My Liver Transplant Story

A Trek to the High Mountains
Introduction

My name is Prospero Galido (Pros), born May 28, 1950, in Loreto, Dinagat Island, Philippines. I am a naturalized U.S. citizen. At age 58, I became a liver transplant patient. I was diagnosed with end-stage liver disease with extensive portal hypertension, hepatic encephalopathy and hepatorenal syndrome. Big ominous-sounding words indeed!

It took me a while to tell my story because, on this fifth year, I still have some issues about my liver health. However, I am now at this point where I am able to interact cautiously with people and I feel that my senses are getting better.

Life with my new liver is a continuing battle and journey, having to cope with various side effects from the transplant and from medications (resulting in chills, night sweats, skin irritations, inflammation, nerve pain, confusion, fever and fatigue). Being immunosuppressant, I must constantly be careful of my eating habits, contact with the public and exposure to dirt, dust and pollution to prevent the risk of acquiring life-threatening infections. I have frequent blood tests and doctor visits to monitor my health. I dread going to the laboratory sometimes as the veins on my arms are constantly in hiding and it has not been easy to draw blood by the phlebotomists. Without fail, I take over twenty pills daily, or my transplanted liver will reject me. My loving wife, Nora, who has been by my side 24/7, has been vigilant in taking care of my needs, making sure that I follow doctors’ orders.

Each day is a blessing, which I savor very much. We are grateful that I am alive, able to walk, talk, and laugh again. The Lord is such an awesome God!
MY STORY

Before the Transplant

It was the end of August when my family had just returned from Maryland for a one-week reunion with my wife’s relatives. I felt I was in good health throughout our trip. The day following our arrival, I went back to work in downtown Los Angeles. There, I noticed that my urination was quite abnormal and I was not feeling well. After work, I went to Kaiser hospital’s urgent care at Bellflower and told the doctor of my condition. The doctor prescribed Cipro for gastroesophageal reflux disease or GERD. At home, I threw up many times and could not sleep. It was a harrowing evening. Nora was very worried and could not sleep either, so she called her cousin, a doctor, in Los Angeles for advice and also e-mailed Pros’s primary doctor in Kaiser Euclid Anaheim, asking for urgent help.

The following day, I went to see a family-practice doctor at Kaiser in Garden Grove. The doctor told me to stop taking Cipro and prescribed instead Maalox/Mylanta for GERD and Benadryl for sleep. On September 4, I went again to another Kaiser facility, in Lakewood Anaheim, to see a gastroenterologist. She suggested that I stop medications as they might be causing my symptoms. The following day, she called me to go to urgent care because blood was found in my stool. My urine looked brown and my eyes turned yellow. I had a CT scan and more blood was drawn for testing. She then ordered me to bed rest for three days. Despite visiting three different Kaiser urgent care facilities four times, I was not feeling better -- it was distressing!

Last Days of Consciousness

September 9 was a day I will never forget. I went for a follow-up check-up. The doctor, in an urgent tone, told me not to go home anymore but to have someone drive me straight to the emergency room (ER) in Kaiser Sunset in Los Angeles. My daughter, Cristina, who was telecommuting at home, immediately brought me to the ER. Thoughts raced in my head as to why I was going to the ER in Kaiser Sunset. I thought to myself, “am I really that sick?”

At the ER, which was packed with patients waiting to be seen, I was asked to have blood tests and given sleeping pills to help me sleep. It was late at night and my wife and children were already gone when I was transferred to the Telemetry Room for observation. More blood tests were done and doctors came and went. One doctor gave us the heartbreaking news that my liver was failing. The doctors gave me a drug that they hoped would reverse the liver failure. The doctors would regularly ask me if I knew where I live, who is my wife, what is my name... such simple questions, I thought. It did not dawn on me that in a matter of hours and days, my mind would go blank. The hospital staff was also adamant that my wife immediately take care of my advance medical directive. We did not have any inkling that something dreadful was about to happen. Thereafter, I went rapidly into a downward course with altered mental state. On September 12, encephalopathy or hepatic coma (a toxic rise in ammonia due to the liver not being able to process waste) was kicking in and I appeared to be confused. My hands were twitching, they observed, and I had a urinary catheter. My son, Pol, who tried to help the nurses, remembers this day clearly. Unknowingly, I bit him due to the pain of having the catheter. Nora and my daughter, Cristina, heard me scream in agony and they both ran away as they could not stand to hear my anguished voice. According to the doctors, I developed hyponatremia (the sodium level in my blood was abnormally low) and had acute renal failure. It was September 13. At this time, Pros was very agitated and, for his safety, had to be restrained. His arms were tied to the bed rails. I was slipping into hepatic coma. Then everything turned dark. I was now placed on full life support. I was now in the hands and care of my family, doctors and nurses.
During the following days and months, all the events that took place about me were conscientiously recorded by my son and my wife for the benefit of loved ones and concerned friends who were awaiting news through e-mail communications and phone calls. Pol kept a daily journal, with Nora’s and Cristina’s input, as I went through this unexpected and perilous life event.

