prepared, and then I drove home with Emily. The next day my back was a little sore. The next day I swam again. Subsequent bone marrow biopsies have proved to me that Dr. Sharp does a lot of these and is really good at it.

Two days later we had an appointment with Ted Arrowsmith. This was the big one. This was the appointment in which Ted could have said, “Looks like you’ve got full blown multiple myeloma with your amyloidosis and we’ve really got a problem here”. It is very difficult to describe how you feel when you know that in the next few minutes you’ll know if you’ve got a real fight on your hands and it is a bit too early to tell how it will turn out long-term and whether your prognosis, even for the short-term is good. My emotions ran the gamut. I was frightened; after all, one of my colleagues at the University had died from this disease. I was unbelievably aware that I had been blessed with sixty incredible years. I was so thankful for the support of my wife and family. I was ticked off and ready to fight. I was focused on my faith. I was told I didn’t have multiple myeloma. We agreed to try to get me into Sloan-Kettering, the Boston University Clinic or the Mayo Clinic so we could fight the amyloidosis as aggressively as possible. Though the bone marrow results which indicated that my bone marrow was not involved meant that I might not have to undergo the stem-cell transplantation procedures with which the clinics had begun to have success, we all wanted to begin aggressive chemotherapy as quickly as possible (this turned out to be incorrect). What a relief. How strange. I learned that I had a very bad disease but I didn’t have a worse one. I was going to have a difficult and uncomfortable time for several weeks it seemed as we hoped and as it turned out, in a hospital in New York City. I was happy. Emily would be with me. Kristen would be there too since she works ten blocks from the hospital. Brian would visit. My colleagues and friends were concerned and supportive. Emily’s superiors in the Hamilton County Schools had been tremendous. I had great physicians caring for me. Life was pretty good.

Part II: The Sloan-Kettering Experience; First Trip

After my consultations in Chattanooga prior to Monday’s initial visit to Sloan-Kettering, things were a little clearer. Even though I did not have multiple myeloma, the chances WERE good that I’d have some sort of stem cell transplant. The reason, of course was because the chemotherapy would kill so many of my white blood cells that my immune system would be shot for a while and reinfusing stem cells that can be manufactured into white blood cells would help me resist disease and recover more quickly.

On Monday I was to check in to Sloan-Kettering, have an EKG, echocardiogram, and pulmonary function test, another bone marrow biopsy and review the slides from my previous bone marrow biopsy and all the x-ray film I’d brought along. I was to meet with Dr. Raymond Comenzo for two hours to determine next steps. He was, apparently, perplexed by my test results since they still had not determined which of the amyloid proteins caused my trouble.

So, we were to fly to NYC early on Sunday afternoon, check in to the Helmsley Medical Tower apartments and meet Kristen. We intended to scope out the neighborhood in anticipation of the next visit. We'd reviewed a document posted on the Internet by a former patient at SKMCC that has been invaluable for finding the location of restaurants, markets, delis, museums and places to shop on the Upper East Side. Tuesday, we'd fly back and await the news about visit number two.

A little bit about insurance. It first appeared that the sole purpose in life for the people working in insurance for the State of Tennessee who must coordinate the insurance coverage with Blue Cross/Blue Shield was to provide a minimal amount of coverage and thus, responsibility for the State. They initially indicated that they would pay for the initial consultation but would not pay for accommodations for the much longer visit we anticipated. The Helmsley Medical Towers charges about \$1400 per week for a king/suite. A comparable room in the hospital, if I had in-patient status, would cost more but the insurance would cover it. There was work to be done with Drs. Arrowsmith's and Comenzo's offices to get the insurance people to understand why I had to go to Sloan-Kettering, why I'd be an out-patient for some of the time (they need the beds) and how the treatment and care-giver requirements work especially, why it wasn't possible to have Emily share a small room in the hospital for a month. My advice, be persistent and have your physicians document everything, especially if you are part of a clinical trial. Blue Cross/Blue Shield folks, incidentally, provided incomparable support.

The trip to NYC was informative, reassuring and intimidating. Our first NYC impression was of the Helmsley Medical Towers, an imposing, tall, gray apartment complex housing offices, residences (complete with many dogs) and several floors of a hotel for patients. Elliott, who very definitely made us at home and proved a substantial source for information about the surrounding area, met us. The check-in procedure at Sloan-Kettering, two blocks south of the HMT was easy. That morning I began a series of tests that included a Pulmonary Function Test, Echo Cardiogram, EKG, bone marrow biopsy, more and significant vampiring of blood and an aspiration of some fat cells from my abdomen, since the pathology department at our hospital in Chattanooga actually sent the slides from another person with me to New York. Dr. Comenzo had no confirming evidence that I actually had amyloidosis. No confirmation, no treatment. This was not good. Check to make sure everything is in order before you leave.

The meeting with Dr. Raymond Comenzo was impressive. He is an expert at the top of his game. The bottom line was that all my tests indicated that I was in excellent shape for a man my age; my disease was in its infancy and had not spread beyond my kidneys. So, due to my good health, they were going to throw the chemotherapy book at me. In order to let them work on me and arrest this disease I signed an eighteen-page clinical trial permission form. Dr. Comenzo reviewed each part including the possible side effects and my overall prognosis for recovery. Typically, sixty-five per cent of patients, many of whom are significantly sicker than I, go into remission following the Melphalan IV treatment. This is determined after three months. In the event that the treatment is not completely effective a nine-month protocol of treatment with Thalidomide and Dexamethasone follows. His overall perspective on my chances was "pessimistically, an eighty percent chance of full recovery." At this point, I'll gladly take it. So we were scheduled for a month-long treatment protocol beginning on October 27th.

The neighborhood around Sloan-Kettering and the Helmsley Medical Towers is wonderful. New York Presbyterian Hospital, the Cornell Medical Teaching College and Rockefeller University are all adjacent to Sloan-Kettering. So are innumerable delis, groceries, restaurants and shops. Bloomingdale's and Central Park are in walking distance. We dined at the York Grill on 86th and York and at an Italian restaurant of high repute. The York was excellent. The Italian restaurant was very overrated.

Part Three: Getting Ready

There really isn't much that can prepare you for leaving home for a month-long hospital visit. We arranged for housing in New York back in the Helmsley Towers though for a few days it looked as though we would have to move out for two days in the middle of our stay. We made flight arrangements for Emily to go back and forth, Brian to come up and return, and for both Emily and I to travel up and back together. Delta Airlines, after I finally got to a supervisor, proved very helpful and flexible since our return day was not sure. Dr. Jesse Register and his staff in the Hamilton County Public Schools provided terrific support for Emily. UTC provided excellent support for me as I made arrangements for my classes to be covered. Leaving my students was not easy. I attempted to complete all my work that I could. There was, it turns out, no way for either of us to do everything to prepare. We simply did what we could. And, of course, we dealt with having to explain the problem again and again to the extent that in spite of the wonderful support and prayers we got from friends, we just want to get started.

The potential insurance problems that I had anticipated dissipated. Clearly, being part of a clinical trial made all the difference since the medicine and extent of care will be very expensive. The only glitch, it seemed, would be that Blue Cross/Blue Shield would only pay \$150.00 per day for room and board. Our caseworker said, however, that there was some flexibility there and, happily, there was.

We also tried to cover all the bases, anticipating everything that could be wrong, with home and cat care with Becca McCashin, our incredible house sitter, and with my son who could relieve her if she needed it. Leaving the cat was especially hard for Emily and for me, too, but she was in good hands. Advice; try to think of everything since you'll have enough to worry about in a few days. Do not be afraid to ask lots of people for help.

Part Four: Return to Sloan-Kettering: Orientation and Treatment Returning

On October 27, 2004 we returned to the Helmsley Medical Towers, were greeted by Elliott who still remembered who we were and unpacked our two suitcases and two carry-ons. Not much stuff for a month long visit but, then again, how many sets of pajamas could I take? That afternoon we were to report to Dr. Comenzo's office at 4:10 in anticipation for our 4:30 appointment. Foolishly, both of us did not anticipate how busy it would be, so neither of us brought a book. We met a nurse who gave me instructions about how to give myself two injections of Neupogen a day and had me demonstrate that I would not faint at the sight of a needle by giving myself a small injection of saline solution as she watched. No big deal. Giving myself shots beat the heck out of coming into the hospital twice a day.

October 28 was a good day. In the morning they decided that I would not need a catheter when they harvest my stem cells. This was good news although I'd have to endure sticks in both arms for two days or so we thought. By late afternoon, I got a schedule that clearly explained all the procedures, medicine, and my outlook for returning to some sort of normalcy after our return to Chattanooga.

Here was the deal. Beginning on the morning of the 28th I injected myself with one and one-half cc. of Neupogen twice a day into a fold of skin in my abdomen. For those of you who don't know, you don't have many nerves down there and it is handy since you just grab a little handle of skin and fat and stick a little needle in. No pain, no transfusions, no screaming or fainting necessary. Your spouse probably won't watch. I was instructed to keep doing this for at least five days. Neupogen is an interesting little drug that is made from the Ecoli bacterium (I think that the reverse is true also and is part of some kind of recombinant DNA technology that I do not understand involving the neupogen gene and Ecoli genome). Nevertheless, just as a flu shot does,

these injections fool your body into thinking it is sick so it produces millions of white blood cells to fight the Ecoli. The good thing, of course, is that you really don't have an Ecoli infection. The side effects, for me at least, were that my muscles and long bones ached. Apparently, the effects can be pretty severe, but that was not the case with me although I did not sleep too comfortably. So, what I had to look forward to was mobilizing the stem cells, harvesting them for a couple of days, resting for a day or two, experiencing two days of chemotherapy and then a period of slow recovery at Sloan-Kettering while my body's immune system started to recover. My return home was to be exactly that. A return to our home where I'd be required to be incarcerated except for very brief outings during which I was supposed to avoid as many people with their pesky germs as possible.

