

# **We're Done....It's All Over**

## **My Liver Transplant Story**

### **By Allen Russell**

Today is Saturday, November 30, 2002. I am healing very well from my liver transplant completed very early in the morning of September 6, 2002. That would be just 85 days ago. This article is intended for two purposes. First I want to capture and organize my thoughts, successes, failures and breakthroughs along the way beginning with the diagnosis of my disorder. Secondly, I want to offer to any interested patients or their friends and relatives my account of the journey ahead should a liver transplant be indicated. In my own 'fear of the unknown' I spent countless hours searching textbooks, internet articles, medical periodicals and any other data I could collect in order to understand the probable future as I stepped through the order of my medical directions as presented by many fine doctors and nurses from Atlanta, GA, then Gainesville, FL, then Nashville, TN.

### **THE DISORDER**

It was April 29, 1999 I was presented a report on a unique lab test conducted on my blood. This test indicated that I had a disorder named "Alpha-1-Antitrypsin Deficiency". It's a genetic birth defect that can be briefly described as a breakdown in the liver of generating the appropriate transporting of a protein enzyme known as "antitrypsin" into the lungs. The purpose of antitrypsin for the lungs is to provide some protection to the lung tissues as pollution, of all types, are introduced into the lungs' interiors. With this disorder, if it is serious enough, comes lung damage in the form of Emphysema and/or liver damage in the form of Cirrhosis. My lab results from 4/29 indicated I had a severely low level of antitrypsin in my blood flow and consequently showed both signs of Emphysema and Liver Cirrhosis. My 'phenotype' measure was "19" on a scale that could reach "350". Found in some research documents, it is referred to as "Null-Null", the absolute lowest category in the measurement. Also, the phenotype indicator classified my condition as type "ZZ". This, too, was the worst category and therefore the most likely condition leading to lung and/or liver transplantation sometime later. Additional research of phenotypes follows:

Based on epidemiologic assessment of AAT (Alpha-1 Antitrypsin ) levels and the risk for the development of emphysema

### Alpha-1 Phenotypes & Serum Levels

Phenotype	Frequency (in population)	mg/dl (Commonly Quoted Levels)	*uM (True Levels)	Emphysema Risk
PiMM	90%	150-350	20-48	No increase
PiMZ	4%	90-210	12-35	No increase
PiSS	1.5%	100-140	15-33	No increase
PiSZ	.2%	75-120	8-19	Mild risk
PiZZ	.02%	20-45	2.5-7	High risk
Null-Null	very rare	0	0	Extremely high risk

\* uM result can be derived from mg/dl by multiplying mg by .1923

\*\*Table columns "Phenotype", "mg/dl", "uM", & "Emphysema Risk", were taken from the American Thoracic Society's guidelines.

The above chart taken from the website <http://www.spiderspun.net/faqs004.htm> for additional reference to these and other Alpha-1 resources please visit this site.

## THE MONITORING

Once diagnosed, I selected a group of doctors in Atlanta that could maintain the status of my disorder. This included a Gastroenterologist, a Pulmonary Specialist, and eventually a Hepatologist. Routine blood tests were performed as well as liver biopsies and lung capacity and damage testing and observations. The first liver biopsy indicated I had already sustained the development of Cirrhosis. With this knowledge, my Hepatologist suggested I would likely need a liver transplant performed in 3 to 10 years. The second biopsy results, along with the declining blood quality, began to add some clarity to the transplant projection.

## **ALPHA-1 ASSOCIATION**

Early in my internet surfing, I discovered an organization based in Minnesota devoted entirely to the research and patient-guidance as involved with Alpha-1-Antitrypsin Deficiency disorder. I promptly signed up as a member to receive existing and new development information. Soon after, I received the announcement of an annual Education Conference to be held in Charlotte, North Carolina during the period April 28 through May 1, 2000. My wife, Lynn, and I returned our registration materials without delay. It was great timing for this as I was now beginning to grow more starved to gather details of my disorder and figure out how to best deal with it. The conference was outstanding, as were the doctors, nurses, and industry consultants slated to teach us critical topics to prolong our lives in the most comfortable ways then known. This launched a critical resource for me through the research being done at Shands University Hospital associated with the University of Florida in Gainesville. For additional information please refer to website <http://www.alpha1.org>.