My Wife and Son’s Journal

From Kaiser to UCLA

Pros remained at Kaiser Sunset awaiting transfer either to UCLA Ronald Reagan Medical Center in Westwood or Cedar Sinai Medical Center in Beverly Hills. We waited anxiously for a room at either hospital as his health was deteriorating. We felt rays of hope knowing that UCLA and Cedar Sinai are two of the best hospitals in the United States. This time, Nora sought the help of her cousin, a renowned pulmonologist in Ohio, who talked to Pros’s Kaiser doctor, a hepatologist. The exchange between doctors gave Pros the Kaiser doctor’s special attention. He assured Nora that Pros would be transferred to the first available hospital that had a room. Pros was accepted at UCLA’s Ronald Reagan Medical Center on September 15. He was prepped for transfer to UCLA and was put on a respirator as a precaution for the ambulance ride. Prior to being sedated with Propofol, it was the last time we were able to communicate with him, although he was not really aware as to who we were. In the evening of September 15, Pros was transported to UCLA’s Intensive Care Unit (ICU), Level 8, the liver transplant floor, his home for the next few months. We felt relief that Pros finally was in UCLA, where the specialists were, but we were still very anxious of his condition, for he was unconscious and on a respirator.

The Liver Transplant Waiting List

The demand for a liver is extremely high and since thousands of people are on the waiting list, we had to undergo a screening process with UCLA. They wanted to be sure that Pros would be a good candidate for transplantation and that he would have all the support he needed to comply with all post-transplant requirements. Several factors and criteria were to be considered and met before he could be placed in line for a liver.

We easily passed the screening process, after Nora was interviewed by the UCLA coordinator and after she completed pages of their questionnaire. UCLA concluded that we had a stable and loving family. Being covered by Aetna and Kaiser medical insurances, through Pros’s and Nora’s employers, also helped. While issues had to be worked out to place Pros in the liver transplant waiting list, Pros caught pneumonia and his heart did not quite make the stress test. He was unfit for liver transplant. Various medications, dialysis, and tests were administered while we anxiously waited for his condition to improve.

We continued to pray unceasingly amid endless communications with family and friends, who were likewise anxious.

On September 24, Pros was finally put on the liver transplant waiting list. His Model for End-Stage Liver Disease (MELD) score was 51, a very high number. MELD score is used to determine the order and urgency of patients waiting for a liver transplant. The range is from 6 (less ill) to 40+ (gravely ill). By September 26, Pros was scheduled to have his liver transplant at noon. One of the surgeons called Nora, who was home and getting ready to go to the hospital at that time, to tell her of the scheduled transplant and of its possible outcome, good and bad, following the surgery. Nora rushed to UCLA to get there before Pros got wheeled to the operating room, only to be told that the surgery was cancelled. She was devastated, and was doubly devastated when the nurse commented that Pros looked ashen or lifeless.
Pros had developed acute respiratory disease (ARD) hence the operation was put off. The surgeons, who were closely observing Pros and who were huddling in his room, said that his survival would be compromised if they proceeded with the transplant. Nora was desperate. She overheard Pros’s pulmonologist remark about the uncertainty of Pros’s recovering from his ARD. She called her pulmonologist cousin, Phil, in Ohio again. It was a relief when Phil spoke with his pulmonologist counterpart at UCLA. Phil assured Nora that UCLA was doing the right thing but he sounded not too optimistic of the ARD. Like a “see-saw”, Nora’s heart sank again. All she could do was beg the Lord for mercy. Meanwhile, Pol, who was also downhearted, went to the Our Lady of Angels Cathedral in Los Angeles. He pleaded for his dad’s survival, prayed intensely to the Lord, and knelt at every nook & cranny in the Cathedral where he could find a saint. He began a devotion to the Little Therese of the Child Jesus, through the encouragement of his aunt, who lives in New York.