Harvesting

The next morning we made our way to the "donor room" so that the "harvesting" of all those millions of cells which fight infection that my body had been fooled into producing, could begin. This was important since I would need them after the chemotherapy wiped out my immune system, taking my white count to zero. When I was reinfused with my white cells and stem cells, as well as red blood cells and platelets, my body would begin to re-establish its immune system. This, it turned out, was a longer and more delicate process than I anticipated. More on that later. The harvesting procedures entailed inserting one relatively large needle into my left arm and another into a vein on top of my right hand then hooking me up to a machine. Blood runs in then blood run out minus the stem cells. Red blood cells go right on back in with the plasma. This was not a wonderful way to spend a morning. Obviously, the vein sticks hurt a little but lying there immobile for three hours with your arms cramping from the tourniquets on them was not too much fun. The bad news was we got to do it all over on the 2nd since we needed more stem cells to reinfuse down the road.

More bad news. Not only did we get to collect stem cells a second time, they hooked me up for a third collection the next day. These collections were not pleasant but they are certainly tolerable and patients should not be too apprehensive about them. Take a book. Watch the machines that tell how much time you have left. Talk to the staff. Make the best of it. Anticipate that you'll be really tired in the afternoons and that you can continue to develop your newly found passion for afternoon naps, without guilt.

Anyway, following the final collection we went back to the good old Silver Spoon Café for another experience with their huge meals. Now, I can eat but I'll tell you if you ever venture into this place at the corner of 70th and 1st Avenue for any meal, especially breakfast, split it with someone. Too much food! So, following the meal it was siesta and rest time and then off for yet another food fest, this time at John's Pizza, a NYC pizza icon. Overrated. Give me those robust Chicago pizzas anytime. As a bit of advice here, I would strongly suggest scouting out restaurants in the neighborhood of your hospital. Before the serious work begins you'll be out and about a little and, if you come from out of town as we did, taking walks, exploring museums and art galleries and eating some really good meals will make the experience better. It will also give caregivers something to do since you really don't want them eating hospital food or going out of their minds watching you for hours on end. How much fun can it be watching someone sleep? We discovered the Manhattan Grill, The York Grill, The Atlantic Grill, Portofino's, The Beach, O'Flanigan's and several others all within walking distance or very short cab rides from Sloan-Kettering. Serendipity of Oprah fame wasn't far either.

Back to business. On Thursday we had another reassuring visit with Dr. Comenzo who gave us another prediction regarding my return to a normal existence. As indicated before it looked like I'd slowly return to a light teaching load beginning in January, start back in the pool in February, get rid of the blahs by March and feel strong and pretty normal by August. This, actually, was a realistic perspective for me, but might not fit a person getting different treatment mitigated by a more serious and/or advanced disease.

So, yesterday, I had another blood test to make sure my platelets were back to normal, was officially admitted to the hospital, had a catheter inserted in a vein under a collar bone and then we found our way to Room 1115. The catheter placement sounds gross but was a very easy and painless procedure with the exception of a few very small sticks of zylocain. The only scary part of the whole day was my first chemotherapy treatment. Following the introduction of some fluids and drugs to prevent the slight but possible nausea that might result, I got 600 ml of Melphalan IV. Now I'm telling you, I didn't know if I'd violently lose my supper, faint, glow in the dark, witness my hair falling out prematurely again or what! Nothing happened. Nothing at all. I realized I'd erred by not ordering more oatmeal raisin cookies at dinner because I thought I wouldn't feel well but other than that mental lapse which, actually, had nothing to do with the chemo, I felt fine. So the evening ended with me wired from anticipation of a bad experience that did not happen and finally drifting off to sleep about 10:30. On Saturday, I sat there watching Ohio State play Michigan State with Emily and Kristen while I got my second bag dripped into me. I fully expected to watch the entire Tennessee game later and pig out at dinner, again. So, there was no big deal with the chemo initially.

About room and board. My 11th floor room faced the East River and looked over the campus of Rockefeller University toward the 59th street bridge that connects Manhattan and Roosevelt Island where, incidentally, I could look over my shoulder and see the NYC marathon being run while I watched it on television (I'd rather been down on 1st Avenue). My view of the bridge and river was really pretty and at night was quite spectacular. Most of the food was pretty good for a hospital (at least until your taste buds run totally amuck a little later) and, as is the procedure on those cruise ships Emily and I like, I could order as much as I wanted from the menu. I could eat over a period of several hours for each meal if I was so inclined. Keep in mind, now, I'd swap the food, the view and this experience for a cruise anytime but I did not want for anything from the nurses, doctors and staff at Sloan-Kettering. They are a good natured, highly professional crew who take great pride in taking care of folks like me, even when they have to wake patients up in the middle of the night for the inevitable vital sign checks.

Stem Cell Reinfusion and the Waiting

Let's start with this. If I'm ever reincarnated I do not want to come back as a Bloodhound or any other kind of animal that can really smell well. Immediately after the reinfusion, I developed an incredibly acute sense of smell and weird things made me queasy. Plastic smells such as those that come when they change the liner to the trashcans or from wraps around food or eating utensils or even the interior of those little Cheerios boxes set me off. I couldn't stand sweet, alcohol based hand soap or the alcohol they dab you with when they clear your dressings. Beef tips turned me off. Green beans were a disaster. Lasagna was fine but some of the rest of the menu was just ugh. I did like the smell of the Italian Ice you could get anytime though. Some of the food I hated was the same food I actually liked previously.

We knew something was up when the doctors and nurses warned us that the reinfusing process itself would be smelly. They actually brought lemons in the room and told us that it might smell like beets, garlic, or just kind of sour. And this just from three large syringes of cells they put back in through the catheter under my collarbone. The procedure was nothing, but the room smelled repugnant for two days and my nose went nuts. That was really about it. I was weary and faced days of the same old same old but, I realized I was half done with this. Tedium was the word of the day though I did find that one of the benefits of this place was a professional, free massage service. Their brochure even mentioned aromatherapy but I thought I'd pass on that one. A rub down might have been good though since my back and shoulders were sore from the Neupogen I was injecting again once daily to rebuild even more of my stem cells but the therapist missed the appointment. Oops.

Last tourist information of the day. Remember those four red and white smokestacks Mel Gibson kept looking at in Conspiracy Theory? They are just across the East River. Strange vistas here but dawns so beautiful that the night nurse and I have been drawn to the window at six a.m. when

she does her rounds even as she says, “Still no changes in blood pressure, pulse rate or temperature.” My weight remains the same too. This was all a clear indication that my body hadn’t reacted to the chemo yet and my cell counts hadn’t plummeted.

Four day past infusion update: People here were still talking about “the event” and my nurses and doctors teased me about it. The event is a relatively short period of time, perhaps, twelve hours or perhaps a day, during which your blood counts really bottom out and it hits you. For example, your white count is supposed to be four to ten thousand. On this day mine was eight hundred and would probably hit zero on the morrow. This “Nadir” is not a good deal since it is associated with flu-like symptoms some of the worst of which are just plain old exhaustion and lethargy plus a probable loss of appetite. After the event they said they’d put me on stronger antibiotics, some antiviral drugs and they’d restrict my appetite so I’m not exposed to any food-borne bacteria. They assured me that it should include a couple of days when I feel as if I’ve been hit by a truck, and then a slow recovery as they got me eating again and transfused me with platelets.

Here’s the bad part about all of it and it is something shared by all people who go through chemotherapy, especially active persons like me who have always been careful about health and fitness. You can’t control any of it and you don’t know for sure when anything, good or bad, is coming. With respect to your “crash” you just know that in a day or two this unpleasant thing is going to happen to you and then you are going to emerge out the other side. So you count your blessings for the support you get from wife and kids, church, colleagues and friends, not to mention excellent and personable doctors, nurses and staff. One of the physicians, upon discovering that I teach teachers, says he was going to bring me stickers (but not scratch and sniffs) from his wife’s third grade class if I was good. The hospital also had the foresight to provide us with literature about what I can eat when I go home. Now, this is something to look forward to since it includes lots of protein and calories since I’ll be skinny and that means exotic milk shakes (buy your Ben and Jerry’s stock now) and a whole bunch of foods I already like. It does eliminate my favorite carbohydrate replacement beverage for a while, so my slow but sure quest for the perfect beer will be delayed. Wouldn’t it be ironic if instead of relishing a great Samuel Smith or St. Peter’s Golden Ale, a Chimay or a Big River brew of the season (unpasteurized-can’t drink it), I end up actually liking stuff like Miller Light; an entire quest gone up in chemo.

Note: This event thing sounds like Stephen King or Rod Serling doesn’t it? Maybe I’ll read “Thinner” again when I’m done with the Gunslinger series which happens to be great and distracting reading at a time like this. Those of you going through this-bring lots of books.

It’s here, Nadir

OK, I arrived at the day when Dr. Comenzo indicated that I’d start to feel badly. This after a day when I felt pretty decent for here; just tired with that constant bad taste in my mouth and the chemo-hiccups. I tried to pull one of the Capitol One island commercial deals with the doctors like the guy who feigns the SOS by pretending that I had a cross between Ebola, pneumonia, arthritis and run-over-by-truck syndrome but it didn’t work. I felt the same. I knew I was lucky and that I’d probably jinxed myself but one of the guys said that possibly I wouldn’t have many of the symptoms associated with coming out of this. My blood counts had bottomed out. For two days the old WBC had been .1 when it ought to have been 4-11 (that’s thousand). Platelet levels were about 54 when normal was 160-400 (thousand again). These were still dropping and if they were to go below 20 I’d have a transfusion or two. In order to be released from the hospital my platelet count had to be above 50. I didn’t have a record of red blood cell count by the machine that measures oxygen transportation though my blood had been happy all along. I had actually gained a pound and, since I didn’t balloon up, it wasn’t water weight.

Let’s talk food. This may be much more informative for people going through this than curious bystanders. I’m pretty sure taste, both before chemo and after chemo is individual. Why else do some of us crave Italian, others Chinese and why does my wife disdain curry when I like it? Taste

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after chemo is one part individual and one part weird. After chemo you have to deal with the fact that your mouth tastes metallic, it is constantly dry and your sense of smell is out of whack. This makes for interesting and experimental eating and is sort of like your diabolical mom saying to your dad, "He's four years old now, let's try out brussel sprouts, tilapia and creamed spinach on him all at once." So here are my dietary reviews for what they are worth.