## **SHANDS RESEARCH**

As I wandered about the exhibits in Charlotte, I was approached by a nurse representing Shands University Hospital. She was recruiting subjects with certain parameters of the Alpha-1 disorder that would be useful in their research. Eventually, we arranged for my participation at Shands during three trips from Atlanta. Our goal was to test a new inhalant medication that could replace the existing liquid ‘replacement therapy’ drug given intravenously to Alpha-1 patients with more severe damage than I had sustained. The studies involved a very comprehensive physical examination as well as two looks at the inside of my lungs with a device that enters through the nose and transports a small camera where the lungs can be effectively studied. Dr. Mark Brantly led this research with the assistance of nurses Gwen (Moen) Carriore and Vince Corcoran. This team not only gave me a thorough assessment of ‘the condition my condition was in’, but also provided the catalyst that I needed to begin a more aggressive search for answers that would later help me build better partnerships with my Atlanta doctors, or motivate me to seek out other doctors that encouraged the partnership arrangement. Patient-centered medical practice is extremely important to me and works best where options for treatment can be discussed, evaluated, and applied with the support of both the doctor and the patient. Think of the doctor as the “coach” and the patient as the “player”. I believe it takes both to reach the best possible result. Dr. Brantly and his team continued to coach me as I established my partnerships in Atlanta. This was also a tremendous resource for me.

## **BUILDING MY CONFIDANT SUPPORT NETWORK**

I decided the likely storms ahead would be too raging to face alone, so I began sharing my situation with a very few personal and work associates. As I 'recruited' these friends, I requested each to maintain my condition as a closely-held secret. I wanted to avoid any situations where I might be construed as handicapped and unable to perform my job. Ultimately, I had built a confidant network of 23 people outside of my family. Each of them offered their unique way of consoling. They were prior bosses, my current one, long-time associates in projects I had completed, and simply good friends that had proven over time I could trust them with sensitive information. The results of having this network were terrific. I often turned to one or more of them just to talk through some new twist in the journey or to share good news as progress unfolded.

The ultimate comfort in having assembled this great group of friends was best realized as I was driven from Peachtree City, GA. to Nashville, TN. for the transplant surgery. Among my very limited 'baggage' was a set of letters or memos from this support group expressing well wishes in resolving my illness and assuring their continued support. Reading and re-reading these memos served as positive-attitude-building and stole the time I would otherwise have been fretting over all the imagined complications I might face in less than six hours! Believe me at a time like this an idle mind can be scary. I, on the other hand, had the benefit of my best friends' cheers and encouragement. I highly recommend anyone facing something as serious as a transplant to follow the path of building a confidant base of support.

## THE SEVEN CHALLENGES I FACED

Just over one year prior to my transplant, I decided to develop a list of what I figured to be the most significant challenges lying ahead. This list came from discussions I had with former transplant patients, waiting-list patients, doctors, nurses, my family, and my minister, Dr. Don Smith. Below each of the seven challenges I've included at least some of what I did to accomplish my goals in that area.

- 1) **Fear of Unknown**... Located liver transplant patients to discuss the events, pros, cons, results and any advice they could offer
- 2) **Obsessed for Knowledge**... Purchased a comprehensive textbook on liver functions, diseases and treatments. (I selected *Dr. Sanjiv Chopra's Liver Book*- copyrighted 2001). I purchased this book at a very popular bookstore. I believe it's widely available. Budgeted time to spend gathering current information from the internet and local libraries
- 3) **Protect Family**... Trained my wife on handling the finances; trained our sons on handling non-clerical home activities; increased life insurance; had our first wills prepared; determined who at my employer should be notified in case of my death and advised Lynn, my wife
- 4) **Self pity/depression**... Sought to help others less fortunate. I found this with service projects through my Kiwanis Club; kept realistic plans in mind for post-transplant period. Found reading material that promoted extraordinary success through adversity (I read *Prescriptions for Life* by Dr. Bernie). Again this reference is easily located in most bookstores
- 5) **Anger**... Continued journalizing positive past and present victories that were divinely led; kept God plugged in. Intended not to allow anger to hurt others; didn't blame anyone or any institution (work, church, schools, etc). Learned to play the cards I was dealt without protest
- 6) **Anticipation/Fear of Pain**... Sought guidance from Dr. Kramer, Atlanta Gastroenterologist and from former transplant patients. Learned and practiced best preparation for tolerating pain (i.e. weight control, physical conditioning, etc.)
- 7) **Job/Career Security/Financial Concerns**... Kept my boss, Wayne, apprised of my condition. Determined who would cover my assignments and trained them; identified all income sources and evaluated when and how to tap