Meantime, the power of prayers went into high gear. Prayers for Pros were synchronized regularly through e-mail and phone communications, from the West to the East Coast of North America to the Philippines. By October 1, another transplant was scheduled, but at the last minute the doctors found that the liver to be given to Pros was too fatty. It was not a healthy liver -- if a transplant were done he would just end up having another transplant later, and Pros was just too ill to accept such a liver due to his worsened condition. On the third liver offer, Pros was again prepped for transplant. Like the first and second offers, the doctors, nurses, respiratory therapist, and other medical staff whirled around Pros’s room, very busy with the preparation. Pros was already being wheeled into the operating room when his operation was halted again for the same reason: fatty liver. The surgeons do not really know the condition of a donor liver until it arrives in the hospital, sometimes “harvested” from a cadaver out of state. A liver, we understand, has a shelf life of a maximum of 15 hours.

Time was running out and Pros’s condition continued to worsen. His color went from purple to dark purple. He was placed on a bed that was programmed to move different ways to help him with his ARD, blood circulation, and to prevent bed sores. It was a nerve-wracking time and although his condition seemed hopeless, prayers continued with greater intensity. My family had been sustained by the prayers, love and support of relatives and friends. We were on a long roller-coaster ride and the nerve-wracking wait had been unbearable if not for our faith in the merciful Lord. Finally, a good match came on October 6 (Praise the Lord!), after a total of 4 liver offers. This had equated to 4 precious lives being lost and 4 lives being saved.

The Day: Final Transplant Day - October 6, 2008

Prayers for Pros continued unceasingly. Scheduled at 10:00 a.m., he was wheeled in at 10:30 a.m. on the second floor, the surgery level. Medical staff and Nora accompanied him. They were met by his anesthesiologists, who were waiting for Pros in the hallway. Briefly, they told us of their role in the surgery. The donor’s liver was from a younger donor, we believed. As a protocol, UCLA does not provide donor identity. About 15 operations were scheduled that day, two of which were orthopedic liver transplants. By 11:00 a.m., he was moved to the operating room. At about 1:00 pm, we were informed that the actual operation had started. Pros had three incisions, a “Mercedes Benz”-shaped incision for the liver, one on his shoulder, and one on his groin. The incisions were to help surgeons maneuver around during the placement of the donor liver, and for various tubes to be inserted into arteries. The actual procedure lasted about 9 hours, although in total he was in the operating and observation rooms for about 11 hours. Families of patients undergoing surgery waited at Maddie’s room on the first floor. It is manned by volunteers. We were given beepers and we sat together in a group, in a semi-enclosed area. The beepers were used to apprise family of the condition of their loved ones who are in surgery. Early in the afternoon, Pol learned that the transplant surgery of one of the patients, who was next to Pros’s room in ICU, was cancelled for reasons unknown to us. We became very worried knowing that Pros could die in surgery. Pol urged us all to go to the 8th floor waiting room. With outstretched hands, eyes closed, we all knelt in deep prayer for God’s merciful love for Pros.
to survive this delicate major surgery. We had never prayed as profoundly as we did that Monday afternoon. It was a long, long wait, full of anguish, as we slowly counted the hours. The volunteers were already gone when the phone rang at Maddie’s room; those waiting at the room were asked to answer the phone. Finally, we were told that Pros’s surgery was over and that he would be in the recovery room for an hour or more. It was 9:30 p.m. when Pros was wheeled back to the ICU. He had lost a lot of blood—around 90 units -- a bloody day, the doctors said. At the ICU, nurses had covered him, except his face, in layers of white blankets because the blood from the transfusion was cold.

**Days after the Transplant**

Pros’s eyes were no longer sunken and he started to open and blink his eyes. It was a blank stare however. One of the attending surgeons came and he recounted how dangerously close the operation was. He said it was extremely difficult because Pros was bleeding ridiculously and that Pros’s liver shrank like his closed fist. Because of the medications that had been administered, Pros had renal insufficiency (kidney damage); hence, for several days, he was on 24-hour dialysis, and his creatinine was monitored very closely. A hardworking ICU nurse, who was very skillful in caring for patients who had recently had a transplant and were on dialysis, was assigned to Pros. We were very grateful that a very capable nurse was assigned to him for several days. Daily, the neurologist waited in anticipation for Pros to urinate, a sign that his kidney was starting to regain its function.

On October 8, the third day following surgery, Pros opened his eyes for the first time in 3 weeks. His eyes remained open throughout the day and night. He was still in a hepatic coma. We were concerned that his eyes were open 24 hours and that they would dry up and that he could not rest and sleep. We took turns in holding his eyelids closed and later, at Nora’s request, the nurse taped his eyes closed, in addition to having an eye mask that we brought from home. The surgeons said he was not yet out of the woods, though the signs were promising.