Good Bad

Breakfast:

Orange Juice Apple juice and coffee (two of my normal favorites)

Most cold cereals but Frosted Flakes are "great" Hot cereals

Banana nut muffins Croissants and bagels

French toast and pancakes in moderation Omelets (but not too bad)

Lunch

Chicken noodle soup and saltines Almost everything else. Nothing heavy.

PB&J or tuna (1) sandwiches

Dinner:

Penne pasta with meat sauce Beef tenderloin tips and any burger

More Diet (dinner continued)

Pork tenderloin Fish (including, by the way, Tilapia)

Glazed apples Any pasty vegetables like taters and also green beans

Dessert:

Strawberry Ice Cream Sunday!!!! Yogurt

Pound cake Other cakes Marion's Italian Ice Strawberry shakes packaged in cartons.

So, that is probably more than you needed to know about the food thing. It is truly weird. Weirder still were my cravings. I would have liked for Bruce from the River Street Deli in Chattanooga to deliver me two hot dogs with slaw, relish and mustard as soon as possible. I could also have used a little prime rib, one of my charcoaled steaks and maybe a good pizza or some shrimp. There were more. I knew I was going to be a mess when I got back.

Here's an update after the highly optimistic, nothing seems to be happening to me way I started this section. The next day my platelets dropped to 13 so I got a transfusion and the day after they were still down at 16 so they gave me another. The transfusing process is just a drip through your lines that takes about an hour. My problem was that the Benadryl they also gave me, in fairly substantial amounts to fight any potential allergic reaction to the platelets, totally wiped me out. Within an hour, each day, I was as exhausted as I've ever been in my life and the exhaustion lasted from noon until 9:00 when I got my night meds and turned out the lights. Then I got night sweats from my bone marrow kicking back in which caused a fever spike that lasted past midnight. After that, however, I slept relatively decently except for numerous trips to the john since they were replacing so much fluid by IV. Not the easiest of days, just ones you get through. Compared to many of the patients here, particularly those in pain like a woman I met yesterday getting a chest x-ray who has had two lung operations, I've had it easy.

Today was the day the doctors were to really determine if I was on the way back. My platelet count, thank God, was at 47 so no more transfusions. My white count was 4.1 which is actually in the normal range. For the next several days I had to prove that I could eat normally again and they had to slowly wean me from all my intravenous and several other medicines. Progress! I had never realized how much better it felt to be tired compared to exhausted. Nap time though.

About those medicines, if you are the type of person who doesn't like to take many other than those obligatory age-related medicines some of us experience like Lipitor (which they discontinue) and, maybe, something like Nexium, be prepared for a shock. You may be treated to an aerosolized Pentamidine to prevent pneumonia, Cipro antibiotic, Fluconazole anti-fungal, Acyclovir anti-viral, Protonix anti-gastritis and, if you need it Oxycodone and Ambien. You may also get to suck on a terrible tasting little lozenge (I've repressed the name) that, ironically, is supposed to repress nausea (it could have been the Protonix). You'll just have to deal with this boys and girls; it is for your own good. Fortunately, these all go away when you go home but the Acyclovir.

Slow Recovery Trapped in Your Room (for a while)

The key word here is slow. The recovery from Day 7 after reinfusion to Day 12 was an extremely slow process, closely monitored by the staff that was tedious and out of my control. It was frustrating. Many foods still tasted terrible, the smells continued to get to me and I still had dry mouth because my salivary glands didn't work unless there was some delectable little tidbit in there. It is not horrible but patients just have to stick with it secure in the knowledge that one day they'll get out of there.

Our day, somewhat unexpectedly, came on Day 12 when we were allowed to return to the Helmsley Memorial Tower. The routines stayed pretty much the same as far as protecting me from people and elements with three significant exceptions. First, even though I still didn't eat much, we cooked using the neutropenic cooking information furnished by the hospital as a guide. Second, we were encouraged to take short walks with me wearing a mask (so get over your self-consciousness). Fortunately, we had 55-degree days so quiet ambles to a little park by the East River when there weren't many people about were a welcome respite. Third, though we recorded everything we could, nobody came into the room and said, "Time to check your vitals."

Part Five: Discharge and Recovery

One the day before Thanksgiving we had our discharge meeting with Dr. Comenzo that included a review of the results from the morning's blood tests. Basically, all my blood counts, especially platelets and WBC, were low normal so I was fit to travel and begin my recovery at home back in Chattanooga. Apparently, I'd come through the treatment very well though I'll admit I still felt guilty about my good fortune compared to others on my floor whom I'd met who were having a much rougher go and difficult prognosis than I.

The trip back home on Thanksgiving Day was not too bad since much of the worst of the rush was over. Here are a few travel tips. Assume that you will be very tired throughout the trip and take steps to make it easier. Make sure you reserve a wheelchair at the airport with assistance. A kind person will take you through security and you can avoid the lines. They will be good to you. Wear your mask. People don't get mad, usually, at folks in wheelchairs and they may actually think the mask is protecting them from you rather than the opposite. Anyway, at LaGuardia everyone was terrific. We paid a one-day fee that allowed us to use the Delta Crown Club room for a little longer than the two hours before our flight boarded. You may wish to consider this if the waiting areas are crowded as they usually are. This was a good investment; very comfortable chairs, few people, snacks and cokes for Emily. We also made arrangements to board first so we avoided all the lines and crowds. Also, when we made our initial arrangements back in early October to fly from Chattanooga to NYC and back we thought about the return trip. We chose

planes and got seat assignments that ensured we'd have aisle/window seat arrangements near the front of the planes. This meant that on the Atlanta to NYC and return portions of the flights we flew on Boeing 767s not 757s since the latter sit three by three. And, yes, I wore the mask on the whole darned trip.

We arrived at home in Chattanooga at about six o'clock had a quick, spaghetti dinner (previously frozen home-made sauce of course) and I crashed. The next morning I awakened tired but not as exhausted as I thought I'd be. Pace yourselves.

Recovery: Week One, Slow but Sure

The most obvious characteristic of week one was that recovery was very gradual. Each day I felt a little better and less exhausted. At first I got winded if I attempted to climb the flight of stairs to the second floor of our condominium at my usual pace. Later in the week the climb was easier, especially as we continued to take short, half-mile, walks around the community. The key, it seemed was to follow that old "listen to your body adage." There were days when I obviously did too much that were followed by days when naps were absolutely necessary. It was very obvious that I was not in anything close to the physical shape I enjoyed before the treatment. Consequently, recovery became a process of setting new goals, some of which might have seemed unbelievably unchallenging in the past, and moving inexorably toward them.

Other slow but sure signs that something good was happening included a return of appetite even though eating large meals was out of the question. Following the instructions given at discharge, especially those pertaining to eating often since I wouldn't eat much, was important. And even though Caesar salads, hot dogs as well as deli food that might actually be good for you and some of that fast food stuff for which I had inexplicable cravings was on my mind there was enough variety to keep me going. There is, by the way, no ban on Ben & Jerry's Ice Cream.

As your body returns to normal you should experience less muscle soreness and fatigue. A mild exercise regimen will also help in this regard and may help break the monotony of days when you are still confined at home. Slowly but surely, your sleep patterns will return to normal except for that one little problem mentioned previously; dry mouth. Apparently, the chemo wrecks your salivary glands. Mine, at least, just seemed to shut down at night. Consequently, every hour or two I'd awaken with my tongue stuck to my palate and I'd experience dehydration worse than I ever did as a runner. Talk about cotton mouth!! We tried everything. I sucked on ice cubes (hard to sleep that way and you'll drool on your pillow), drank water (good for a hour then you are up again cause your bladder control ain't quite what it used to be for a while), and ate stuff from Famous Amos cookies to Jelly Bellies to gobs of peanut butter (OK for short periods but try to sleep with a Jelly Belly stuck between your cheek and gums). The only thing that worked, at Emily's common sense suggestion, was gargling very warm salt water to get that awful film out, taking a small sip of water and then using a product called Oral-Gel to coat my palate and gums. Keep that Oral-Gel nearby because you may need it often, but it does provide some relief.

About being self-conscious. I came back skinnier, balder and pale. The pale goes away pretty quickly. I'm adjusting to looking like a very slim Frank from [Everybody Loves Raymond](#) (with apologies here to Peter Boyle). Deal with it. People are going to be so glad you are back that your physical appearance won't matter much to them. And besides, there is some mystery here. My beard stopped growing too. Didn't shave at one point for two weeks. First time that has happened since I was thirteen. Now it is coming out on my upper lip in different colors. I thought, "What's going to happen to my head? Will I get pimples? Will my voice change? Do I get to experience adolescence again?" I hoped not. The possibilities were mind-boggling.

Recovery: Not So Fast; Setback

I can just hear Lee Corso saying, "Not so fast my friend" to Kirk Herbstreet on ESPN. Here's what happened. At this point, nine days after our return to Chattanooga and about four weeks

after chemo I got a little reminder that, even though I was beginning to feel much better and see some discernible progress, all was not right with me yet. I visited my office at the university once to pick up some material and saw a couple of people there though I made sure none of them got within my new “personal space” that has a radius of at least ten feet, Emily and I had two friends over for dinner, and I went into a drug store early one morning when it was nearly empty. Somehow I caught a bug. At noon that Sunday my temperature was 99.5 and I was hot. By 4:30 p.m. it was 102.5 and we were on our way to the emergency room. Three hours and several Tylenol later it was back down to 100.5, I’d had the obligatory blood tests and chest x-ray (clear) and had begun a regimen of antibiotics that was to last a week. For the next two days my temperature stayed at about 100 and I was exhausted and hardly ate a thing. As the week progressed it settled into the 99s and by Friday it was back to normal. That Sunday, seven days and numerous visits to Ted Arrowsmith, my oncologist, after this little relapse began, I felt decent again but knew I’d lost a week of progress and five pounds. We never did find out what caused the problem.

Wow, what a message! Even though my blood counts including my white blood cells indicated that I should have been no more susceptible to disease than anyone else, this was graphic evidence that if I did catch anything, my body couldn’t fight it worth a darn. Even though I didn’t feel we’d taken any appreciable risks before, we became even more cautious. For the next two weeks I shut myself in except for walks. We allowed ourselves a dinner out in a quiet, uncrowded restaurant on Christmas Eve and celebrated Christmas with the kids and another couple, even more mindful of my new and even more extended personal space. That was weeks two and three.