## THE SYMPTONS FIND ME

For just over 46 years I had experienced the development of Alpha-1 Antitrypsin Deficiency without even knowing it. Once diagnosed and my probing of consequences began, I soon discovered logical explanations for a few otherwise unexplained nuisances. The first two I can recall were shortness of breath and early morning aversions to eating. Eventually, over the next three years, I developed numerous other medical problems as noted below:

**Ascites** (fluid-based swelling in my abdomen and ankles)

**Digestive problems**- bloating, gas, cramps, diarrhea, bowel pain, and constipation

**Physical coordination** declined (I'm told this was 'muscle mass degeneration'); affected my golf, basketball and running balance

**Short-term memory lapses**, concentration ability, focus on work assignments more difficult (Hepatic Encephalopathy)

**Bleeding varices** (esophageal and gastric); these are vessels that contain the overflow of blood not able to pass through the conventional liver-routed network

**Enlarged spleen** pressing against the inside of my rib cage, housing a huge percentage of my blood platelets, causing dangerously low test readings

**Various blood indicators** (e.g. bilirubin) beginning to approach thresholds of irregular limits

.....

Without a doubt, the most aggravating symptom was the lower abdominal cramping associated with the gas accumulations. The pain was often so disruptive, I would find only hot showers and high doses of Aleve would relieve me.

Likewise, the most frightening symptoms were those associated with the Hepatic Encephalopathy. My work with BellSouth began to suffer as my focus became more strained. Eventually, I was unable to assure my quality and results and decided to retreat into a medical leave status so I could devote fulltime to resolving my medical issues.

## WHY I CHOSE VANDERBILT

I think it was in high school football that I was taught the famous saying, “Luck is when preparation meets opportunity!” Over the years I also learned that life is fullest when my circumstances and I meet God. My circumstances at the time I was referred by my Atlanta doctor for a liver transplant evaluation included those symptoms just listed, being out of work on a medical leave, and sensing the Hepatic Encephalopathy taking over more and more of my rational thinking. Timely execution of a plan was critical since the problems were anything but static.

First, I had to find out my insurance options. Having the surgery at Emory University Hospital in Atlanta was not an option. My call to setup an evaluation to qualify for the surgery was returned with the news that my insurance company had no arrangement for this with Emory. Well, that led me to a very helpful lady who supplied me with a U.S. map with all the transplant centers available to me. There were plenty, and I could choose any one I wanted! I would be provided a travel expense budget throughout the process including follow-up visits.

Second, I wanted a transplant center with the option of doing a “Living Donor Transplant”. That would involve removing roughly half of the liver of a live donor and placing that portion where my discarded one was removed. At this juncture my understanding of the average waiting period for a full liver from a deceased donor was approximately 18 months. Knowing how quickly my health declined in the previous 12 months to this point, I wanted the option of a live donor transplant if needed to provide me a better chance of achieving a successful surgery and complete recovery. I was certainly blessed when I discovered there were three (3) viable and willing donors ready to help save my life! My brother, Gary, my cousin-in-law, John, and my great friend from college days, Arthur. Talk about unselfish sacrifice! These guys knew it well.

Third, I wanted a transplant center with a track record of competitive organ availability and a high survival rate for liver patients. In an internet site I discovered, Vanderbilt ranked 8<sup>th</sup> in the nation for the lowest “median wait” period. In a three-year tracking cycle, Vanderbilt’s patient survival exceeded the national average by 6 percentage points (82 vs. 76).