On October 9, the blinking of Pros’s eyes had become regular, and his eyes moved a little to the direction of whoever was speaking to him. The respirator oxygen concentration was now down to 30%, from 70% after surgery, which meant that he was breathing more and more on his own. We were informed that a tracheotomy had to be done to transfer the respirator tube from the mouth to the trachea to avoid damaging his voice box. My family had mixed emotions of fear and relief about the tracheotomy but had complete trust in the doctors. Their hope was that Pros would be able to speak in due time.

Doctors said that the recovery would be slow because he was very, very sick and weak before the transplant, and it would take long for the body to get rid of the toxins. About 20 types of medicines were prescribed, and he had to take them during the first 3-6 months, to be gradually reduced in the long term. The anti-rejection drugs have to be taken 2x a day for life, and not to be delayed or missed even once due to danger of rejection. Since the anti-rejection drugs suppress the immune system, these will be balanced with antibacterial/antifungal drugs to fight infection. Many other medicines are needed.

On October 11, five days after transplant, Pros was still non-responsive and his eyes were always open. A neurologist came to see him to assess his condition. MRI showed some brain injury because one side of his brain had been deprived of blood during surgery. The good news, however, was that he now had a feeding tube, and his digestive system seemed to be taking the liquefied food. He didn’t have fever and the respirator readings looked good. He appeared to be improving, though he was still unconscious.

**Succeeding Days at ICU**

Pros’s eyes remained open, with a blank stare and blinking regularly, yet he was still
in a state of coma. He had gotten skinny and had muscle atrophy. He could not move his hands and the rest of his body. His eyes continued to be open for 5 straight days and nights. The neurologist had earlier reported a possible stroke. This worried my family a lot knowing that Pros might be paralyzed. The part of his brain that was affected was in scattered areas around his frontal lobe. They said this is the part that controls emotion.

By October 13, an open tracheotomy procedure was performed. A size 8 tracheal tube was placed in Pros’s neck. As phlegm built up in his trachea, constant suctioning was necessary. He would choke and struggle in pain during the suctioning periods. Once, in exasperation, he said he was giving up. During this moment of surrender, while we were praying the Chaplet of the Divine Mercy, we felt God’s strong intervention. Immediately, the UCLA Chaplain came to pray with us, followed by a nurse from South Africa who told Pros to fight. A caring attendant, who befriended Pros, also came to comfort him. All of them, coming one after the other, lifted our spirits. We thought “the Lord had sent these angels to comfort and strengthen us.”

More tests and procedures were performed: blood tests, daily three-hour dialysis, ultrasounds, MRIs, X-rays, more blood transfusions when hemoglobin readings were low, liver biopsy, Thoracentesis procedure (blood is drawn to determine cause of fever) etc. Pros continued to have fever episodes caused by infections in his trachea and in the central lines. One night when he had a high fever, the nurse thought it best to cover Pros with a rubberized frozen blanket to lower his temperature. When we arrived in the morning, we cried to see Pros freezing - Pros loathed the cold, cold blanket when his body was warm. We felt relieved when the blanket was set aside. Subsequently, on October 30, the central lines were replaced by a peripheral central catheter by his shoulder because the central line in his neck for taking blood no longer worked.

From time to time after October 19, Pros’s ventilator would be disconnected. He could now breathe on his own and at the same time, he was able to exercise his lungs. JP drain tubes had to be cleaned. At this time, Pros had become semi-conscious and had awakened from his coma. Pros was showing great signs of improvement.

For the first time, on October 21, he used the cardiac chair. The chair elevated Pros from the waist up and provided relief to Pros’s lungs and enhanced his circulation. But there were more issues: Pros was still shivering quite a bit. He was also coughing a lot due to the phlegm in his trachea tube. He needed more constant suctioning. Eighteen days after transplant, Pros still could not talk but he was now fully conscious and responsive. A nurse gave him a communication board to allow him to spell out letters to form a word. Understandably, Pros was frustrated on not being able to communicate or talk.

By November, Pros transitioned to 3 times per week dialysis. On November 19 he started to write and was able to communicate partly. He actually sketched himself on a piece of paper and expressed in writing: “Pain in the Butt”, i.e., when he was left on the cardiac chair long enough.

On November 26, his tracheal tube was downsized to a size 6 hole. By November 28, a device called the Passey-Muir Valve, which covered the hole to his trachea, was made available for Pros to be able to speak. Then on December 2, after so many months, Pros passed the swallow test and took the first bit of real food -- a puree.

