

My Life with Dialysis

Dominic Noronha

Dedication

I dedicate this book to my late parents; my late, beloved wife, Merlyn;
my daughter, Sandra and her husband Claude;
and my son, Roy and his wife Olga.

Forward

When I was asked to provide a forward to this most fascinating book, I was honoured but also anxious. Honoured because Mr. Noronha's story is so inspirational, despite so much personal adversity. Anxious because I have never written about my patients for wide public consumption. My Life with Dialysis reminded me immediately about my favourite John Steinbeck book; My Travel's with Charlie. Unlike Steinbeck who travelled with his French standard poodle, Mr. Noronha travels with his constant companion, the need for dialysis. However, like Steinbeck, Mr. Noronha has faced many health care challenges and his travels were motivated by his desire to see places of importance to himself at least one last time. This book is a testament to human courage and inner strength and what is shared shows us what is possible when these strengths are combined with human curiosity and the desire to enjoy life to the fullest possible.

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Preface

After returning from San Francisco, California where we attended my son, Roy's wedding on July 17, 2009, Lynne Peressini mentioned that it was quite amazing how much travelling I have done since I started dialysis 14 years ago. In addition, I am wheelchair bound as both my legs have been amputated about 5 years ago. She suggested a book, for people who have just started on dialysis or confined to a wheelchair, would show them they can still enjoy their lives and have a lot to contribute to society. I started dialysis when I was 66 and I am now 79 years of age. I will recount some of my experiences over the past 14 years and hope that I can provide inspiration and assistance to others.

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My Life with Dialysis

Introduction

On Friday, May 3, 1996, I had surgery to repair an aortic aneurysm at Scarborough General Hospital in Scarborough, Ontario, Canada. When I awoke the next day I was told the surgery was a success but my kidneys were not functioning as they should but hopefully in the next day they would. Most of us take our body for granted and do not know in detail what all the various parts do. For example, what is the function of a kidney? The human body has two kidneys. They “are bean-shaped organs, each about the size of a fist. They are located near the middle of the back, just below the rib cage, one on each side of the spine. The kidneys are sophisticated reprocessing machines. Every day, a person’s kidneys process about 200 quarts of blood to filter out about 2 quarts of waste products and extra water. The wastes and extra water become urine, which flows to the bladder through tubes called ureters. The bladder stores urine until releasing it through urination”¹. I went to bed that night wondering if my kidneys would be functioning when I woke up on Sunday. When I opened my eyes, there was Sandra, my first cousin, Amrith, (my father’s younger brother’s daughter) and a gentleman I did not know standing over me. Amrith was asking me to add 17 and 3. I replied 20 and there were smiles all around. The gentleman next to her said something and she said “add 25 and 40” and I said “65”. Both times Amrith asked the questions in Konkani² and then she continued talking to me asking me questions about Mangalore³. Then, the gentleman asked Amrith, in English, if I answered everything correctly and she said yes. As I am fluent in both Konkani and English I did not realize that we were talking in Konkani and the others could not understand. I was then introduced to Dr. Chan, who asked me a few more questions before he left saying that I appeared to be

1 <http://kidney.niddk.nih.gov>

2 Konkani is a dialect spoken predominately in Mangalore and Goa in India

3 Mangalore is a port city in the coastal region of Karnataka State in India.

alright. Upon his departure, I learned that I had been unconscious for over a month. I also discovered that I did not appear coherent when I woke up. When one is older and awakens from an unconscious state it is not uncommon to revert to one's childhood and the language spoken then. This was the reason I was conversing easily in Konkani and having trouble with English. I discovered that it was a month after my aortic aneurysm surgery and my kidneys did not function the weekend of the surgery, and after having been resuscitated, I then became unconscious. During this time, I was kept alive by dialysis treatments, an oxygen mask, and intravenous feedings.

Now awake, my mind was racing with a thousand questions. The first being what is dialysis? Dialysis is a medical process through which a person's blood is cleansed of the toxins the kidneys normally would flush out. It is generally used when a person's kidneys no longer function properly. This can be a result of congenital kidney disease, long-term diabetes, high blood pressure or other conditions.⁴ The second question was why was a transplant not in the cards for me? I was told that I was too old to receive a transplant even though both my children were willing to provide a kidney if it was a match. How was the dialysis going to be performed? I was told there are two main kinds of dialysis: peritoneal and hemodialysis. Peritoneal dialysis can be done in the home, by the patient, either alone or with a helper. Peritoneal dialysis uses the body's peritoneal membrane, inside the abdomen, to infuse a glucose-based solution into the abdominal cavity. The solution remains in the abdomen for about four hours, and is then drained out. This process is done 4 to 5 times a day or overnight. A surgeon must place a tube with a titanium plug inside the patient's abdomen for this procedure. The patient must also be trained to perform the procedure. Absolute attention to sterile procedures is required, or peritonitis could result. This is especially dangerous in patients whose immune systems may already be compromised or suppressed.⁵ I did not qualify for peritoneal dialysis as the peritoneal membrane was affected during the aortic aneurysm surgery. The alternative, hemodialysis, is probably the procedure that

4 <http://kidney.niddk.nih.gov>

5 <http://kidney.niddk.nih.gov>

most people are familiar with. This procedure is performed at a hospital or dialysis centre. The patient is hooked up, via a tube in the veins, to a machine that circulates the blood through a machine through semi-permeable filters. These filters take out the toxins in the blood. The procedure usually takes four hours and is done 3 times a week. I was told that while dialysis may be a life-saving procedure, it is not perfect. Patients must follow a specialized diet that is higher in protein and lower in phosphorus and potassium (Appendix 1 and 2), since these minerals tend to build up quickly in the blood. They must also limit their fluid intake, as water removal during dialysis is limited to how well the patients tolerate dialysis. Infection is also an ever-present spectre, since a permanent access point must be created in the body for either dialysis procedure.⁶ Therefore, the dialysis machine works as an artificial kidney.

My first dialysis treatment after recovering from my unconscious state was enlightening. I had discovered a tube in my arm and was told that it was a “fistula”. The fistula establishes connection between the vein and the artery and is usually done in the forearm by a surgeon in an operation room usually under local anesthesia.⁷ A large machine was placed by my bedside and a nurse put a needle in each end of the fistula. These needles were attached to tubes that went into the machine. Soon I saw my blood going through the various tubes. The only painful part of this procedure was the insertion of the needles. After 4 hours the nurse took out the needles and put a gauze



On a dialysis treatment

6 <http://kidney.niddk.nih.gov>

7 http://www.medindia.net/patients/patientinfo/Dialysis_fistula.htm

where the needles had been. She said to leave the gauze there until the blood stopped oozing. Apparently, there was nothing much to a dialysis treatment!