Weeks Four and Beyond: Cautious Progress

Once again the key word is cautious and to it we can still add the fact that the progress is frustratingly slow though it is inexorable. My advice here is to set day-to-day goals that culminate in weekly and monthly accomplishments. Take walks, record your weight and build an eating schedule, lift light weights, take rides in your car just to get out even if it means just driving your spouse to the grocery store and sitting in the car (put a bag over you head if you need to) or driving to a quiet park for a walk. Get into a routine that is designed to make you stronger physically and, mentally, gets you out of the rut you are in since this whole business is aggravating.

I also think you should set long-term goals. For example, as of this date, I have been home for seven weeks. I know that in four or five more weeks I’m getting back in the pool to slowly begin my workouts again. I’m going to start slowly and don’t even know if I can swim 200 yards nonstop. I’ll set goals and add one length a day until, sometime next summer, I’m back to 2000 yards again. I know that in six weeks Emily and I are going to go out to a really good dinner and toast our anniversary with a glass of champagne albeit a very small one. We go back to Sloan-Kettering in seven weeks to get what we hope is a good report. Sometime along in there I’m going to be allowed to have some real, not too good for me, deli food that will undoubtedly include a hot dog or two with mustard, slaw and relish and a good beer. I don’t care if it makes me delirious and I have to take a nap immediately afterwards, I’m looking forward to the event. In ten weeks we are going to drive over to Asheville, North Carolina via Gatlinburg and the Blue Ridge Parkway to stay in a Bed and Breakfast we’ve wanted to visit. Next summer we are going to explore parts of Utah and the Grand Canyon. And so on. We are not going to let this interfere with the quality of our lives and our life-plans any more than it has to or should (see below).

I’m also getting back to work. I’m a professor and now that we are two months away from my transplant, I’m going to teach an online course and work with my dean to prepare the college for an accreditation visit-from afar (me not the visit). Basically, I’m going to hide in my office, avoid advising appointments for a few weeks and not teach students face-to-face. The latter is a “bummer” since I’ve always loved the interaction with my students but perhaps I can learn to challenge and aggravate them on-line. The point, of course, is that I’m doing something. I’ve got to be careful to not wear myself out and need to be extremely cautious about those bugs (I seem to

be going through antiseptic hand lotion by the pint) but doing a bit will help my recovery. Hopefully, others in my position will have circumstances and supportive people who recognize that work becomes therapy and will let them begin to take their places and contribute again. I guess this applies mostly to people who actually like their work but that's another problem.

Addendum (a little later)

I've reflected a bit on the most frustrating part of the period between leaving the hospital and the intense part of the treatment and going back for your first checkup. Undoubtedly, it is related to the lack of control I've mentioned previously. You hope that everything is going well but you just don't know and you have to wait and wait. In my case which, again, is not typical of everyone, I was feeling really well, had begun my swimming regimen again and found I was still fairly strong, was back at work part-time and loving every minute, but there was just no way of knowing how I'd fared with the treatment. The sitting on pins and needles and being thankful for every good day you have takes some getting used to. You try to balance realistic optimism with the possibility that you could still be in for more treatment. I'm sure everyone goes through this and the key, I'm sure, is to really focus on each day all the while setting some long term goals, but it is not easy.

Part Six: Lessons; Support, Faith and Future Perspectives

Support Systems

I'm a very independent person in some ways. I seem to be mentally tough and have withstood some of life's trials such as the death of my parents and back surgery that ended a lot of what I wanted to do in athletics, fairly well. I cannot overstate how much my family's support and especially that of my wife's, who was with me everyday, meant in getting through this ordeal as simple as mine was, comparatively easily. The information we received from Sloan-Kettering emphasized the role of caretakers. Aside from just being there through all the tedium that must come from watching a drugged-up human sleep some days away, caretakers are there when you are afraid, when you go through all the tests you don't like, when you are uncertain about all those procedures and drugs and when you just need someone by your side. They listen when you are cranky and complain about the food and the boredom. They are essential. You have to relinquish some control to them. They, if they are really good as my wife was, become part of your strength. You grow much closer. It is worth it.

There is another issue about caretakers and support. Who should you tell about your disease? I didn't want my colleagues at the University, in an association I serve as Executive Secretary and the folks with whom I work in the State Department of Education or my friends to think I'd just disappeared. They could think the worst; that perhaps I'd been hurt in a car wreck or had really gotten fed up and was on a world cruise (sure!). So, I told them. I let them know about the disease and I let them know that my prognosis was pretty good. I described the protocol I'd experience at Sloan-Kettering and I told them I was nervous.

The reaction was incredible. I have never been so humbled or thankful for the concern and prayers of people who know me and who recognized that Emily shared this burden too, as I have been for the past three months. The point is, if you don't tell people, they don't know (sound like an AFLAC commercial?). People want to care. Sometimes **we** think it will be a bother for them so we don't let them know about our plight-whatever it might be. Or, maybe we just have too much pride to let anyone know we need help. Regardless, we deny them the opportunity to reach out to us and deprive ourselves of the uplifting experience their support can provide. We both lose. All of us should know that it is good to help others and, if not, we need to learn. Here's another tidbit. Cancer patients and others who have dealt with difficult diseases are everywhere. They've been through it. They know what to do. Reach out for their help and support them too.

Faith and the Message

I remember reading a book on astronomy by Stephen Hawking or some other brilliant person who wrote at one point that non-mathematicians might want to skip a couple of chapters since his discussion was going to get technical. Now, I'm not going to get technical at all but I do want to say a couple of things about faith and what I've learned from all this. If you are uncomfortable with these types of things maybe go get a sandwich since you need to gain weight and resume your reading a little later if you are still with me after all these pages. My perspective is Christian. Persons from other faiths may still have experienced similar thoughts from other perspectives.

My experience with religion in general and Christianity in particular began at a Methodist church in Culver, Indiana fifty years ago when my Sunday school teacher, Sam Medbourn, informed his young students that the Bible was puzzling. It seemed to be filled with inconsistencies and contradictions and sometimes seemed quite confusing. He emphasized that we should look for the major messages in the text and that it might not be a bad idea to look at Jesus' life and his teachings. He got me curious and started a very personal quest of mine to find meaning in the Bible and understand my relationship with God. Later in my adult life, his approach was reinforced by Leslie Weatherhead's book, The Christian Agnostic, in which admonished his readers to put the inconsistencies and questions in a drawer entitled "awaiting further light" and, especially, to not be too put off by all the denominational interpretations and squabbling that sometimes distract us from "the message". So, I've been on a quest and this chapter in my life has provided me with quite a bit of motivation to reflect.

First of all, I've reflected on my relationship with God and how he has figured into my experience. For a long time I've felt that God might not directly intervene in our lives. Stay with me here. I felt that God started all these processes going like the big bang and theistic evolution and that He sent his son as a messenger and that maybe even He's sent other messengers. What mysteries. I also felt that it would be odd for God to answer my prayers but not those of others. I couldn't explain why He would let some of my friends die young when they were good people in my estimation and had plenty of folks praying for them too. As for children such as the ones I met at Sloan-Kettering with Neuroblastoma who had just a few years to live, how could I explain my good fortune in comparison? Why me? Did God have something he still wanted me to do and so he intervened directly? Then why not them? How can you explain so many things like AIDS epidemics, whole countries starving and tsunamis? All of this was perplexing since I felt unworthy even as I recognized that we are all imperfect in His eyes. These were difficult questions for me and I almost felt guilty asking them as though they indicated a lack of faith or confidence in God.

What is the basis of my faith? I believe in God. I believe He sent His son as my savior. I believe He loves me and forgives my sins. I believe I must constantly seek His guidance. I believe He has reserved a place for me when I die. I don't think I learned everything I need to know in kindergarten, I think the roadmap for my life is in the Bible. I believe that the message is as clear as day and it is that we should love one another. Expand that as you want and include admonitions about being peacemakers and good Samaritans, welcoming prodigal sons, loving friends and enemies, honoring parents, treating spouses well and with respect and helping the poor. He doesn't have to intervene directly in my life for me to get the message though sometimes it seems I'm too busy, distracted, hard-headed and selfish to pay attention to His will. It is all right there. So, I still have difficulty understanding why he would have chosen me, apparently, to come through this experience with good results and not others but I do know what I need to do. I know some of you think that I'm so close to eternal damnation my feet must be on fire but the remarkable thing is that my faith is stronger than ever. But what about prayer you may ask? I still pray and I believe some of my prayers have (directly) been answered especially those pertaining to my father's death, my marriage and family and my responsibility to use Jesus as a role model. Reflecting back I think I understand why God didn't intervene and help me with physics exams, sporting events and getting dates when I was so shy in college. Perhaps it had to do with whether my prayers were in line with His purposes. Confusing and contradictory isn't it? The quest goes

on. Sometimes I envision a future conversation with my Father when he says, "Son, I love you a lot and I'm really glad to see you, but I want to tell you that even though you got a good bit of it right and in some respects did pretty well in that life you had, I need to fill you in on some things you just plain missed."

This leads me to what really matters in my opinion. Not many of us, myself included, are going to have a profound impact on the world. We'll leave that to the Rembrandts, Mozarts, Einsteins other great geniuses and men and women of influence. Hopefully, some people might say I was a good teacher or person and they might want to emulate me. Who knows? At this point one could get quite cynical like one of my colleagues and decide that what we do here and what we are about really does not matter. He's dead wrong. What matters are people and relationships whether or not they or we change the world. We are diminished to the extent that we do not influence people positively and to the extent that we do not take every opportunity to care for one another. This applies to people with whom we interact but don't even know. My parents taught me that this was just common courtesy. It applies to all people; rich or poor, white or people of color, and all ethnicities and religions. It especially applies to family.

So what's the message? We need to make ourselves into the kinds of people with whom others want to have relationships. We have to seek relationships because in this world work, play or personal priorities distract too many people and they forget others. We need to get past the obstacles and the hurt, reach out and especially, forgive. How many Christs, prophets, poets and songwriters does it take before we hear the message and decide that regardless of all our imperfections, we need to love each other?

That's it. Love each other. Reach out, especially to family and people who need you to care. Life is much too short to squander opportunities. Make others your priority never forgetting that you'll always get back more than you give and you'll find strength and completeness in the knowledge that other peoples' lives have been made better because you cared.