The day before the transfer from ICU to the regular hospital room, for the first time, the ICU nurse and an attendant wheeled Pros on his cardiac chair, with oxygen in tow, through the hospital corridor and to the patios outside the hospital. He looked around at all the surroundings in amazement and excitement, as he had never seen the hospital building. He sat outside for about 2 hours, often closing his eyes and taking a big breath of fresh air.
Rehabilitation

Because Pros was in bed for many months, his muscles had atrophied or hardened. He could barely move: he could not lift his arms, he could not stand and could not walk on his own. His triceps hardened like a piece of wood and his knees would buckle up if he stood. He had to learn how to move all over again. A gentle and soft-spoken in-house therapist did his range-of-motion exercise daily.

In mid-November he was assigned a physical therapist. First, he was given a pedal exerciser and later a chair lift to help him balance when he tries to stand. The therapist challenged him every time he came. He struggled really hard, determined to stand on his own. Pros was very disappointed on days when the therapist could not come due to a high demand for his services. In the following days, when he was in the regular room, Pros underwent physical therapy on the horizontal bar in the rehabilitation room on another floor or walked by the handle bar on the 8th floor hallway. By December 20, Pros was able to walk about 40 steps with the help of a walker, a wheel chair and a nurse and/or Pol behind him. The therapist was so proud of Pros’s achievement that he even showed off Pros’s progress to his doctors.

The Big Move from ICU

The ICU has state-of-the-art equipment and is not lacking in anything. It has, among other things, ample supplies from small things like grooming supplies to hard boots to prevent a patient’s Achilles heels from dropping, a “bear-hug” blanket to keep the patient warm, a muscle-contracting gear to promote blood circulation on the legs, a bed that has all kinds of monitoring devices & tubings, and many others. Every patient also has internet access. In the ICU, a patient is assigned a well-trained nurse who is stationed in front of a patient’s room. There are occasions, depending on the severity and needs of a patient, or when a nurse is on training, when two nurses are assigned to a patient.

It was December 6 when Pros moved to a regular room. He had been in the ICU for three months. Nora was concerned with the move not knowing what was going to happen in the regular room.

Conditions were getting better after those long agonizing months. His creatinine reading had gotten better, too. Like in the ICU, the surgeons, accompanied by a contingent of staff, did their rounds in the morning. The nurses were also capable. Pros continued to have suctioning on his trachea tube and blood transfusions when his hemoglobin levels were low. He still had swelling of his legs and feet, and more tests were done.

On December 17, Pros’s three plus-month-old feeding tube was removed, a big relief to get that tube out of his nostril! There was a time when he had two tubes in his nose: one was deficient and a new one was being tested if it would work. This tube was also used for his medications as he was unable to swallow yet. What a pitiful sight! Pros did not like it at all. Pros was eventually put on a restricted diet. As things were getting better, a transfer outside of UCLA was arranged. His last day of confinement at UCLA was on December 23 (Nora’s big birthday present), after 4 months and 7 days of excellent care by UCLA doctors, nurses, and support staff, not to mention the polite food servers and housekeeping staff. We are very grateful to them all.

The UCLA Ronald Reagan Medical Center has a world-class transplant team of surgeons (led by world-renowned Dr. Ronald Busuttil), specialists and doctors, well-trained nurses, experienced physical and respiratory therapists, technicians, care partners, compassionate lifting team, and many, many other dedicated staff. These special people and other criteria make UCLA No. 1 in the West and No. 5 in the Nation.
Moving On

We were quite apprehensive to leave UCLA when Pros still looked so fragile and since all of Pros’s liver specialists were in UCLA; however, the doctors thought it best for Pros to undergo full time rehabilitation. Pros’s physical therapist at UCLA was quite busy and could not devote more time to him. Somehow, we were also relieved that we would not have long freeway commutes anymore. St. Jude Medical Center (St. Jude), in Fullerton, North Orange County, was only a few miles from home. Because of St. Jude’s outstanding rehabilitation and wellness program, Nora insisted that Pros be transferred to St. Jude instead of to other medical facilities that had no in-house doctors. St. Jude is a part of the St. Joseph Health System, which Pros’s Aetna insurance covered. An ambulance transported Pros from UCLA to St. Jude. He was assigned to Room 279, in the Rehabilitation wing. We were pleased that UCLA and St. Jude coordinated closely with regards to Pros’s continuing treatment including taking Pros’s daily blood test and reporting back results to UCLA. St. Jude also had to get UCLA’s approval on any changes to Pros’s medications. Daily, Pros was scheduled one-on-one with a well-trained therapist. The intensive therapy consisted of:

- Physical Therapy
- Occupational and Recreation Therapy
- Speech Therapy
- Neurological Therapy

We spent Christmas 2008 and New Year at St. Jude. We were happy to have compassionate nurses and goal-oriented therapists. Pros had a surprise visit from our dear dogs, Chingching and Snowy, which he had not seen for months. He also spoke to his family in the Philippines via Skype. It was truly a blessed Christmas -- Pros was alive and he was getting better. His trachea tube was removed and by January 3, he walked 400 steps. He took his first shower with the help of his occupational therapist on January 6. Three days before being released, St. Jude allowed Pros to go home for a day from 9 a.m. to 6 p.m for a trial home visit

Pros speaks: Home At Last

Finally, on January 14, 2009, our 29th wedding anniversary, I was discharged from St. Jude. I was so relieved and felt victorious and ecstatic. Though I have not won a lottery yet, I felt that I was like winning the lottery! My family and friends came to welcome me. We were all thankful to the Lord Almighty for bringing me back home. A banner hung by our entry way which said: “Welcome Home, Pops! You made it! We love you and we’re so glad you’re home.” Another sign was on our bedroom door which said: “Our one & only Papa, the sunshine of our lives, the best honey bunny and Pops. We’re so happy you’re home! Praise the Lord!”

More Physical Therapies

Upon my release from St. Jude, my rehabilitation (rehab) doctor directed me to enroll in the rehab program at St. Jude Care, Rehab & Wellness Center (CRW) in Brea, a few miles from home. The program’s goal was to further strengthen my muscles and let me balance and walk. Nora took me to CRW on a wheelchair, which was not easy. The wheelchair was heavy and it was too cumbersome to take out & put back in the trunk of the car. Eventually, I was able to walk on my own. In addition to having therapy at CRW, I had daily home exercises. I also walked in the park 3 times a week with Nora and our dogs. I was a new man when I completed the program in about 3 years, except for my neuropathy. Periodically, I also visited my orthopaedic surgeon at St. Jude Heritage Medical Group.
More Doctor Visits

A week after my discharge from St. Jude, I returned to UCLA Pfleger Liver Institute for a follow-up visit with my surgeon. Thereafter, I regularly reported to my hepatologist (liver doctor) and nephrologist (kidney doctor) who monitor my liver and kidney health. The procedure is to have a comprehensive blood work prior to seeing the doctors. We were fortunate Cristina, who telecommuted for work, could drive us during the early morning hours. I had been treated by various specialists for neuropathy in the legs and feet, for high ammonia level and confusion (neurologists), frequent nose bleeds (head & neck doctor), for skin rashes and itching (dermatologist), etc. I also had to undergo blood tests, ultrasound (with & without contrast), CT scan, MRI, PET Scan, chest x-rays, biopsy, etc. The doctors were quite thorough and did not want to second guess my condition. There were numerous trips to and from UCLA, and interactions with my liver coordinators who are very compassionate and who are my lifeline. Nora has established a very good relationship with them.

Bumps, Bumps, Bumps

Together with my loving wife and children, I have travelled a long, long, bumpy road. We all worried a lot as we did not know where the road would lead us, but we prayed constantly and remained steadfast in our faith in the merciful Lord. I am also thankful for the vigilance of Nora, who communicates promptly any issues I have with my UCLA liver coordinators. They are quite knowledgeable, act fast, and have direct contact with my liver doctors.

I had encountered the following medical conditions after transplant, which some liver patients also experience:

• Pleural Effusion is a condition in which excess fluid builds around the lungs. Excessive fluid accumulates because the body does not handle fluid properly.

On January 19, 2009, just after I had been discharged from St. Jude Medical Center, I was brought to St. Jude Medical Center ER due to sharp pains on my lower right rib, and I was running a fever. I also had difficulty breathing. The findings revealed that I had pleural effusion in my right lungs. My primary doctor at UCLA monitored my pleural effusion and did not recommend extracting the fluid from my lungs. Over time, he said it would go away.

• Portal Hypertension is caused by a partial blockage of flow of blood passing through the liver from the portal vein to the hepatic vein. The blockage increases the pressure in the portal vein, which is called portal hypertension.

Due to this condition, I had an interventional radiology procedure done where the doctors slit a small opening in my neck with an instrument that was inserted down the jugular vein using x-ray guidance. The instrument was then inserted between the portal and hepatic veins within the liver. This rerouted the blood flow in the liver and helped relieve pressure in the abnormal veins.

• Ascites is a condition in which excess fluid collects in the abdominal cavity. In most cases, this occurs as a result of advanced liver failure.