In Ontario, dialysis treatments are paid for by the Ontario Health Insurance Plan (OHIP). The rest of Canada has other health plans. As I was recently retired, I was looking forward to continuing with my travels. Now, this all seemed impossible and I thought that I would have to resign myself to only memories of my extensive vacations. I believed this would be the hardest thing to deal with due to my love of travelling. But this was God's will and I was determined to enjoy my life and not let the rigour of dialysis be a deterrent. Armed with this knowledge, a list of dos and don'ts in terms of what to eat and drink, an exercise regimen and a barrage of pills, I left the hospital with a positive attitude on August 7, 1996.

It was a hot, muggy Friday evening when I went home after dialysis. Sandra, ensuring that I did not have more than my allotted 4 cups of fluid a day, tried to quench my thirst by giving me a variety of fruit including watermelon. Unfortunately, the liquid in fruits goes towards the fluid allotment. Since there was no way for the fluid to leave my body it started building up in my lungs and I had trouble breathing. I was rushed to the hospital by ambulance on Sunday and given emergency dialysis. I returned home a few days later, not any worse but we were all wiser about the importance of following the fluid restrictions provided by the hospital. A few of my favourite fruits are bananas, papaya and mangoes but these are very high in potassium. However, I have found that I can have a banana the day of and before dialysis. As for the other fruit that are high in potassium I have them in moderation on different days.

My weekly routine started with dialysis on Monday, Wednesday and Friday at 12:30 p.m. at Sunnybrook Hospital. Each dialysis treatment was 4 hours long. Every station is equipped with a television set so the patient can watch any show to help pass the time. On Tuesdays and Thursdays afternoon I would go for congregate dining. When I retired, I pursued my



*My Beetle with licence plate
BATMAN8*

enjoyment of playing cards by learning to play bridge. Once I was proficient, I joined the Scarborough Support Services luncheons twice a week where I enjoyed a nice lunch and played bridge for a couple of hours with other seniors. I was able to go to and from dialysis and to the lunches in my new car which was a nostalgic purchase upon my retirement. My first car in Kampala, Uganda and, my car in Kuwait, were Volkswagen Beetles.

First Trip after Starting Dialysis Philadelphia, Pennsylvania

My life returned to my pre-surgery days except for the dialysis schedule and my inability to travel. Amrith invited the family to come to Philadelphia, Pennsylvania, to spend the Christmas season with her family. Sandra discovered that there was a hemodialysis centre in Exton, close to my cousin's address. The cost was \$300.00 U. S. per treatment, with us providing the Eprex⁸ and the centre accepted patients from other countries. The Ministry of Health and Long-Term Care (the Ministry) pays CAD \$210.00 for every treatment outside of Ontario if the cost is above CAD \$210.00. If the cost is below CAD \$210.00 then the Ministry pays the Canadian equivalent of the dialysis treatment. The Ministry also provided an interest free loan for the cost of the dialysis treatments while on vacation to be paid after 3 months. The difference between what one pays for dialysis when one is travelling and what one receives from the Ministry can be claimed as a medical expense on one's Income Tax Return. In addition, the hospital or dialysis center provides the traveller with the appropriate amount of Eprex for the trip at no cost to the patient.

With this information, we booked our flight for Philadelphia and arranged the dialysis for the 2 week time frame that we would be there. Travel insurance

8 Epoetin alfa (rINN) (pronounced ee-POH-eh-tin AL-fuh) or Eprex is a synthetic form of erythropoietin. It stimulates erythropoiesis (increases red blood cell levels) and is used to treat anemia, commonly associated with chronic renal failure and cancer chemotherapy. Epoetin is marketed under the trade names Procrit and Eprex. <http://en.wikipedia.org/wiki/Eprex>

is very important to have but is not easy to purchase when one has a pre-existing medical condition. After many telephone calls to various insurance companies, we found Ingle Travel & Health Insurance Services Inc. based in Toronto. The company covers “pre-existing conditions that are stable in the 365 days prior to the commencement date of a covered trip”⁹. If one’s pre-existing condition has not been stable for a year prior to travel, the insurance company will cover the individual but not for anything related to the pre-existing condition. As I had been on dialysis for less than a year, I purchased travel insurance that did not cover my pre-existing condition and found the premium to be reasonable.

I boarded the Air Canada flight with some trepidation as this was the first time I was travelling since starting dialysis. We arrived on the Saturday morning and my first dialysis was on Monday afternoon, just like in Toronto. The clinic had a very clean, pleasant environment and the transition from my dialysis treatment in Toronto to that in Exton was seamless. It was arranged that my niece, Andrea, and nephew, Ajesh, would be my chauffeurs for the 20 minute drive for the 6 treatments. After my first dialysis treatment in Exton and my relief that everything went well, I was free to enjoy my vacation.



Amrith performing a skit with her husband Dolphy watching on.

First Trip Overseas London, England

When I returned to Toronto, I felt that the world of travel was available to me again and that my requirement for dialysis was not a detriment. In May of 1997, I underwent a quadruple bypass. I went for a stress test in the morning and had the surgery in the afternoon. This time I awoke to no surprises other than the knowledge that the main vein in my right leg had been removed and grafted to the coronary artery. The main vein in my left leg had been removed during the aortic aneurysm surgery and grafted to the aorta. I was out of the hospital shortly after the surgery and I was back to my routine within days. Hemodialysis is an inconvenience but when scheduled appropriately, it can be taken in stride and be part of a regular pattern such as going to work.

In the summer of 1998, Roy and Sandra were going to take a tour of Italy with their cousin Andrea. Having become familiar with the travelling and the availability of hemodialysis abroad, I thought of travelling to London, England and meeting Roy and Sandra after their trip to Italy. So Sandra made the flight arrangements to London, together with dialysis requirements at a clinic in East London for 2 weeks. I needed 6 dialysis treatments at a cost of 300 pounds each with us taking the Eprex. The cost of a taxi to the clinic was 10 pounds one way. The dialysis in England was expensive as the reimbursement was CAD \$210.00 per dialysis treatment and the equivalent of 300 pounds was over CAD \$600.00. I was able to avail of the interest free loan from the Ministry. This helped with the finances as the payments for dialysis in foreign countries, we discovered, usually have to be paid before each dialysis treatment. In addition, the difference (about CAD \$400.00) I was able to claim on my Income Tax return as a medical expense.