I’m a native of Nashville. In fact, I was born less than a mile from the campus. Since the Russell family is based in Nashville, I was hoping to find encouragement and support for myself and my immediate family throughout the ordeal ahead. As it turned out, this hope was far exceeded! For more detail, please see website <http://www.mc.vanderbilt.edu/transplant/liver.htm>.

## GETTING WITH THE PROGRAM

June 4<sup>th</sup>, 2002 was my introduction to Vanderbilt University Medical Center's outstanding transplant program and my lead-in doctor David Raiford, Hepatologist. I invited my brother, Gary, to join in the first part of the consultation with Dr. Raiford since I wanted to include some discussion of live donor surgery. Then later in the meeting, I invited my wife and mother. I figured I was a bit too assertive when I overheard (by design) Dr. Raiford ask my wife if I was "coachable", as we were exiting the meeting. This prompted me to encourage Dr. Raiford that coaching me was not only possible, but fit my style very well! I'm inserting below the text of a fax I sent to Dr. Raiford about 3 weeks after our initial consultation. This was intended to be my plea for consideration in a light, yet respectful manner. I certainly hope he accepted it that way. Thus....

Dear Coach Raiford,

Tomorrow will bring us to 3 weeks since my consultation in your office. My wife, mother, brother and I enjoyed the opportunity to begin this journey with you and Vanderbilt. You seemed to have a determined intent to identify all my medical issues, solve what could be solved prior to a liver transplant, then move ahead carefully and promptly to put the gears in motion to facilitate the transplant with an appropriate professional urgency. I believe your intent is genuine.

I am anxious to schedule the 3-day Evaluation.

As we left your office on June 4<sup>th</sup>, your question to my wife was, "Is he coachable?" I've thought about the question for 20 days, and wanted to answer for myself. I began playing sports, guided by coaches, when I was 8 years old and continued through my first year of college. I relate best to football, since that was always my dominant sport. The very best coach-player relationships I recall were those times I was trained to do my best, shown how to win, then allowed to use my new or improved skills to help win the game. I didn't like many, perhaps most, of the plays I was told to run, but I ran them. I believed that in the long run my Coach would send in the plays that really counted, as today, a liver transplant. I still follow that philosophy, and I'm ready to run some plays I may not like, for the long run.

Yes, I am coachable.

Please call me soon about the next play. The sidelines are stale.

Thanks, Allen

## **BEING EVALUATED**

Beginning July 10<sup>th</sup>, 2002 and lasting three (3) days, I was evaluated by the Vanderbilt Transplant Team to determine if I qualified for the program. As I understood the criteria, two very important conditions must be concluded through the evaluation. The transplant would be the only alternative possible to restore my health effectively, and there was a probable expectation of success.

The testing included the following:

Ultrasound of Abdomen

Meeting with one of my Transplant Surgeons (Dr. Gorden was designated)

Meeting with my Transplant Social Worker (Erik Lillie)

Pulmonary Function Tests

Upper Endoscopy (included banding one of my varices)

CT of Abdomen

Thallium Stress Test (waived)

Echocardiogram/EKG

## **STEPHEN MINISTRY**

By mid-summer... confusion, stress and doubt began to join my other challenges. I fortunately found a friend named Phil to help me discover a better track for this mayhem threatening my well-ordered style. In other words, my grip was slipping! Here's where Phil came in...

I discovered a new concept in ministry that reduced my 'carbon' stresses into manageable perceptions of the 'diamonds' that came to be. I faced uncertain health and career issues that might have taken me to near death or poverty. The feeling of having little control of the issues before me was a daily burden I needed to resolve through divine guidance and a real attitude adjustment. I happened to come upon a small unassuming brochure in the foyer of our church that described a program known as the "Stephen Ministry". From the moment I called to request a leader to help me sort out the 'carbon', I began feeling a sense of teamwork with a new friend...one brand new and ready to help me tackle the issues through study, discussion and prayer one evening each week. I'm one who needs feedback as I make decisions and seek to resolve problems. The Stephen Minister provided this along with a vote of confidence by showing that God wanted good things, 'diamonds', to come out from what had been struggles beyond my reach as I went my own way before finding this ministry. Believe me, it really made a difference in my understanding of God's perfect will and gave me a greater appreciation of the power of Christian fellowship and counsel.