Three years after transplant, I developed ascites. I had already had a liver transplant so this condition was not normal. Several treatments were administered to reduce the amount of accumulated fluids in my abdomen:
- Restricting sodium (salt) intake;
- Diuretic therapy ("water pills") to increase urine production and help the body excrete extra sodium and water;
- Paracentesis (using a local anesthetic to insert a needle through the abdominal wall) was done three times to draw out fluids that had collected in my abdominal cavity.

Paracentesis was done twice at UCLA, and once in Medical City. I acquired an infection while travelling to Seoul, Korea and Manila, Philippines. Because of this infection, my high fever episodes were non-stop, thus my hospitalization in Seoul and in Manila.

**Hospitalization in Seoul, Korea and Manila, Philippines, August 2010**

Nora and I had been to Korea in 2008 for a seven-day vacation and we enjoyed very much exploring Seoul and the countryside on our own. In August 2010, on our way to the Philippines to attend Nora's family reunion, we made a side trip to Korea so that we could share our 2008 experience with Pol and Cristina. I also wanted to visit the city of Naju, where the Blessed Virgin Mary had an apparition. Because of the hot weather in August in Korea and having had a paracentesis at UCLA recently, I was prone to infection. Sure enough, I had an infection and ran a high fever. The procedure for liver patients is to go to the ER if fever is 100.5F. We came prepared and knew which hospital to go to as I did some research in case of an emergency. Asan Medical Center (Asan) in Seoul does transplants and had received many awards. Communication was difficult, however, and it was frustrating that no one could understand us. The admitting nurse, however, did her best and I was assigned a small bed, a size that would fit Koreans. My feet dangled out. Even in this foreign country, God did not abandon us! The Lord sent me a young, very kind, and good looking English-speaking Korean doctor! Nora was relieved. The doctor used to work in the Korean army in a U.S. base. What a big blessing! The doctor assured us that Asan did thousands of transplants and that he would do his best. The next day after sitting on a chair in the ER the whole night, Nora pleaded with the doctor to release me so that we could fly to Manila as scheduled. Back at the Renaissance Hotel, my fever returned. Nora applied cold packs after cold packs on my forehead and arms with towels that she would freeze in a refrigerator in our hotel room. Nora wanted to return to the U.S. right away and was very worried. Questions raised in our minds: Where was the Asiana Airline office? We doubted that the airline was open on Sunday. Does the airline employee speak English? How do we use the phone when instructions were in Korean characters? We didn’t want the hotel staff phone when instructions were in Korean characters? We didn’t want the hotel staff to know that I was sick. Otherwise, they might call an ambulance and we would be stuck in Korea. My fever came down the next day so we decided to proceed to Manila where family could help us.

In Manila, I was glad to see my brother & sisters and their families. We also joined the reunion’s (main reason why we were in Manila) welcome party of Nora’s relatives, many of whom we had not seen for years. I felt relieved that we were in Manila but was not feeling quite well. I tried to enjoy the delicious and sumptuous buffet table at the hotel and gathered my and Nora’s family for a small get-together party. The best part of our trip was seeing family. After a few days, I had fever again. So we went to the ER of the Medical City and asked for Dr. Janus Ong, a hepatologist who trained in the U.S. He was well-recommended by my doctor cousin. Again, the good Lord sent another angel in the person of Dr. Ong. Dr. Ong knew my doctor in UCLA as they were in Virginia together for their residency. Dr. Ong e-mailed my UCLA doctor to let him know that I was his patient. Despite having another paracentesis at Medical City, I did not improve. Nora decided that it was time to return to the U.S., at whatever cost, and booked the first available flight to Los Angeles.

- Peritonitis. Spontaneous bacterial peritonitis is an infection of the ascitic fluid.
Upon arrival at the Los Angeles International Airport, Nora’s nephew drove us directly to UCLA’s ER and I was admitted on the 8th Floor, Liver Unit. My surgeons at UCLA diagnosed me with peritonitis which developed in Seoul and Manila. I felt so miserable and was in a lot pain. My abdomen turned reddish and was tender. When Dr. Busuttil (Dr. B), the No.1 liver surgeon in the U.S. saw me, he immediately scheduled my surgery that same day. The surgery was a wash-out of my abdominal cavities that were infected. The operation took around 4 hours including my stay at the recovery room. While at Maddie’s room, Nora was dumbfounded when Dr. B came to see her. Fear was her first reaction. Why would the great Dr. B come? Did Pros make it? She felt relieved when Dr. B, with a little sparkle on his eyes, told her that I was in the recovery room. She thought Dr. B, the top brass of UCLA, was so down-to-earth. According to Nora, Dr. B said that his team took long to work on my abdomen due to a previous gall bladder operation that got messed up and that my colon was so tangled. He also said that I was not out of the woods yet and that we needed to wait if my colon would work. I was again brought to the ICU where I would be well attended. Because I was in pain, I was given a control switch to use if I needed morphine. I had hallucinations and was afraid of being alone. Unlike my previous ICU experience in 2008, I was very much aware of the pain & discomforts of being in the hospital. I called this life-threatening hospitalization “my second trek to the high mountain”.