We stayed with our long time family friends, the Pereira family, whom I had also visited in 1959 when they were living in Tanganika. The dialysis treatments in England were the same as if I was in Toronto with the clinic being very clean and the staff professional. On the days I did not have dialysis, we did a lot of sightseeing including Trafalgar Square, Buckingham Palace,



Hampton Court Palace

Southall, and Hampton Court Palace.

It was an excellent holiday with lots of food, drink and socializing with old friends. Mrs. Irene Pereira is a wonderful cook as can be seen by the spread before us.



*Grace
before meal
"Lord,
Bless this
bunch
as they
crunch
their
lunch"*

Trip to my hometown Mangalore, India

Unfortunately, all good things must come to an end and we returned to Toronto and our daily routine. The next year we received an invitation for the wedding of Athena, Amrith's second daughter, for December 30, 1998 to be held in Mangalore, India. Having attended Anjali's wedding (Amrith's oldest daughter) in Treasure Island, Florida, in 1995 and with my new found freedom, I considered travelling to India for the wedding. It was a big decision as India is half way around the world and a third world country with many of the medical facilities we take for granted in Canada not as easily accessible. However, this was the place of my birth and an opportunity to see my siblings, extended family and friends. Many of the dialysis centres worldwide are located at www.globaldialysis.com (Appendix 3). Other resources include the Kidney Foundation of Canada and any hospital or clinic that performs dialysis. We proceeded to look for hospitals or clinics that provided dialysis but the closest location was about an hour away at Manipal Hospital. It was a challenge for Sandra trying to deal with the hospitals and clinics over the phone due to the 12 hour time difference and for the most part English is not the first or second language spoken by the majority of the employees. Through perseverance, we found Mangala Nursing Home and Mangala Kidney Foundation that was to receive a brand new dialysis machine from Bangalore similar to what I used in Toronto. It was supposed to be installed and functional 6 weeks prior to my arrival in India. The cost of each dialysis session was 5,000 Indian Rupees (approximately CAD \$165.00) if we brought the required Eprex. Mangala is located about 15 minutes by car from where we were to stay at the Eden Country Club. I was very excited about this and we booked flights for Sandra, Roy and I to go for the wedding. We had also received invitations for Ashok Pinto's roce¹⁰ and wedding (another nephew), as

10 Part of the Mangalorean wedding tradition is the Roce blessing ceremony. This is where the elders of the family (the bride's side or the groom's side) gather a day before the wedding, and bless the couple and other single members of the family, with coconut milk and oil.

well as Athena's roce, and Christmas and New Year's parties. Three weeks before we were to fly to India, Sandra called to confirm that the dialysis machine had arrived and all was ready. However, we were told that it had not arrived yet but they were expecting it any day as it was on the truck. A week later we received the same story but, fortunately, the week before we were to fly the machine was set up, working and we were told that the nurses were trained in the operation of the machine. I boarded the Air Canada flight with a feeling of dread as I was not comfortable knowing the dialysis machine had been running for only a week with nurses that had very little experience, but I put my trust in God that the trip would be a success.

When we arrived in Mangalore, I was scheduled for dialysis that day and went directly to Mangala. This was due to the time difference caused by the distance flying to India. We had rented a van with a driver to take me to and from dialysis. When I arrived at Mangala, I was directed to a specific room which had the dialysis machine set up next to a bed. The room was very clean and quiet. The nephrologist¹¹, technician for the dialysis machine and two nurses were in readiness for the treatment. My anxiety was alleviated as the nephrologist hooked me up to the dialysis machine and remained with me for the full treatment. In fact, the nephrologist attended all of my dialysis treatments which was a great comfort. I was extremely relieved after my first dialysis session and went to Ashok's roce. It was a great reunion for me as most of my relatives were in attendance for the occasion.

Both Athena's and Ashok's wedding were on the same day. We attended both weddings which were on a very large scale conducted with pomp and grandeur.

While we were in India, going from one party to the next and eating at various people's home, everyone was very considerate in terms of my diet and what food I could eat. One morning, I woke up with shortness of breath and was rushed to the hospital. I was given an emergency dialysis treatment. The nephrologist explained that I had too much fluid in my body that had gone

11 A nephrologist is a physician who has been educated and trained in kidney diseases, kidney transplantation, and dialysis therapy.



Family at Ashok's roce

into my lungs. I mentioned that I was very careful with my fluid intake including fruit restriction. One thing none of us thought of was the amount of salt that is used for cooking the various dishes and this is what the nephrologist presumed happened. The nephrologist said that one sign of fluid retention in the body is bloating or swelling around the face and joints in the legs and arms. I was released after the treatment but ensured that I mentioned the salt requirement along with the food items that I was able to eat with the rest of our invitations.

When I returned from India I was confident that I could travel to any part of the world. However, every trip required a lot of planning in advance. Not only the part of the world to be visited, but the dialysis locations and the cost of dialysis, ease of transportation, the proximity to the residence (hotel



Athena and Suraj at their wedding reception.

or family/friend's abode) had to be determined before the flights were booked. Once these were decided on, the flights and the travel insurance could be booked (Appendix 4). Unfortunately, this means no last minute specials!

Back to the U.S.A. Fort Lauderdale, Florida

In the spring of 1999, Amrith, Dolphy, Athena, Suraj, Sandra and I went to visit Anjali, Rich (her husband) and Ariana (her daughter) in Fort Lauderdale. We found a dialysis clinic close to where we were staying and the arrangements were accomplished easily. As we had rented a car we had no problem with the transportation to and from the dialysis centre. It was an enjoyable week with an Enchanting Four Hour Dinner Cruise, the World Famous Jungle Queen Riverboat Sightseeing Cruise and an Airboat Tour of the Everglades with crocodiles close and up front.



A crocodile eyeing one of us for dinner!