## **MAKING THE LIST**

I was soon notified that effective July 29<sup>th</sup>, 2002, I had been placed on the official UNOS Patient Waiting List for a donated liver. See the website <http://www.unos.org> for additional information. I was also informed that my initial MELD Score was 9 (on a scale of 0 to 40). See the website <http://www.mayoclinic.org/gi-rst/mayomodel5.html> for additional information. My initial score was determined by my creatinine, prothrombin time, and bilirubin blood measurements.

## **RE-DEFINING MY JEOPARDY**

My 3-day evaluation also indicated the lung disease we knew was progressing, and the new finding of an aneurysm located near my liver. I was informed an appeal to raise my MELD Score was in process based on these 2 additional findings. The appeal was successful. My MELD Score soared to a 24 in a few days, and well, read on...

## **THE CALL**

For the next several days things were pretty quiet. I did manage to complete an appointment on August 9<sup>th</sup> with the Psychiatric Coordinator in the Transplant Program, Karen Starr. Very knowledgeable and pleasant to talk with, Karen helped me define my expectations in the program ahead. This certainly filled a void in my previous level of confidence. On this same day I also snuck in 2 minutes to lobby Dr. Raiford for some progress in evaluating one of my donor volunteers. This was to be Arthur, my college friend. I was encouraged to contact the Transplant Group for instructions. I contacted one of the nurses and felt we were now moving ahead.

September 5<sup>th</sup>, 2002, at 9:08 AM I was watching the movie *The Family Man* starring Nicolas Cage. It was way too soon for me to feel tears coming on. I paused the DVD and answered the phone. The caller identified herself as Jerita from Vanderbilt. She said they had a liver for me. I asked if she was joking. She insisted she wouldn't joke about this. She wanted to know when I could arrive for the transplant. I recalled our last drive to Nashville took just over 5 hours, then added an hour to leave my home in Peachtree City. She agreed that was okay and we hung up. **Hello tears!** Was I ready for this? No time to ask! I immediately contacted my wife with the news, then my parents. The wheels turned rapidly to get me to the Music City. I rode up with my parents as Lynn gathered our sons and got them all packed. I arrived at Vanderbilt about 3 PM.

## THE TEAM STARTS THE PROCESS- ALL 100

Dr. Raiford had mentioned several days earlier that my transplant would involve about 100 medical professionals. I figured that must be some BIG operating room! Seriously, he counted the entire group of doctors, nurses, surgeons, prep staff, admissions group, etc. As I rushed toward Admissions, I was encouraged to be in pre-op quickly. Off I dashed through a door as a big plastic bag was handed to me. This was to hold my street clothes, shoes, etc. as I slipped into the more comfortable breeze-in-the-back gown. My bow in the back was not yet settled before I took the supine position on the transitional bed. Still no time to tender my fear, the nurse carefully started my IV as the first doctor, my Anesthesiologist, approached the opposite side of my bed. I recall signing and initialing some statements. The doctor then asked the nurse if I had yet been given the “I don’t care pill”. She said “No, do you think it’s time?” That’s the last thing I remember hearing.

## WHEN DID THAT HAPPEN ?!!

After what seemed like maybe 8 or 10 SECONDS of my dozing, my eyes opened and I remember asking my friend with the Pill (see above), “When are we going to get started?” and he said, **“We’re Done. ...It’s All Over.”** I’m told my surgery lasted approximately 8 hours. And it seemed like seconds. What amazing medical technology. And to top it off, I recall no pain whatsoever. Remember, that was one of my 7 challenges I worked on.

Over the next several hours, I conversed with the many friends and relatives that visited me in the Intensive Care Unit. They tell me of our discussions and I can’t remember ANY of them. Thank goodness I behaved myself. At least they said I did!