- **Peripheral Neuropathy** is a common neurological disorder resulting from damage to the peripheral nerves. It is a type of damage to the peripheral nervous system. It affected my legs and feet. I had a lot of sleepless evenings due to the feeling of discomfort. It was an unpleasant abnormal sensation which is a combination of numbness, tingling or pain. My legs felt heavy and it caused me to lose balance.

A team of UCLA neurologist saw me and did several tests on my feet. I understand that the strong medications that I took while in ICU could have damaged the small nerves on my legs. Also, my anti-rejection pill could also cause neuropathy.

For several months, I also reported to an orthopedic doctor at St. Jude Heritage Medical Group in Fullerton who recommended that I continue my outpatient rehabilitation program.

- **Neurological Disorder** This condition was mind-wracking. I had a lot of anxieties and worries. Would I be a normal person again or should I suffer more than I could handle? Please help me, Lord!

In my fourth year of post-transplant, I was diagnosed with a neurological disorder of the brain and was treated by neurologists both in UCLA Santa Monica and in the Neurology Center of North Orange County. I underwent electromyography (EMG) and nerve conduction velocity test (NCV), Catscan, MRI, Electroencephalogram (EEG), PET scan, and a lengthy cognitive examination.

Fortunately, my disorder was found to be caused by my aggressive medications and high ammonia level, not a brain-related disease.

- **Hepatic Encephalopathy** is a worsening of brain function that occurs when the liver is no longer able to remove toxic substances in the blood. Ammonia, which is produced by the body when proteins are digested, is one of the harmful substances that is normally made harmless by the liver.

On March 15, 2013, I had encephalopathy which was triggered by my high ammonia level. The brain disorder caused my confusion. Nora knew I was having another bout of confusion. Coincidentally, on the same day, luckily, I had a UCLA doctor’s appointment at noon. I was in a bad mental condition. Nora said that I was acting weird. For some strange reason, however, when Nora asked me to pray the Divine
Mercy Chaplet on our way to UCLA, I prayed without hesitation and I looked okay. When at Pfleger, my nurse practitioner noticed that I was not acting normal, and so she tested me to confirm my symptoms. Immediately, she directed staff to take me to the ER for evaluation.

At the ER waiting room, Nora said that I continued to be confused, did not even recognize her and was unreasonably mad at her. The ER was so busy and it was not until morning when I moved to the 6th floor. The resident, the fellow, and even my surgeon, who was very caring, came daily. I was fortunate to have the attention of my surgeon who ordered that I be examined thoroughly. I had an ultrasound and biopsy of my liver. On March 20, after 5 days in UCLA, I was discharged. I had to take more medications to prevent recurrence of my encephalopathy.

My 5th anniversary of liver transplant is on October 6, 2013. I am so blessed and thankful to the Lord Almighty that I have reached this milestone. I am also thankful for the loving care, inexhaustible patience and understanding of my dearest wife, Nora, and children, Pol and Cristina. They are my reason for living!

In closing, I reflect on this particular verse from the Scripture: Sirach 2:1-6:

“My son, when you come to serve the Lord, prepare yourself for trials. Be sincere of heart and steadfast, undisturbed in time of adversity.

Cling to Him, forsake Him not; thus will your future be great. Accept whatever befalls you in crushing misfortune be patient;

For in fire, gold is tested, and worthy men in the crucible of humiliation. Trust God and He will help you; make straight your ways and hope in Him.”
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   Cruz Families                       St. Bruno Bible Study Group
   Diaz Families                      Sisters of the Lovers of the Holy Cross
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Erlinda E. Panlilio, who edited and critiqued my story.
This painting is a depiction of Pros's journey from the time he was brought to the E.R. at Kaiser Sunset Blvd., then admitted at UCLA Ronald Reagan Medical Center for a liver transplant, then transferred to St. Jude Medical Center for rehabilitation, and finally going home. It also shows his medicines & its side effects, his family, a sunflower & a rainbow signifying hope and a brighter future.