Barbados and the Bahamas

In the next couple of years we went to Barbados and the Bahamas. Vacations to the Caribbean Islands are nostalgic. The tropical weather and the vegetation are very similar to Mangalore, my hometown. Coconut trees are found all over the islands and I relished drinking fresh coconut water right out of the coconut at every opportunity. As both islands are relatively small, it was easy to get a dialysis location close to the hotel we were staying at. Additionally, there is not a variety of dialysis locations but the ones we found were very clean with professional and helpful staff. On average, the cost of each dialysis treatment was \$400.00 U.S. with me bringing the Eprex. In each location, we rented a taxi to take me to and from dialysis for approximately \$10.00 U.S. each way. We used taxi drivers to take us around to the different venues on the islands. We found they loved to discuss cricket and were extremely knowledgeable about the sport and the various teams around the world. It was a sport that I played in my youth and have enjoyed following through my life. Cricket is a sport that has been played around the world for more than eight centuries. Cricket is played by two teams of eleven players each, which take turns to bowl a hard-leather ball. At first view, cricket looks similar to baseball, with players batting a ball and trying to score as many runs as possible. The differences, however, are many. For starters, cricket is played with a flat bat, rather than a rounded one, and players do not run in a square to score a point, but instead run forward in an effort to reach the opposite end of the pitch. If the ball is hit hard enough to go far, a player may keep running back and forth between the opposite ends, scoring one point every time they complete the full distance.¹² As we drove around we saw many young boys playing cricket with their home made bats and balls made out of string. I remembered how I started playing cricket when I was their age. While in Barbados, I went to the Kensington Oval; one of the most famous cricket grounds in the world. There were stands named after the 3 W's (Worrell, Walcott and Weeks) and another stand for the great cricketer Gary

12 <http://www.wisegeek.com/what-is-cricket.htm>.



Kensington Oval Grounds

Sobers. I saw the 3 W's playing in England in 1963 when I was attending a Management Training Course sponsored by Barclays Bank, London, England.

We also went to see Harrison's Cave which is a magnificent, crystallized limestone cavern that is considered one of the wonders of the world. The cave has many flowing streams of pure clear water that has helped to make beautiful stalactites and stalagmites.



Harrison's Cave: "I saw a saw, such a saw, I never saw before"¹³

13 A Best of Barbados Ltd. Production Photography by Roger LaBrucherie Printed by COT Baribbean Graphics

During one of our tours, the tour guide announced “there is the beautiful church of Our Lady of Assumption whose feast we celebrate on August 15 each year. Next to it is the cemetery of the Holy Trinity, which is a quiet, nice and peaceful place and people are ‘dying’ to go there”!

In the Bahamas, we stayed on Paradise Island with the world famous Atlantis Resort and Casino built over a 7-acre lagoon. Inside is one of the world’s largest marine habitat with many exotic sea creatures. On the outside was a large lagoon with sharks.



A view of Paradise Island

Andrea's Wedding Reception

In May 2001 we received an invitation for Andrea's wedding, Amrith's third daughter. She was to be married on June 2 in Puerto Rico. Unfortunately, I was not able to attend as we were not able to make the travel arrangement for the weekend. Even if the plan is to travel for a weekend, dialysis arrangements should be made in advance, especially abroad. However, to my distinct pleasure Andrea and Shaun decided to have a wedding reception in Toronto on June 30, 2001. It was a grand affair and I was honoured to be the toast master.



Cake cutting ceremony for Andrea and Shaun

Las Vegas, Nevada

My first helicopter ride

The Christmas season of 2001, we spent with Amrith and her family and then went to Las Vegas for a week. This was a more challenging vacation to arrange as we had to ensure dialysis was organized in two states in the U.S. The staff of the dialysis clinic in Exton was used to me by now and showed genuine pleasure in my visits. Las Vegas had a variety of clinics but the cost was quite prohibitive for the majority. We finally found one that was around \$450.00 U.S. per dialysis treatment. Sandra and I stayed at the Luxor hotel, which is a pyramid shaped hotel. As we had no transportation, I took a taxi to the dialysis clinic which cost about \$10.00 each way. The hotels on the Las Vegas strip all have their own unique appeal.

We decided to take a Grand Canyon Tour, so we took a small plane from Las Vegas to the helipad at the top of the West Rim of the Grand Canyon.



Luxor Hotel by night¹⁴

¹⁴ Tiffany Design Las Vegas, NV.



Sandra and I in the helicopter

We then took a helicopter flight descending about 4,000 feet and landing on the Canyon floor. My first trip in a helicopter was quite exhilarating. At the bottom, we took a boat ride on the Colorado River. After ascending by



From the floor of the Grand Canyon

helicopter we took a bus to the edge of the Canyon for a BBQ lunch. It was a once in a lifetime experience which included a variety of modes of transportation – plane, helicopter, boat and bus.

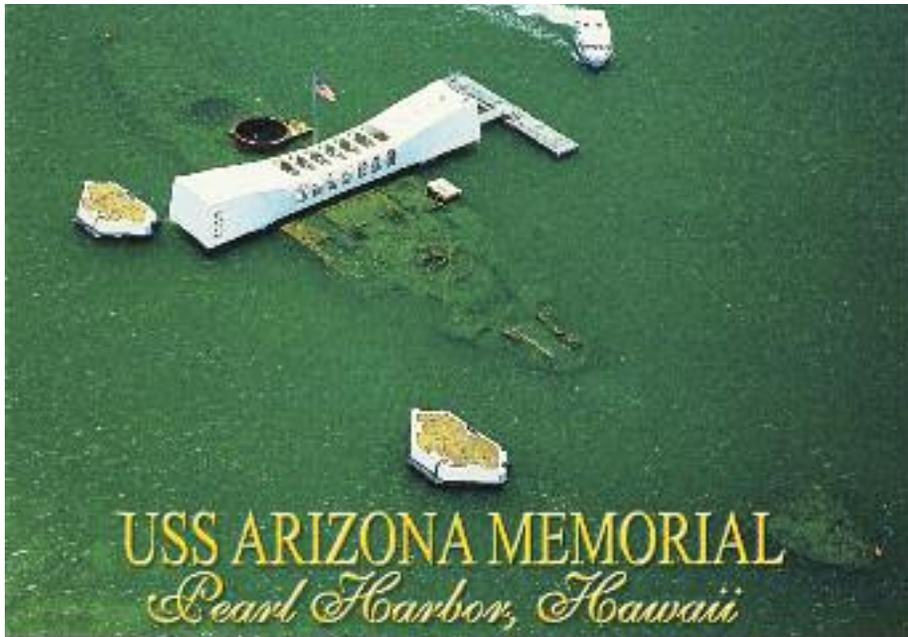
We were fortunate to be able to take a tour of Las Vegas by night in a helicopter. I was now experienced in riding a helicopter as this was my third flight in a week!