## THE RECOVERY BEGINS

Over the next five days I accomplished a great deal in restoring my health confidence. I believe I left the ICU for a regular hospital room during the second day after the surgery. I think I was walking again within a few hours after that. My diet was regular food. This became my most significant problem...the eating and especially the digesting part. I couldn't keep my food down. So, the decision to insert a hose through my nose and into my stomach became reality. Dr. Melissa Kaufman convinced me it was the right thing to do. 'Convincing' was what I needed because I knew it would be unpleasant. For a bit more illumination I'm including here a copy of my follow-up letter to Dr. Kaufman. As follows:

Dear Dr. Kaufman,

I am writing to thank you for the way you treated me during the early days of September following my liver transplant (completed 9/6). You may recall a tall 49-year-old whose digestive tract decided to stall leading to a tube being inserted through my nose leading to my stomach. This was NOT my fondest memory, but one where your persuasiveness coupled with keen professionalism convinced me the nose hose was really the best option. It worked as you predicted and my recovery pressed on!

What then seemed like many more days, you always shot straight with me on your rounds, often shared with the other young doctors. I admired your knowledge and hope you will continue in this manner for the hundreds of patients ahead you'll surely treat.

Finally, my parents were among the group of "Waiting Room" folks as my transplant was in progress. They recall a lady giving information covering the entire transplant surgery process and remember it to be extremely helpful as they sought to understand what was happening with me. I believe the lady was you, and wanted you to know the very positive impact you had with my parents.

My plans do not include anymore transplants, so I may never see you again. But, I wanted you to know what a positive influence you were, and hope that future patients find what I found in your approach. Thanks very much for all you did.

Sincerely,

## **EARLY RECESS FROM VANDY**

The original plan for my stay in Nashville was to be about six weeks. Arriving on September 5<sup>th</sup> and being discharged on September 13<sup>th</sup> was great. Then I moved into a very convenient hotel, The Guest House, where many hospital patients reside for a time after discharge to continue outpatient treatments and allow careful monitoring by their surgeons. I remained at The Guest House until September 25<sup>th</sup> when I was released to return to Peachtree City, 296 miles south! That was a total of 21 days at Vanderbilt as compared with a six-week plan. I'm told my progress was both extraordinary and in many ways miraculous. Could this have been me and my circumstances meeting God? I feel certain that's true.

## **BLOOD MONITORING AND MEDICATION TUNING**

Over the course of the past 85 days since the surgery, I have been given several types of drugs to help my healing and keep my 'T Cells' at bay, so to speak. I've been given at least 3 anti-rejection drugs (also referred to as Immunosuppressants). Included have been blood pressure, iron deficiency, reflux, infection deterrent, and appetite medications. My blood is tested a minimum of once per week, unless a problem in certain indicators shows up. Then, we've looked at it as frequently as 4 times in 8 days (after my second rejection episode). I have traveled to Vanderbilt, with a family member, every other week since being released September 25<sup>th</sup>. These visits have included bloodwork, an exam by my primary surgeon, Dr. Wright, and a period I could ask the many questions that I've brought to better understand my condition and healing. Following the analysis of my blood, I have sometimes had adjustments made in my medications, by type and/or by dosages. When certain indicators peak out of range, it indicates a possible rejection episode in progress. My first episode was caught October 30<sup>th</sup> – October 31<sup>st</sup> by an Ultrasound and Liver Biopsy. The resulting treatment involved 3 days (at an hour each day) of high dosages of steroids, a version of Prednisone I believe, administered through an IV. On day four I was released with certifiably good blood! The second episode was detected about two weeks later and was 'fixed' remotely by medication adjustments. At this point (December 1<sup>st</sup>) I have had no further episodes of rejection. I believe the first few months are generally considered the most likely for rejection.

## **RETURN TO WORK**

It's now Friday afternoon, December 6<sup>th</sup> and I have completed 5 half days at my office in downtown Atlanta, 40 miles north of home. Next week I plan to extend my days to the routine 8+ hours. I will say my energy level has climbed as I progressed through this past week. That's good, and probably an indication my muscles are re-learning their job in all this.

My associates at the office have been terrific throughout the week. Some of the most concern came from folks I hardly knew before leaving. It was evident that timely and complete updates on my 'journey' were shared widely and often. This is certainly not surprising since I've known all along about the quality of support we share at BellSouth.