Isn't it strange that for many people, myself included, it takes a crisis for us to get the message? Two of my good friends, one in Nashville who has a multi-handicapped son and one here in Chattanooga whose son has cancer, commented on how their experiences have strengthened their faith but also lessened their tolerance for bureaucracies and policies that get in the way of relating to people and, for that matter, of negative people who never count their blessings. As I reread my friends' e-mails, I hate to think of how many times I heard about colleagues and friends who were seriously ill and I was too busy to even send a card. I've done those convenient payroll deductions to The United Way but somehow forgotten to give to relief agencies for hurricane or tsunami victims in the past. As for working directly with poor people in this community or the sick, not me.

I won't belabor this anymore except to say that I never thought that having Amyloidosis could, in any way, be a blessing. I suspect that many of us, Christian or not, have had thoughts similar to these.

The Future

Who knows? For right now, slow and steady progress to get better. After February 23 we'll know if the Melphalan IV protocol worked. If it didn't I've got nine months of Thalidomide and Dexamethasone in store for me. Regardless of my long-term prognosis, life is different now. I'm much more focused on doing what I want for myself, my wife and my family as opposed to what others expect of me than before. I'm savoring every day and looking for those simple pleasures. We are looking at retirement options so we actually get to enjoy it before time it too short. And, yes, it is time to pay a lot of people back for their kindness. I'll keep you posted. Did you notice that incredible sunset or are you still oblivious.

One Other Thing: A Concise Overview of the Treatment

I'm not sure at all that my treatment was typical of folks other than those who were going through the protocol our clinical trial experienced, but here's an overview with my reactions, in brief, to the treatment. I am counting my days from our arrival for our registration and first appointment at SKMCC. The clinical trial actually labeled this as day -11 or eleven days before stem cell reinfusion that they counted as day 0 (see positive numbers in parentheses). It really won't matter but perhaps this chronology will explain the month a little better.

Days 1-4 On the first day we registered at the hospital, got a brief orientation and I was instructed on how to inject myself with the Neupogen (GCSF), twice daily. These were easy days although I had some muscle and joint discomfort due to the injections. We did most of our exploring of the Upper East Side on these days, probably walked 15-20 blocks each day and ate at some fine restaurants.

Days 5-7 These were stem cell collection days along with the shots. The procedures tired me out and even with a nap our walks were shorter. We still dined out at night though. Didn't feel like a tourist anymore.

Day 8 Final meetings with Dr. Comenzo and staff before admission to the hospital the next day. Transplant orientation. Really good dinner (Manhattan Grill).

Days 9-10 In the hospital. Got my Melphalan IV chemotherapy. Worried. This is serious stuff. No ill effects.

Day 11 Day of rest. Nothing happened.

Day 12 (0) Stem cell reinfusion. Other than the stink in the room, I felt no ill effects.

Days 13-18 (1-6) Three days of injections of Neupogen again but no real problems. Appetite still fairly good but the food selection was changed to the Neutropenic diet that really limited choices (ugh). Day eighteen (6) was when I was supposed to get really tired but I didn't. This is not to say that I was spry through this period. It was hard to sleep well due to the dry mouth, frequent trips to the john and nurses checking my vitals, so I was tired and impatient to hit bottom then recover. I had just expected worse. Being confined to the room was the pits.

Days 19-20 (7-8) So, of course, it got worse. Since my blood count was low I received a platelet transfusion on these days and the Benadryl absolutely wiped me out. No fun at all. Exhausted.

Days 21-23 (9-11) Slow progress as blood counts return to normal. Worked hard to eat as I should and to keep from being incredibly bored.

Days 24-28 (12-16) Released from SKMCC and allowed to stay back at the Helmsley Medical Tower. What a great relief. Cooked our own meals following their diet. Began to eat a little more and sleep a little better except for the persistent dry mouth. Took walks. Got used to wearing that darned mask.

Day 29 Thanksgiving Day: Came home. Not a bad trip since we paced ourselves and Delta helped so much. What a great Thanksgiving even without a turkey dinner. The rest, days 30+, is just slow but sure recovery, prayerful thanks and hope.

Part Seven: What's Next?

Return Visit and Checkup

I imagine that everybody responds to their return visit differently having been sitting on pins and needles for a month or so while you actually began to feel good again. I really wanted to get in there with Dr. Comenzo and have him tell me that it was over, I was cured. Deep down inside, however, I wondered just how fast he could do the blood and urinalysis, examine the echocardiogram, aspirate the bone marrow, analyze it and give me a report. I wanted him to be able to tell me right then and there what the situation was but he couldn't. We'd have to wait for a few days. So, be prepared. You are going to have to wait a little longer.

This is not to say that you aren't going to have a good visit. It is very nice to know that all your blood work is normal and that, at last, you are being released from food and people prison. I'm back on my normal diet again and can interact with all the people I want as long as they pass my healthy criteria. It is almost March. We can even take in some basketball tournament action. And, frankly, any visit with Dr. Comenzo is worth the trip for informative and interesting conversation though it would be preferable to have some of it over dinner instead of in a small room while he aspirates your bone marrow.

We also took advantage of the return to drop in on our friends at the donor room (Marjorie, Monica and Joannie) and see a few of the doctors and nurses on the 11th floor who had taken such good care of us. Be prepared for them to say that you look great even though you don't have the results back and you are still wondering. This can be a little disconcerting. And since a visit to New York City is always an opportunity for out-of-towners, we had two excellent dinners at spots we've gotten to know; the Atlantic Grill on 3rd Ave. and 76th and the Manhattan Grill on 1st Ave. and 64th (ask for Rosario). You can probably get on their websites and read the menus. You'll pay, but the food is marvelous and fits the occasion if you are an optimist and celebrate almost anything.

Results and reaction:

The results weren't what we wanted. There is still some plasma cell disease left and although the treatment reduced it by 45%, there is work to be done. I don't know the specifics about the regimen at this point since I, literally, got the news less than a half-hour ago but I do know a couple of things that are very important to me. One is that Dr. Comenzo, whose support has been indispensable, is still confident that we'll beat this thing. The second is that the therapy we'll administer here in Chattanooga should not interfere with my daily life and exercise schedule though with the medicines that I'll take to prevent side effects, "the regimen can be a little complex."

How do I feel? I am determined, frustrated and a bit let-down and discouraged. I am also still optimistic. My optimism and determination will win out but for right now, sitting here with my thoughts and hopes dashed that this might be over, I am pretty angry. Once I get over my initial reaction I'm just going to count on the support I've been given and my faith and go about kicking the living stew out of this.

One day later. I'm still mad but today I deliberately accomplished some things at work that have given me pleasure (I have a job where I can actually do this) and I've made sure I had some fun with my colleagues. Dr. Comenzo in an extraordinarily kind and encouraging email to me said, "As a wise man wrote, 'I am savoring every day and looking for those simple pleasures.' And yes soon spring will arrive with many of those pleasures, simple and special and most welcome." There is no doubt in my mind that this is sage advice and that simple pleasures can keep us going.

Preliminary Details:

Well now, I'm taking twenty-three pills a day to start out including Thalidomide, Dexamethasone and a host of pills to combat the flu, other viruses, bacterium, constipation in addition to my usual regimen of Nexium, Singulair and eventually, Lipitor, again. I'm to increase my Thalidomide periodically until we find out the maximum dosage that I can tolerate. The first two months of this has me on Dexamethasone four days on and four days off. After two months the regimen is just one four day step per month.

So far all this hasn't made me crazy though when you read the side effects you anticipate you might become lethargic, somewhat hyper, suffer from loss of sleep, bloated even though your appetite my suffer from some pills but may be increased by others and you and your family may get to experience mood swings. The mood swing reported to me was that I might become more hyper though in my case most folks agreed this might not be too possible, I'm already there. What a mess of pills. Make a chart and buy one of those daily pill containers for your trips.

Webpage Note: At the conclusion of each month beginning this month (March) I'll post an account of the treatment, my reactions and any information I have about results (or maybe I'll also just add stuff). The next big date for me will be at the end of April or mid-May when we'll discover if I'm responding to this round of treatment. If I am we keep going. If not, there are a couple of fallbacks including additional clinical trials that could be possibilities. We'll just have to see. Keep the faith.

A Mid-March observation:

Earlier this week, a group of us were waiting for the lab at the clinic to open so we could participate in a little pre-work bloodletting. We didn't know each other but we began swapping stories about our chemo, the fact that since one fellow no longer had much of his intestinal tract it played havoc with spicy Mexican food and how another who now had only one lung was actually enjoying the challenge of getting back in shape by walking four miles a day. As we talked and laughed about our travails, hopes and the optimism with which we greeted each new day I was struck by the incredible camaraderie that immediately existed between total strangers and the power it has for focusing a person's spirit toward combating disease.

I was also struck at how our diseases had become a focal point of our lives. These crises had not so much made us self-centered as totally self-aware. All of us knew the stakes. All of us knew that our time could be limited. We remembered Bonnie Raitt's line from her CD *In The Nick of Time* that "Life is more precious when there is less of it to waste." And, yet, we felt that we were more alive and appreciative of our world and each other than ever. Once again, it took a crisis to focus us on what really matters.

That evening I watched the Paula Zahn special on breast cancer and observed how families can be drawn together when a member or members face major illnesses. I sometimes wonder how our loved ones cope. My illness has changed me. It has influenced the way I treat people, view the world, appreciate my faith and how I live my life. I monitor my physical condition constantly. I wonder if I'll ever really get back in excellent shape again. Partly because my father was a physician I'm really inquisitive about all the medical procedures I'm going through and the effects of the pills I'm always ingesting. And I want to celebrate those many blessings and make lots of future plans because I want every day to count.

I must be insufferable. Am I overcompensating? Perhaps, I need to continue to be my normal optimistic, happy self but spend a little more time realizing that in spite of the fact that I'm doing just fine thank you, some of the folks who love me might be really scared. I've got to remember to listen. Just a thought.