Honolulu, Hawaii

In the fall of 2002, Roy was working in San Francisco for Wells Fargo & Co. He was to go on a conference to Hawaii and asked if Sandra and I would like to come to Hawaii after his conference. The arrangements were made for dialysis in Honolulu on the island of Oahu so we made our hotel reservation at the Sheraton Princess Kaiulani. The dialysis clinic was about a 15 minute taxi ride and cost about \$10.00 U.S. per trip. The dialysis treatments were \$400.00 U.S. The highlights of the trip was attending 2 luaus, afternoon tea on the Banyan Veranda at the Sheraton Resort, taking a tour of Pearl Harbour, the Dole Plantation and the famous Waikiki beach with the hundreds of surfers.



Some of the performers at the luau



The USS Arizona was hit by a 1,760 pound bomb and it sank with a crew of 1,177¹⁵

Mangalore, India again

During 2003, I started experiencing pain in the toes of my left foot and by the summer I was told that it was caused by gangrene. Gangrene occurs when tissue dies (necrosis) because its blood supply is interrupted. I was told that if the pain did not alleviate I would have to have the foot amputated. Gangrene is very common among people on dialysis as many of them are diabetic. This is because the high blood sugar levels, which are common in diabetes, may eventually damage the nerves, especially in the feet.¹⁶ However, in my case, I am not diabetic, but the removal of the main vein in my leg during my aortic aneurysm caused the blood flow to be interrupted. Around this time, I received an invitation to attend Fr. Theo Pinto's 25th anniversary of priesthood (my childhood friend) in Mangalore, India.

15 Published by 2004 Maui Pacific Traders www.islandergroup.com Printed in Australia

16 <http://www.medicalnewstoday.com/articles/158770.php>

Sandra and I decided to attend this momentous occasion. This would also provide me an opportunity to see my family and friends and try some homeopathic remedies for my foot. If the remedies did not work, I would have my foot amputated on my return. Dialysis was arranged at A.J. Hospital which was a 5 minute drive from where we were staying with my cousin Ashok, Amrith's brother, and his family. The hospital was a fairly new and modern hospital. The dialysis treatments were 1,800 rupees (CAD \$51.00) including the Eprex. A far cry from the 5,000 rupees per treatment 7 years earlier. Also, we found that there were many more places to get dialysis at a reasonable cost.

Unfortunately, my foot got worse while I was in Managalore and I had to have amputation surgery at A.J. Hospital in January 2004. My left leg was amputated below the knee. For the two months after my surgery, I remained at A.J. Hospital where I had a lot of physiotherapy to help me regain my strength. I was also fitted for a temporary prosthesis and taught to walk using it. After my surgery, I still would feel pain from where my toes were. I was told this was "phantom pain". Phantom pain sensations are described as perceptions that an individual experiences relating to a limb or an organ that is not physically part of the body. Phantom limb pain is the feeling of pain in an absent limb or a portion of a limb. The pain sensation varies from individual to individual.¹⁷



*A.J. Hospital,
Mangalore
India*

17 http://en.wikipedia.org/wiki/Phantom_pain

Back in Canada

I was glad to return to Toronto in April 2004 even though there was a long road ahead. I was scheduled for more physiotherapy for my strength and a permanent prosthesis. I was fortunate that OHIP covered my medical expenses while I was in India. One must be careful when travelling because in many cases, medical charges exceed what OHIP will reimburse and then the individual is responsible for the remainder of the costs. However, the medications were not paid for. In addition, the Assistive Devices Program (ADP) paid for part of the prosthetic leg and part was paid for by the health insurance company of the firm I worked for before I retired (Canadian Imperial Bank of Commerce - C.I.B.C.). The objective of the Assistive Devices Program (ADP) is to provide consumer centered support and funding to Ontario residents who have long-term physical disabilities and to provide access to personalized assistive devices appropriate for the individual's basic needs. Devices covered by the program are intended to enable people with physical disabilities to increase their independence through access to assistive devices responsive to their individual needs.¹⁸ An employee from the Community Care Access Centre (C.C.A.C.), an organization that is funded by the Ministry of Health and Long Term Care, assessed my needs as I required help bathing. By the end of the summer, I had mastered my prosthetic leg and was strong enough to get around. I was back to driving my Beetle to dialysis and going for lunch at the Scarborough Support Centre.

However, by the end of 2004 my right leg showed signs of gangrene and in January 2005 I had surgery at Sunnybrook Hospital to have this leg amputated. During my quadruple bypass my vein had been removed from this leg. This was a very difficult time for me but this was God's will and with His help I would persevere. I was then moved to St. John's Rehab Hospital for physiotherapy and to learn to walk with two prosthetic legs. However, it was soon apparent that I did not have the strength required to walk with two prosthetic legs. I was then transferred to Tendercare Nursing

18 http://www.health.gov.on.ca/english/public/program/adp/adp_mn.html



My new home

Home until I could get a place to live. My house was not wheelchair accessible and the cost of renovation was prohibitive. Therefore, it was sold and a condominium was purchased. Sandra had to make a few minor changes to make the condominium wheelchair accessible such as adding a wooden ramp to the balcony so I could go out and enjoy the fresh air; making the bathroom door wider; and removing the vanity cupboards in the bathroom. Our condominium is on the top floor with a wonderful view of the CN Tower, the world's tallest free standing structure, and gorgeous sunsets.

I was resigned to life in a power wheelchair and my travelling days over. My days of driving my Beetle were over and as we needed transportation Sandra looked into the alternatives. She discovered that I could buy a van and have it modified for wheelchair accessibility. In addition, if I qualified, the Ontario March of Dimes would provide a grant of about \$15,000 for the vehicle modification. The website for this information and other assistance offered by the Ontario March of Dimes is <http://www.marchofdimes.ca>. The company we used for the modification was Kino Mobility. We were advised to use an EZ Lock Wheelchair Docking System as it “easily secures a wheelchair to the vehicle floor; saving both time and effort”¹⁹. It was an additional \$3,000.00 but we have found that it has been money well spent.