## **FUTURE PROSPECTS**

I feel confident I will continue improving over the next year or two. I'm expecting to have a greater physical and mental capacity because so many functions I now have were near crippled just 3 months ago. I have indicated to my Atlanta liver doctor that I'm hoping I can work with full 'steam' for at least 10 more years. He seemed to agree that was realistic.

Frankly, my only reservation about the future is the diet I will probably have to adopt in the next few months. The dieticians at Vanderbilt have met with Lynn and I twice to review the guidelines, restrictions, and the benefits I will gain from eating low sodium, adequate protein, low fat and cholesterol meals. The 4-ounces-per-day limit on meat products will be a significant drop for me, but I keep telling myself I must be dedicated to the BIG picture...my health in general.

I'm anxious to resume the activities that have been taboo for the past couple of years...sports (in and out of water), having a glass of chocolate milk each night, consuming Mellow Mushroom Pizza (with only 4 ounces of pepperoni and sausage, of course), and more time camping in our tent.

The next few years will see me reaching out to Alpha-1 and Liver-diseased patients offering my assistance wherever possible to ease their fears of the unknown, their anger, and their need for knowledge. I certainly don't have all the answers, but I can share a few that will hopefully be useful.

## **BUILDING DONOR COMMITMENTS**

Without our national donor program, United Network for Organ Sharing (UNOS), we, the patients, would be like ships without rudders. The system of managing the donations is strong, but the system needs more organs to fill the demand we're seeing across the United States. I admit I gave little thought to the importance of organ donation until I began studying the numbers. And, I was motivated to become familiar with this due to my own need for a transplant. I sincerely hope that anyone reading this who is not committed to being an organ donor will seriously consider the meaning to others, like myself, who could have several more years of a high quality life. In Georgia, my state of residence, you simply initiate your donor status through your driver's license agency. The donor whose liver I've received also made possible the transplant of two lungs to a new friend of mine. So, at least two lives have been renewed due to our donor's unselfish courage and dedication to helping others. I'm closing my story below with the letter I sent for the family of my donor. Hopefully, the letter speaks for itself.....

October 24, 2002

Dear Donor Family Member(s),

My name is Allen and I'm very fortunate to have received a liver from your family member about seven weeks ago. I am married to a school teacher and we have two sons. Mark is 17, a senior in high school and David is 11, now in 6<sup>th</sup> grade. We also have a very friendly dog named Rocky, a mixed breed chow that really loves to be around people.

I am employed by BellSouth here in Georgia. Next month will be 20 years since I started with them. I will be returning to work in about two weeks, allowing a bit more time to heal. The incredible expressions of concern from my friends at work have indeed made my recovery much easier. Also to help my recovery, I had enjoyed jaunts through the woods near our house and attending my usual activities such as Kiwanis Club and my church's Building Committee meetings. The Presbyterian Church where we attend has about 600 members and also has been a tremendous support for me.

The reason I needed a liver transplant began with a defect I had since birth. I had a disease known as Alpha-1 Antitrypsin Deficiency. This problem caused my liver to progressively decline over my lifetime until the liver could no longer provide support to all its functions. The donation of your family member's liver has helped me survive and gives me hope for many more years of happiness with my family and friends. I am sincerely grateful for this gift, and truly appreciate any part you had in making this possible.

Sincerely,  
Allen

## **DEDICATION**

If I listed every person who has brought peace to this journey, it would take many hours of reflection and a lot more paper. I have, hopefully, expressed my appreciation in at least some small way during the past couple of months.

I would, however, like to dedicate this story to some friends who gave me confidence that this would all work out. They challenged me in many ways to learn all I could about my condition and be active in resolving the problems. They worked tirelessly on Alpha-1 Antitrypsin Deficiency research. And I think we are close to seeing Alphas realize a quality life without resorting to a transplant. I never waited more than a couple of minutes to receive a callback from my many pager messages.

They are...

Dr. Mark Brantly, Gwen (Moen) Carriore & Vince Corcoran  
Shands University Hospital  
The University of Florida  
Gainesville, Florida

Thanks to you all. You really made a difference!



Please send your comments or questions to me at this address:

<mailto:stingem@bellsouth.net>

I really appreciate your input.

Thanks, Allen