End of March Observations:

I am now two weeks into my Thalidomide/Dexamethasone regimen and I'm still trying to figure it out. I'm always aware of the drugs in my system and although it isn't really pleasant and I look forward to the day when I'll really feel clear of them again some time in the distant future, the regimen is quite tolerable. Sometimes I'm a bit light headed and at others, especially when I'm on my four-day Dex sequence, I'm wired but life is pretty normal. The only side effect that is noticeable is that whether I need to or not, I could eat a horse, anytime. Keep those snacks away from me and give me some lousy unbuttered popcorn to fill me up. I don't gain weight easily at all but I realize that without some restraint I could balloon after several months of this. Moderation appears to be the key as usual and let's just say it also pays to be careful when I'm driving, exercising or operating as usual.

My latest blood work was completely normal except for my cholesterol level which had skyrocketed into the 400s. HDLs nice and high. LDLs, ridiculous. Apparently the chemotherapy influenced this development and with the help of my faithful Lipitor it should normally go back down to the 160s or so again, but this is a concern. Perhaps I shall be more moderate with my Ben and Jerry's and cheese as well. I'm not sure how many people who have gone through chemotherapy experience problems getting back into shape but I have never had so many muscle and tendon aches and pains in my life. I'm easily swimming a mile nonstop again and can churn out a reasonable 500 meters with absolutely no cardiovascular stress but I've pulled a hamstring muscle and now I've got a very tight Achilles tendon and something that resembles the worst case of plantar fasciitis I've ever had. I'm sure all the walking we did in Asheville over Easter had something to do with it but even with plenty of stretching it is an unexpected and bothersome inconvenience. I knew this somewhat aged body would not bounce back as quickly as it used to but this is a bit frustrating. Pass the aspirin and an ice pack please.

Speaking of driving and walking, here's an unsolicited testimonial. Emily and I just returned from Asheville, N.C. where we had a beautiful quiet drive in the mountains and stayed at the Richmond Hill B & B. This is in keeping with our too long delayed treat ourselves right policy which means that every so often we are going to go to wonderful places and celebrate. If anyone wants an incomparable Mobil Four Star B & B experience, go to this place. Yes, it is expensive but it is worth every dime. Check it out in the Select Registry online. Consider the croquet cottages and definitely eat at Gabrielle's (even if you don't stay there).

Here are a couple of unexpected benefits. I'm going to get a haircut this week I think. First one since October 15 or so. I don't have much hair anyway (it's a back of the neck thing) and my haircuts are inexpensive, but I figure I've saved \$75.00 bucks so far. That's a wonderful three course dinner for one at Gabrielle's at Richmond Hill. The gas I saved by not driving around for two months probably paid for the rest of the meals. Perhaps the best benefit, however, comes from my pill container. Since I take 20-25 pills a day at four different times we got one of those big old 4x7 compartment trays so I could keep track. Here's the deal. The box says that when you are done with your pill regimen you can use the thing to store fishing lures. How about that! I don't fish.

I am, however, so thankful to be enjoying this beautiful Spring.

April 15 Observations:

At this point, four cycles into my Dexamethasone/Thalidomide regimen I've noticed a few other minor symptoms that are interesting. My hands are warm, my fingers if I keyboard a long time feel something (not burning, electric currents or tingling but there is a feeling there), I occasionally get some swelling in my feet, workouts or just a hot shower cause a rash that goes away quickly, and I bruise pretty easily as when slapping one's thighs when a basketball player makes a

bonehead play. And my emotions are on edge. Highs are high, lows are low but, fortunately, there are not too many of the latter. This, I'm told is a function of the steroids. Is that why major league ball players pound their lockers and throw bats? Nothing really big, no neuropathy, just some things that remind you that you just aren't normal anymore.

Here's another one of those "what this experience has meant to me" entries that several people suggested that I place on the website after I taught it in Sunday School. It contains some advice for others and some that I'm still working on for myself. Pass it by if you want. There is more medical stuff further on.

Sunday School Message: April 3, 2005

Where does this (the experience) leave us personally? What do we know now that we apparently did not before?

Before you know something is amiss:

- Get off your duffs and get in shape. Being in shape may not extend your life (as in amyloidosis) but it sure will make the treatment and recovery much easier. This is a matter of priorities.
- Get your tests done and get them often. There are a lot of fun and not-so-fun little diseases out there that will kill you. Some of them are undetectable until it is much too late so do not procrastinate because you feel good or because you think you are too young to have problems.

When you know something is amiss:

- Do not accept an easy diagnosis from any physician. Many diseases have the same symptoms. Make sure you understand your symptoms. Read everything you can about what could be causing them. If your physician gives you a quick and easy remedy and tells you to come back in three months you should ask him or her to provide you with evidence that severe illnesses have been ruled out.
- Once you are sure of your disease, do your research, particularly if it is a killer. If it is a killer and it is rare, it will probably not respond to conventional treatment. The amyloidosis literature indicated that "the standard treatment is generally unsatisfactory." In layman's term this means with standard treatment you may die in two to four years. If this does not encourage you to investigate the best treatment programs, nothing will. Go into your doctor's office with a plan. Know where the best treatment centers are and read the lead physicians' research articles. Be able to justify your plan with insurance companies which may be reluctant to help you until you can provide them evidence that without the newest treatments you will die in a relatively short time. Some insurance companies love clinical trials.
- Reach out to support systems including church and many others locally and nationally. Knowing you are not alone is a great help. This does mean that you will have to let people know you are sick. This is a big step since there is still a bit of a stigma about being ill. People are more than willing to help but they cannot if they don't know about you.

As you progress through your treatment and recovery:

- Count your blessings; there are so many.
- Re-examine your faith; get the message.
- Slow down and smell the roses (become little Ferdinand the bulls)
- Celebrate every day.

- Celebrate your friends and families.
- Help others and thank others for helping you.
- Make plans especially with loved ones and make them highest on your priorities.
- To the extent you can, do what you want to do not what others expect you to.
- Do not wait to do the things you've wanted to do or visit the places you've always wanted to visit thinking that you'll have time later. You won't. At the rate you are going and the way most of us drive ourselves in our jobs, we overlook too much of this incredible world and its people and what they can offer us. You do not want to arrive at the point where you are incapacitated and you "wish you'd done that". Look at the little book "A Thousand Places to Visit Before You Die" and make plans to go to some more of them.
- Splurge some (life is too short to drink lousy wine and not visit AAA Four Diamond B & Bs. on occasion)

April 15 Appointment:

I'm going into this appointment frustrated. Tuesday I was swimming along calmly thinking about a banana smoothie when about twenty laps into my twenty-five for the day, I felt a slight pop in my elbow. By the time I finished it was slightly sore. Two hours later it was swollen and red and resting on one of my handy ice packs. Wednesday and Thursday and today, Friday, I've had to miss my workouts. This is ridiculous.

Nevertheless, my appointment was a good one. All my blood counts remain normal and my doctor and I agreed that most of the problems I'm having with symptoms as outlined above in the April 15 observations paragraph have a lot to do with the Dexamethasone and, while, bothersome, aren't problematical. Just grin and bear it. Three more cycles of this four days on and four days off to go then just four days of the steroids per month. I'm looking forward to this since I still have to work hard not to eat all the time and the steroids still make me more hyper than usual. I weight 175 now which is where I started last July and want to keep it there or a couple of pounds lower. My real aggravation comes from my tendon pulls that are keeping me from getting back into shape. Yesterday, I finally got back into the pool again with no bad results so I'll just have to take it easy, stretch a lot and slowly build back up again.

We increased my dosage of Thalidomide to 150 last night and this morning I felt a little drowsy when I got to work at 8:00. I'm also on my fourth day of a Dex cycle so there may be some interaction there. I'm just going to have to watch how I feel all day and see how the interaction of all my drugs plays out as I add more Thalidomide. We hope to go to 200 mg in a couple more weeks. Of course, I'll also keep track to watch out for the more severe side effects from the drugs, anticipating none but being careful anyway.

May 27: A Month of Frustration and Set Backs

My apologies to anyone who has been following this little saga and was expecting me to be true to my word by providing timely updates. It seems like I've been waiting to be able to provide good news and while I have no very bad news to report the road to recovery has gotten really bumpy as of late. Here's what has transpired and the lessons I've learned.

When I last made an entry to this chronicle the doctors at the clinic had convinced me that the discomfort I was feeling in my forearms, especially the left, after I swam each day was simply due to the fact that tendons and joints recover so slowly. This was not the case. One afternoon as I was changing in the locker room yet another physician friend of mine took one look at my arm and said, "You have superficial thrombophlebitis." He pointed out three distinct blockages in one vein and directed me back to the clinic.

The doctors at the clinic having been alerted to this diagnosis decided to treat it with blood thinners using Coumadin (Warfarin). I began a series of visits to the clinic to make sure my INR was stable and we began with nightly doses of 5 mg. About this time we were also fighting what appeared to be a minor respiratory infection using Levaquin, a drug with which we'd had success before. The pharmacy was told that I was taking two mg of Coumadin, not five. In the words of my pharmacist, "I'd never have let you out of the building if I suspected we'd mix Levaquin with that much Coumadin and I'll be calling your doctor." A conversation ensued the result of which was that we switched from Levaquin to Spectracef and lowered my dosage of Coumadin to 4 mg.

Right about this time my left eye hemorrhaged. Other than looking really ugly and making me continue to wonder what the heck was going on it didn't present any problems. However, I wrote up a description of all the medications I was taking, took one set to the clinic and mailed one to Dr. Comenzo at Sloan-Kettering. I received an immediate and concerned response from Dr. Comenzo who wondered why I was still taking Bactrim, Fluconazole and even my morning aspirin with the potential interaction problem. He informed me that I should do otherwise while I was taking Coumadin. My response was that nobody had noticed that this could be a drug interaction problem.

All the while this is happening I had continued my thalidomide/dexamethasone regimen and it had finally worn me down. In an email to Dr. Comenzo I indicated that I had almost no energy, often felt dizzy, had lost my sense of taste and smell making it difficult to eat, was experiencing some shortness of breath, continued to have some swelling in my extremities and I'd lost thirteen pounds. His response was 1) to take me off the regimen completely and give my body a rest and 2) to request that we travel up there as soon as we could to determine what progress we'd made fighting the disease (and there were some good signs here) and to determine how we'd proceed.