¹⁹ <http://www.ezlock.net/>



Our rear entry wheelchair accessible van

It was decided that it would be better for me to have a power wheelchair instead of a manual wheelchair. The cost of a power wheelchair is around \$10,000 which I could not afford. However, the ADP has established the Central Equipment Pool for high technology wheelchairs to assist clients to purchase power wheelchairs. ADP paid 75% of the purchase price of the wheelchair, my health insurance company paid 80% of the 25% left and I paid the rest. This made the purchase of the wheelchair affordable. C.C.A.C. assessed my new needs and allotted me the maximum number of hours available for someone in my condition. Unfortunately, the number of hours provided only covered the morning hours. For the evening hours we had to apply to the Project Information Centre (PIC) run by the Centre for Independent Living in Toronto (CILT), Inc. Regrettably, there is a waiting list as this service is covered by the Ministry of Health and Long Term Care and therefore, free. After some research, Sandra found St. Paul's L'Amoreaux Centre that provided a personal caregiver for an hour every night at a cost of \$450.00 a month. This was expensive and, to my good fortune, after 5 months I was called by the PIC and was assigned caregivers that are covered by the Ministry.

My 75th Birthday Party

I got my strength back and became quite adept at handling my wheelchair. I left Tendercare and came to my new residence a week before my 75th birthday. Sandra and Roy had planned an elaborate celebration with many of my relatives and friends in attendance. The Hon. Jim Karygiannis P.C., Member of Parliament, Scarborough-Agincourt came and made a speech.



Jim Karygiannis giving me wishes from the House of Commons

My niece, Andrea, for whom I was the toast master at her wedding reception, was the toast mistress. I even received a driving licence and licence plate for my wheelchair from my niece Joanne.



Everyone dancing to their own beat!

My life in my new home started to develop. I would go for dialysis on Monday, Wednesday and Friday in the afternoon. Alwyn Nazareth and Theo D'Silva, two of my relatives would and still do take me for dialysis on Monday and Wednesday. On Friday, I would be picked up by the Toronto Transit Commission (T.T.C.) Wheel-Trans²⁰ and Sandra would pick me up on her way back from work. We discovered that I needed help getting in and out of the condominium and the Ontario March of Dimes came to our rescue again. The Home & Vehicle Modification Program (HVMP) provides a grant of up to \$15,000 lifetime maximum for home modifications. I qualified for an Automatic Door Opener which allows me to go in and out of the condominium with the door closing behind me when I leave and open for me when I want to enter. It also allows me to open the door for my personal caregivers from another room of the house when they come in the morning and night. I returned to Scarborough Support Services for the congregate dining program with lunch and bridge on Tuesday and Thursday afternoons. I was taken and brought back by Wheeltrans. Having the automatic door allows me to come and go freely. In addition, I learnt to play bridge on the Bridge Base Online website (<http://www.bridgebase.com>) which helps me to pass my time enjoyably.

Now, I really thought my travelling days were over because even though we knew getting dialysis for a vacation around the world could be accomplished, I now required wheelchair accessibility as well as a personal caregiver. Impossible!

20 Wheel-Trans provides door-to-door accessible transit service for persons with physical disabilities using accessible buses, contracted accessible and sedan taxis. <http://www3.ttc.ca/WheelTrans/index.jsp>

First Trip after my Amputations San Francisco, California

Roy was living in San Francisco and we thought it would be nice to visit him. We were able to get dialysis but it was a 20 minute drive from Fisherman's Wharf where we were planning on staying. We would need transportation and the cost of a taxi in San Francisco for that drive would add up. Additionally, we would require a vehicle to go sightseeing. After much searching, Sandra found a company, Wheelchair Getaways²¹, that rents handicap accessible wheelchair vans. She was, also, able to find Professional Healthcare²², a company that would provide a personal caregiver for an hour in the morning and an hour at night at a reasonable rate. Most caregiver companies require a minimum of 2 hours per session but I only require one hour each session when I travel. Based on all this information we decided to venture west and made all the required reservations. We had, also, decided to take my power wheelchair and were told that it had to have a dry cell battery. This battery had to be disconnected for the flight which Sandra was able to do.

I was very excited to travel again and had no trepidation when I boarded the flight. It was a new experience boarding a flight since my legs had been amputated. At the airport, I was wheeled to the door of the plane in my wheelchair. I was then transferred to an aisle chair²³ which was wheeled into the plane. There were trained personnel to transfer me from the wheelchair to the aisle chair and from the aisle chair to the plane seat. The flight to San Francisco was uneventful with the same process occurring when we were deplaning with the aisle chair. Roy was at the airport to meet us. We picked up the wheelchair accessible van at the airport and noticed it was very low especially at the rear compared to our van (see page 24). With the added weight of the luggage, ourselves, the weight of the power wheelchair (which

21 <http://www.wheelchair-getaways.com/>

22 <http://professionalhc.com/>

23 An aisle chair is a specially designed wheelchair capable of fitting down the narrow aisles of a plane. The aisle chair has multiple straps used to secure someone to the narrow chair. <http://enablemob.wustl.edu/AYW/Travel/Airline/boarding.htm>



Wheelchair Getaway van rental

is about 350 pounds) and the many steep hills in San Francisco we were very surprised that we did not scrape the underside of the van.

The ride to and from dialysis was a bit arduous as it was outside of the city and the traffic in and around San Francisco is heavy and continuous. The clinic was clean with professional and pleasant staff. The cost of dialysis was \$450.00 with us bringing the Eprex. The caregiver, Mark, came promptly in the morning and at night and was a very pleasant individual.

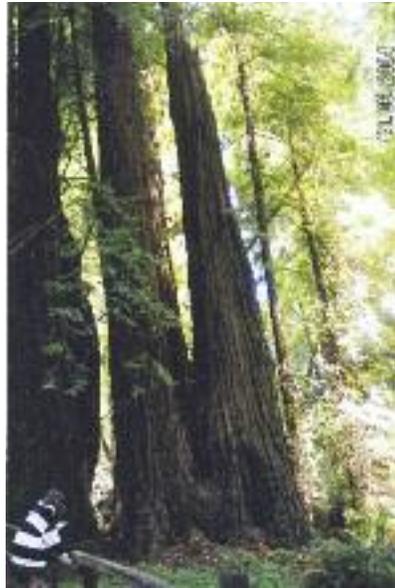
San Francisco is a very beautiful city and we were able to do a lot of sight-seeing as all my necessities were taken care off. We saw and heard the many seal lions lazing on the dock at Pier 39, Fisherman's Wharf; and the Cable Cars that San Francisco is noted for. I was able to go up and down the various city streets to view the many charming buildings in my power wheelchair as the sidewalks are all wheelchair accessible. We visited SBC Park the home of baseball's San Francisco Giants; China Town; the Wells Fargo Museum; Union Square which is the heart of the city with its many shops, hotels and theatres; and the majestic California Redwoods at Muir Woods Natural Monument.

We went outside San Francisco to the University of California, Berkeley; the beautiful grounds of Stanford University and Palo Alto; Oakland and McAfee stadium to see the Oakland A's baseball team playing a game,

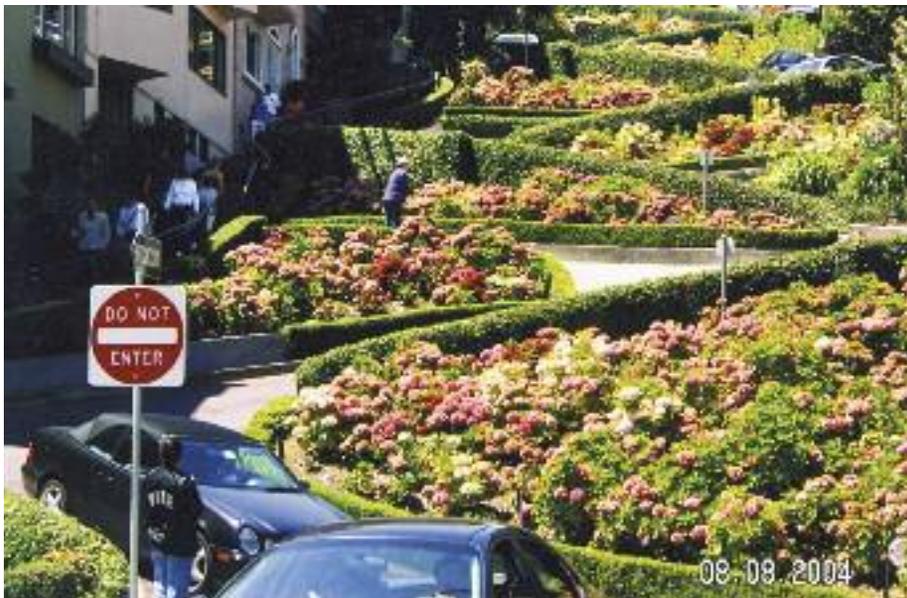
crossing the famous Golden Gate Bridge on a few occasions. The winery tours of Napa Valley and Sonoma Valley was where Sandra decided to embark on wine making at home. However, even though she makes red, white and ice wines she does not have a vat to stomp on the grapes as in the famous “I Love Lucy” episode in Turo, Italy!

We drove down Lombard Street which is well known for having a steep, one-block section that consists of 8 tight hairpin turns.

I was able to board the ferry to Alcatraz Island where we went through Alcatraz Island Prison which is now a popular tourist sight. However, in the past it was a high security jail housing many famous criminals and the subject of many books and films.



California Redwoods in Muir Woods



Lombard Street

Mediterranean Cruise

I had a great vacation and my travel bug had returned. I had always wanted to go on a luxury cruise but thought my dialysis restriction would be an impediment as it is hard to organize dialysis at different ports of call. However, Sandra discovered there are few companies that have dialysis services on a cruise ship. One of these companies is Dialysis at Sea Cruise (www.dialysisatsea.com). The company has been in operation since 1977 and they arrange all the requirements for the dialysis machines as well as hiring a board eligible/certified nephrologist and one or more dialysis nurses depending on the number of dialysis patients on board. The dialysis treatments were \$450.00 U.S. per treatment. The patient must have a companion and the cruise must be booked through Dialysis at Sea Cruise. We found the cost of the cruise being booked through the company was a lot higher than booking through a travel agent but the company's justification was that it included the cost of paying for the nephrologist and the dialysis equipment. As this was a life long dream of mine, I was delighted when Sandra, Roy and I booked the cruise. My niece, Sarita, joined us. Fortunately, we were all able to book our flights using frequent flyer points, which defrayed some of the travel costs. We chose to do a Mediterranean Cruise setting sail from Venice and the ports of call were Dubrovnik, Croatia; Corfu, Greece; Alexandria, Egypt; Kusadasi and Istanbul in Turkey; Constanta, Romania; Odessa, Ukraine and Varna Bulgaria; and ending in Athens, Greece. The dialysis was arranged and we ensured the ship was wheelchair accessible as well as access to the ports of call with a wheelchair was possible.

We left Toronto on May 13, 2006 with our Eprex in hand and power wheelchair in the cargo hold. I was now familiar with the transfers that had to be made to get me on and off the plane. We had a stopover in Frankfurt as we had to change flights to go to Venice. It was challenging getting from the Venice airport to the port as a wheelchair accessible van that had been arranged prior to our embarking on our trip was not available. However, the Holland America Line staff at the airport were very helpful in finding a van large enough to hold the wheelchair. 4 men helped to lift the wheelchair into

the van and lift me into the front seat of the van. When we arrived at the port, there were 4 men ready to take the wheelchair off the van and put me on the wheelchair. After that everything was smooth sailing!

The M.S. Rotterdam, the name of our ocean liner, had a crew of about 300 members and carried about 1500 passengers for this trip. The cost of the cruise was all inclusive in terms of accommodation, four meals a day, snacks, all non-alcoholic beverages and nightly entertainment. Dialysis was set up for three times a week but at an early time. This allowed my fellow patients and me to go on the daily excursions at the various ports of call. At my first dialysis treatment on board I was greeted by the nurse that provided my dialysis treatments in Exton, 10 years earlier. What a pleasant and wonderful surprise to meet someone 10 years later and a continent away! For those passengers that did not want to leave the ship there was an assortment of onboard diversions. These included sports such as swimming, volleyball, basketball, and tennis; card games, bingo, internet, library, shops, crafts, a 5000 piece jigsaw puzzles that various passengers participated in completing and a casino.