The visit was set for the 23rd and 24th. Both Emily and I looked forward to this trip immensely since we'd get some concrete information, know how to continue and determine how to stop making treatment mistakes. Early in the morning on the 20th I experienced some fairly significant pains in my chest and back and by 9:00 a.m. Emily had delivered me to the emergency room at Memorial Hospital. Five hours later after more chest x-rays, echocardiograms, EKGs and ultrasounds it was determined that I have a very healthy heart but that I also had a pulmonary embolism. My pain, which by the afternoon was about a 7-8 when I moved, was caused by a blood clot that had migrated from somewhere, probably my left leg, to the lower quadrant of my left lung where it was lodged. I spent four days in the hospital and the next few quarantined in my home except for two short excursions to the university on Wednesday and Thursday when Emily delivered me so I could teach my night graduate classes; the best tonic you can imagine.

So now what? I've been off the regimen and were it not for all my other problems, I'd actually feel good. It took about a week for my senses of smell and taste returned. The latter didn't seem remotely possible until one of my students gave me a Skittle during a break in class and said that surely I'd taste it. It was lemon. Made my whole day. Taste was completely back in three days and I could look at steak commercials without suffering. Only problem was I couldn't go out. But, I'm not tired or dizzy and the rest of the symptoms are abating as well. We'll reschedule the New York trip when it is advisable for me to travel. The main emphasis now is to dissolve the clot in my lung and to prevent the one I have in my left leg from taking a trip, especially to more dangerous locations. To that end I am giving myself injections of Lovenox each morning and evening. This, with careful monitoring, could go on for a long time. After I've had about a weeks rest I supposedly can resume normal activities. This is a ridiculous statement for me since I'm just not normal. What is really means is that I'm out of the pool for a while, I avoid strenuous activities, and take it easy. Basically, I use common sense. I can do that. Nevertheless, the constant succession of problems, some which I felt could have been prevented or at the very least monitored much more effectively, has been very irritating especially since they have shifted the focus away from exclusively dealing with the Amyloidosis.

Lessons:

- Read everything that you can about your medications especially the parts about drug interactions and problems you might anticipate. I'm not sure whether my hemorrhage was caused by a drug interaction but the fact that I was mixing drugs that should not have been mixed should have been noticed by me and especially by my physicians. The same was true of the Coumadin/levaquin mix.
- Talk to your pharmacists. If you have knowledgeable pharmacists, and I do, they are a great second line of defense and may know as much or more about drug interactions and dosages as your physician.
- Keep accurate and complete lists of the medicines you are taking and the dosages. Do not assume that, even in your clinic, everyone will have a complete and accurate record. They will ask you your dosages even if you are taking ten medications at dosages they change and will expect you to be accurate. This when they should have complete and updated records right down the hall.
- Demand to see all of your test results and do not be afraid to ask why you have been advised to take certain medications. Do not be afraid to ask whether there could be drug interaction problems. Do not be afraid to ask your physician what problems might be associated with every new drug you are prescribed.
- If you go to a really busy clinic do not assume that your physician can remember everything about you, your medications, your symptoms right there on the spot. It will be your responsibility to slow your doctor down, to provide reviews of your progress and to have questions prepared for your visit. Take a notebook. Do not leave until your questions are answered. Do not ever acquiesce to a "let's try this and see what happens" mentality without explanation.
- If you have two doctors who should be communicating; one from your clinic and one who manages your protocol, make sure they do.

Feelings:

For the first time throughout this whole experience I've been discouraged. What incredible ups and downs and uncertainties. Just when I'm working out and beginning to feel strong again the phlebitis shows up. Then I have medication problems with both my phlebitis and the viral infection I'm fighting. After two hopeful good days my eye hemorrhages. Just as things are looking up, all the bad symptoms from the adjuvant therapy that can possibly happen seem to converge on me at once. We stop the therapy. I feel better. We're going back to NYC to see how I'm really doing, finally. Then the pulmonary embolism occurs. What a bummer this month has been. May in Chattanooga is a beautiful time of the year and there is so much to do in this great little city. I wouldn't know this time.

So, here I sit slowly rebuilding my confidence and optimistic outlook. I'm still looking for that visit to the clinic when I'll get good news. Had a CAT scan of my abdomen two days ago and will have those results today so maybe today is the day when I get a "no problem down there" report and we go on being cautious with my blood clots. Hopefully, we can get up to Sloan-Kettering soon and I can get some definitive answers to a lot of questions and get geared up and enthusiastic again.

Surprise:

The CAT scan proved to be negative. I do not appear to have any abdominal problems. What a relief. Over the weekend I actually felt really good. So, up we go to Sloan-Kettering on June 13/14 for a little more lab. work, a progress report and some ideas about where to go from here we the treatment. My deal now is to get as much of my strength back as I can and remain somewhat sedate in order to not break loose another blood clot. Life goes on.

The Sloan-Kettering NYC Fall, 2005, Visit (wow!!):

First, the medical information: showed up a Sloan-Kettering with my usual jug of urine in hand that I'd unobtrusively carried up to NYC in a UTC backpack. I suppose folks thought I was going climbing when I went to restrooms in the airports but, of course, this was not the case. Fortunately, I didn't even have to explain what all my stuff was to the airport security people.

You do know don't you that you won't get results back on the urinalysis for at least a week after the rest of the tests that are administered at Sloan-Kettering, so don't feel let down when they can't tell you the most important news from what they learn about the protein in your urine. My blood work, we learned the day after it was drawn, was excellent. Getting your blood drawn up there is just another opportunity to get reacquainted with more of the fine folks in Dr. Comenzo's office.

So, we waited for about a week and got an email from Dr. Comenzo that had some very interesting language. He said "the results were quite good" and then explained that my serum free lambda light chains were "very, very low" and "the kappa remained undetectable." Later on he indicated that "the ordeal with thalidomide and dexamethasone clearly was worth it" and I was now in "what can be called a 'complete hematologic response'". Now this sounded really good and the actual figures and short comments on the lab report did too. Since I was still not completely sure what this all meant I made a series of phone calls and determined from talking to Dr. Comenzo that "the serum and urine immunofixation studies and the serum free light chain levels indicated that the plasma cell disease had responded to the short-course of thal/dex". It was impossible to determine the amount of progress we had made with the amyloid organ disease without a bone marrow biopsy (scheduled for 10/05) nor could we estimate the durability of my response to the treatment. Still, this was absolutely excellent news since I had responded very well to the thal/dex regimen and the prognosis was that when we resumed the treatment as soon as my strength was back and the problems with my blood clots were over, I'd continue to respond equally well. We have accomplished a lot and, now, for sure I can anticipate a very positive result in the future.

As I've gathered my wits about me I realize that I need to be in serious pay-it-forward mode now and help other people realize that there is hope through all of this. I need to communicate regularly with a fellow who has just begun his treatment up in NYC this week. I have lots of people who prayed for me and gave me all kinds of additional support to thank as well.

Now here's the deal with me as I look toward future treatment. Because of the embolisms I described earlier I've finished up my Lovenox shots and switched to Coumadin. We'll check INR levels often and stick with it for about a month until the clots are gone. Up until that time I'll be cautious and will avoid any kind of strenuous exercise. Hopefully, by August I'll be back in the pool, walking and trying to get back into shape. Even though my weight is about the same as it was a year ago by about five pounds (under) my muscle mass has deteriorated noticeably. I have some very hard work to do to return to my 2004 self and I'm anxious to get going. I'm actually looking forward to beginning my thalidomide/dexamethasone regimen again since I'm positive that it works very well and I know what to expect. We will modify the version that caused me so many problems and proceed with the treatment into the fall, checking to see how I am doing in October back at MSKCC.

Enough on that medical stuff and all that good news. Just thought you might want to know some more tourist information about NYC since I'm getting some feedback that people actually pay attention to the restaurants I've mentioned. We went to three restaurants on our latest trip. One is called Cibo and is down near the United Nations. It is not that well known but it had very fine food and excellent service. I had mussels for an appetizer and they served me a huge bowl with twenty-four of them. Excellent! We also visited a place called the Trattoria Dell'Arte on 7th Avenue and 57th near where my daughter works for lunch. It's Italian if you haven't guessed and serves incredible antipasta. They actually have an antipasta bar with forty choices. We chose the "large platter" that included three seafoods and five vegetables (plus a couple of treats they just threw in) and it fed all three of us well. This place is excellent as well. Right across the street is a

Greek place called Molybos that is also supposed to be superb. Next time. Finally, we went to the Grand Central Oyster Bar. This is one of those places that is rated one of the top ten seafood restaurants in the county. The Delta Sky magazines say so and therefore it must be true, right? Don't believe it and don't go there. It is noisy, the service is so so and the food is just adequate. They do have a huge oyster menu and a lot of fish choices but we just were not impressed. Don't even think about any ambience. We intend to explore a lot more of the many smaller, quieter and better seafood restaurants in the city and may just go back to the Atlantic Grill on the Upper East Side where we've had two excellent meals.

So there is your news for now. I'm about to head out west with Emily for a much needed break for both of us then attend a conference in Denver and do some exploring during that trip with my daughter, Kristen. Life is certainly good.

September, 2006, news:

Nothing but good news. After another battery of blood tests and another urinalysis, both of which were completely normal, Dr. Comenzo has determined that my plasma cell disease is in "complete remission" and even though we have not done a bone marrow transplant lately, he is apparently confident that my amyloid organ disease poses no current problem either. I'm still going to NYC for a checkup in October carrying the inevitable jug of urine in my backpack and we may have a bone marrow at that time. Until then we shall watch my blood and urine repeatedly to see if the amyloidosis returns. Even if it does, we certainly know it responded to the Thalidomide/ Dexamethasone regimen very well even if I did not. It seems I have a little genetic problem called hereditary coagulopathy also known, I believe, as Factor Five Leiden. This means I have a higher risk of forming blood clots than would be normally expected and since Thalidomide can cause them, continuing the treatment, for now, is not worth the risk. So here I am off the treatment, feeling great and deeply humbled by all of this. I'm not sure that I could adequately explain the emotions associated with feeling like you truly have a second chance to anyone except to state that they are a mixture of joy, astonishment and appreciation for so many people. There is also this strange feeling that comes with understanding you were really fortunate but others were not. I suppose this is why so many survivors of diseases like amyloidosis or cancer feel that it is their turn to pay it forward and why, perhaps, we see so many blessings in every single day.

On the lighter side, I'm in lousy shape. I can hardly swim a half-mile nonstop much less a mile fairly quickly. I figure it is going to take at least a year of hard work in the pool until I get back in 2004 shape again. I have also decided to quit making excuses (my back hurts from my surgery two decades ago (!)...I don't have time) and take up golf again. My first return to the links experiences after eight years indicate that even though I can't swim worth a lick for the time being, I'm still better at it than I am at golf. What a strange game. There is hope however since I have yet to hit an innocent human bystander walking a dog (or vice versa) near the course or damage a house near a fairway.

The October/December 2006 Report (and subsequent test results).

October 17: We found ourselves once again at Sloan-Kettering lugging a jug of urine along in a knapsack as we traveled from Atlanta. And, yes, I was glad to get rid of the thing though in the big picture it is a very minor inconvenience. That morning was simple; the usual drawing of blood, another, and this time, painless bone marrow biopsy and an encouraging meeting with Dr. Comenzo. From what they told me from the initial blood analysis it still looked like the disease was in remission but I was told, of course, to wait and see until all the tests were complete.

I did learn a few more things about bone marrow biopsies that might be helpful to some of you, however. Apparently, some folks are extremely sensitive to Zyllocain. JoAnne made a point of this before she began to inject me with the pain-killer and I told her that it had never bothered me at all. She said I was unusual but we already knew that... Anyway, she injected 13ccs into me this time. A lot it seems, but I hardly felt a thing other than a slight burning sensation at first. A couple of minutes later Dr. C. was poking around back there and said, "Did you feel that?" "No, I said, and it's a good thing too since you just made your incision didn't you." After answering in the affirmative they proceeded and after a bit I asked if he was taking his little core sample yet. He replied that he was already done and was "on the way out." After a brief look at the sample and a pause in the action to stop a bit of bleeding I'd caused since I'd had an aspirin early that morning which thinned my blood, I was up and away. The whole process took less than fifteen minutes. The next day we drove up to Vermont to mix a little trip with the Sloan-Kettering visit. My back was sore for the drive and for the next few days but I never did feel any really painful discomfort. Many people, I guess, aren't this fortunate but it seems that the perceptions we have about bone marrow biopsies from some of the medical programs on TV are just dead wrong as long as the biopsies are performed with care. From my perspective, they just aren't worth worrying about.

October 20: Emily, I and my cousin Peter McKinney were wandering through the Boston Common on a clear and brisk afternoon when the call came from Dr. Comenzo. The gist of it was that according to all the test results, the amyloidosis was gone. Complete remission. This left me almost speechless. He and I did agree that even though it looked like there might be a 90-95% chance it would not return in the next five years, we'd certainly know how to treat it because I responded so well. This wasn't going to be the disease that kills me. "Something else will, but not this and probably not soon," he said. Wow.

As I related this to Pete and Emily, I received some older, more experienced cousin advice. Pete, who had served as a faculty member and in several administrative roles at Harvard University advised me that society had sold us a bill of goods; that we needed to be productive all our lives. This, he said, was hogwash and that it was time I decided to be much less "productive." I should much more seriously consider retiring under my university's phase out program which would allow me to teach for one-half my normal load for half my pay and keep my medical benefits for the next four years-until my social security kicks in at age 66. My load can be negotiated with my dean. He asked what other work I do just for the fun of it and I mentioned some research projects and an administrative job I have done with a major state organization for the past ten years. His advice was that I keep them but to avoid what could be my tendency to work just as much for half my pay. Wise words. He informed me that he gets up every morning, is very happily busy all day long and "accomplishes nothing." Perhaps, other than the fact that he is extremely well read, interacts with people and his family all the time and is having a great time playing his clarinet with a couple of bands again. It seems to me that he and I just have to redefine accomplishments and productivity. Maybe I can measure my productivity by a declining golf score since working one-half time will allow me to have a much more flexible schedule.

December 21: So, I'm still speechless and a little stunned when I look back over my fears at the start and my thankfulness now. My feelings are a mixture of relief, a little bit of concern about the future and the possibility, no matter how remote, that this could come back, a renewed focus on every single day as well as really wanting to plan realistically for the future and a resolute perspective enabling me to count all of my many blessings. Perhaps it is appropriate during this season of hope for all of us who fight terminal and crippling diseases to recognize that we must press on, be confident, care for those who care for us and to always hope and have faith. [The Anatomy of Hope: How People Prevail in the Face of Illness](#) by Jerome

Groopman is an interesting testimony to people's hope and perseverance that was beneficial to me as I thought about my attitude through all of this.

I feel very uncomfortable offering much more. I'm not a medical authority so my experience and thoughts about treatments don't apply to everyone. I also worry that I've communicated my experience in a way that makes people think I special. I'm not. I was fortunate to have caught my disease very early and to have responded so well to the treatment. I had tremendous support from my family, friends, and my church. I kept my faith and my optimism (hope). I've learned to be very proactive in dealing with physicians and understanding illnesses. I worry now about people who are not as well read or perhaps do not have the confidence or knowledge to investigate their illnesses and treatments and to question doctors and not be intimidated by them. I still feel frustrations in dealing with hospital bureaucracies. I reflect back on a gentleman at my clinic who needed me to read for him and I understand his need for support better now. All in all, I consider this past year as the greatest blessing of my life. My focus is better. My faith is stronger. I just hope I can act the part of a man who has been given a second chance and respond as I should.

Since writing this I've received yet another good report and am looking forward, actually, to seeing Dr. Comenzo in NYC in a couple of months. I've talked to a few folks who have actually been helped by some of my ramblings and will try to keep up with them. What a lucky guy I am. I'll post more occasionally with respect to future check-ups and maybe I'll see some of you as we travel or hit the links.

2007/2008 News (April 4, 2008 entry):

I'm still here. Sorry that I've let some readers down by not continuing this as diligently as I promised. On a personal note, I have retired and am on a "post-retirement" program at the university. This is an interesting title for the program since I've always thought retirement was what you did when you quit work and post-retirement was death. Not so here. You have to retire so you can work again but in a different capacity. So I'm working one-half time for half pay all the while drawing full retirement pay and keeping my medical benefits as stated above. This goes on for four years. What a great gig. No committees, new advisees, meetings and as little to do with university bureaucracy as possible. My colleagues on this program and I have adopted Bartleby the Scrivener's motto (read your Melville) who said "I prefer not to do that" when asked to do tasks he didn't like. He, of course, met an untimely end. We are just following the outlines of our very limited contracts. And, of course, my golf handicap has improved down to a twelve.

My medical news is equally good. After each battery of tests here in Chattanooga and after each visit to MSKCC I've been told I'm still in complete remission. I've had some fluctuation in my twenty-four hour urine protein but Dr. Comenzo indicates that it has been virtually unchanged for the last two years and both he and my doctor in Chattanooga said the fluctuations were normal. Two weeks ago I went thorough what may be my last battery of tests at MSKCC including another visit to see JoAnne for another relatively harmless bone marrow biopsy. Dr. C. informs me that if my light chain amyloids remain at their present levels, I can have all my subsequent tests run here in Chattanooga. I'm to call him in January of 2009 for a consultation and if everything remains constant, I won't need to fly up again. I do not think that Dr. Comenzo would object to my giving you the contents of my latest email from him. Here they are:

"Complete hematologic remission is maintained. Immunoglobulin levels are near normal. 24-hour urine protein is 689mg (2005 = 5534mg, 2007 = 1379mg). Creatinine is 1.1 (2005 = 1.1). Albumin is 4.5 (2005 = 3.6). You get 100% plus extra credit!"

I'm not sure how the news could get much better or how the world could have seen any brighter on the day I got this short, simple message from him. Wow!! Boy, is life good.

For those of you going through this, you probably need to be aware that your insurance will probably continue to pay for the medical aspects of your return visits since you were part of a protocol but you may not be able to be reimbursed for flights and lodging. Our solution was to make the trips coincide with university/public school breaks and couple a visit to MSKCC with short side trips to Vermont, Boston,

Mystic Seaport and Cape Cod. My guess is that many of you will be near enough to your treatment center that this may not be as big a concern as it was to us.

Finally, anyone reading this who is about to start his or her fight with this disease needs to really research the hospitals where you will get your treatment. I know that Sloan-Kettering, Boston University and the Mayo Clinic are right out front. Other centers may be good as well but you need to remember that "standard" treatment is still not good enough. Dr. Comenzo has started two additional protocols since mine began forty months ago using Melphalan IV but not with Thalidomide. Each, apparently are having very promising results and one, I believe, provides real promise to patients whose disease recurs. He has also developed an antibody that flat kills the disease and is completing the preliminary phases of this protocol, again with very promising results. The antibody development is significant because it cures the disease. He informs me that once the research results have been validated and published a deliberate effort will be made to inform physicians across the country about how to diagnose the disease before significant organ involvement occurs. This is truly good news.

My advice to anyone who has been diagnosed with amyloidosis is to be sure that your doctors are up-to-date about the latest treatments. If they are confused about what you have, make sure they look into amyloidosis. Once they've found it, it will probably be up to **you** to determine what they know about the latest treatments so read up before your treatment goes too far. Make sure you know which hospitals have very successful track records with amyloidosis treatment such as the ones I've mentioned. I know I've said all this before but I cannot stress it enough based on the feedback I've had from numerous people who have called me and from my doctors.

Also, you might think about long-term health care programs but if you haven't and you've got amyloidosis you probably won't be eligible. I waited too long but now that I'm forty months out from the disease I just need to remain in remission for twenty more and then I can reapply for the program I want.

End-Notes:

Unless something unwanted happens such as a reappearance of the disease, this is probably my last entry. Hopefully, I'm just in for checkups every four months or so with normal results. If I do get amyloidosis again I'll be right back at Sloan-Kettering and will start this all up again. So readers, no new news is good news.

And finally, don't ever give up hope. Suffer through the therapy with a mix good humor, inquisitiveness, confidence in your physicians, optimism and, of course, faith. Set goals for your future and have a lot of fun along the way. Every day is precious. It is raining today but the cherry blossoms are in bloom, my tulips are coming up and I think I just might play golf anyway.