Some of the sights that are memorable for me are the houses in Dubrovnik with the clay tiles on the roofs which reminded me of my hometown, Mangalore.



A view from above the city of Dubrovnik

The excursion to Paleokastrista a picturesque resort on Corfu included a visit to the Paleokastrista monastery with a beautiful church surrounded by lovely gardens and covered archways that enhanced the restful atmosphere. We also stopped at the 100 year old Achillion Palace built by the Empress Elizabeth of Austria with its beautiful array of statues, mementos and the wonderful views of the countryside.

In Kusadasi we visited the house of the Virgin Mary, where Jesus' mother is said to have lived the last years of her life. The sight has been declared as a shrine of the Roman Catholic Church and was visited by Pope John Paul VI.

On to the ruins of Ephesus which was very hard to navigate with a wheelchair because of all the narrow, uneven streets with broken stones and rubble. However, it was very interesting especially the Great Theatre where St. Paul preached to the Ephesians. Many artists' performances are still held here as the acoustics are excellent.

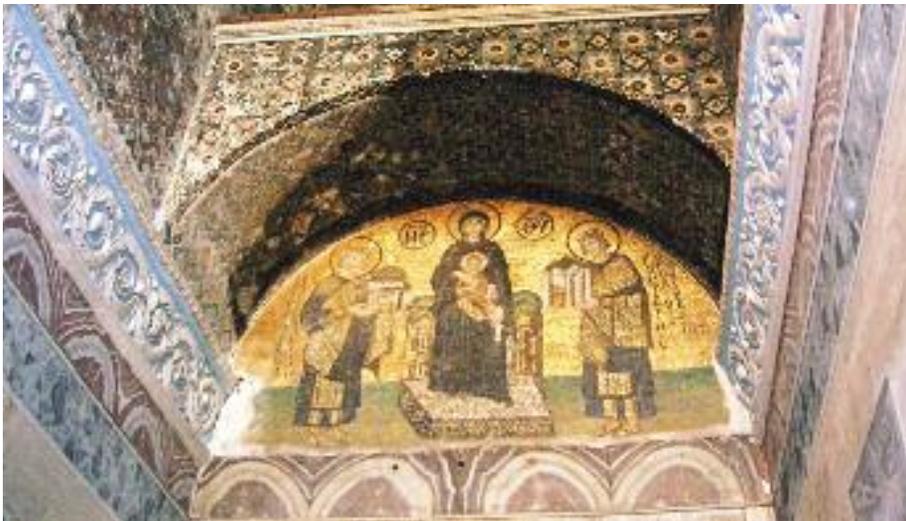
The city tour of Istanbul showed many buildings with stunning architecture. We stopped at the Blue Mosque which is named for the vivid Iznik tiles that line the interior. We were told that it would not be a problem to enter the Blue Mosque as it was wheelchair accessible. However, when we arrived,



The Great Theatre

there were about 10 steps in front of the entrance. The tour guide, not phased, stopped 4 men on the street and asked them to carry me in my wheelchair up the stairs. Et voila! Wheelchair accessible! We then went to the Museum of St. Sophia which was originally called the Church of Divine Wisdom built in the 4th century. Then it was converted to a mosque and now is a museum that is considered the epitome of Byzantine architecture. One of the mosaics that is being restored is shown below.

Topkapi Palace was next on the tour. "The Treasury of the Museum of Topkapi Palace is considered one of the most famous treasuries in the world. Indeed, the numbers of maces, pendants, daggers, chests, book covers, candelabra, rings, and various decorative articles adorned with such stones as diamonds, emeralds, rubies, brilliant's, chrysolite, and turquoises are incalculable, and no price can be placed on their worth. We saw the Spoon-maker's Diamond, which is one of the largest diamonds in the world. It is a bright and shining oval gem shaped like the bowl of a spoon. Forty nine separate brilliant's surround it, which in this fashion gives it the appearance of a full moon lighting a bright and shining sky amidst the stars."²⁵



"Virgin and Child flanked by Justinian I and Constantine I"²⁴

24 http://en.wikipedia.org/wiki/Hagia_Sophia

25 <http://www.ee.bilkent.edu.tr/~history/Ext/Spoondia.html>

We arrived at Pireus, our last port of call on May 26. When we drove through the beautiful roads we could still savour the distinctive flavour of Olympic celebrations of 2004. Our flight back was eventful as we changed flights in both Frankfurt and Chicago. My power wheelchair was left at Frankfurt airport and all our luggage was left in Chicago airport. I was provided with a manual wheelchair at the Chicago airport which I was able to bring home until my power wheelchair was returned the next day.

It was a remarkable and memorable cruise. None of us had any sea sickness or any other illness. I was able to enjoy this trip because the dialysis was close at hand and the wheelchair accessibility gave me the freedom to go around the ship as well as sight seeing. The ship had a manual wheelchair which I availed off for the excursions at the various ports.

Trinidad

In June of 2006, I had a mild stroke which caused me to lose the use of my left arm and sight in my right eye. Due to this, I had to request the Ontario March of Dimes for a portable ceiling lift. The lift assists the caregiver in safely moving me from the bed to the wheelchair and back. This was approved and installed in July 2006.

One of Sandra's friends, Marina, who lives in Trinidad, invited us to come at the end of the year. Marina was very persuasive as she said the hospital across from where she lived offered dialysis and she was able to get caregivers. We did not take the power wheelchair as we did not know how it would be transported in Trinidad so we rented a manual wheelchair.

Marina has a beautiful condominium overlooking the Caribbean Sea. The hospital for dialysis was clean and the staff were professional and helpful. The cost of dialysis was \$400.00 U.S. per treatment with us bringing the Eprex. I was able to do quite a bit of sightseeing with me being carried in and out of Marina's car. It was quite a challenge but people were extremely helpful. Sightseeing included one of the most important temples in Trinidad, Karya Siddhi Hanuman Temple. The 85-foot tall idol of Lord Hanuman is the centre of attraction here. The temple, light rose in colour, is built on Dravidian architectural lines. Marina



The beautiful view from Marina's condominium

was surprised when we told her about it as she had not heard of or seen this temple. It is true what people say – we don't see what is in our own backyard!

We also went to see Pitch Lake at La Brea (Spanish for "pitch") on the southwest coast of Trinidad. This is the largest deposit of asphalt in the world, measuring 300 feet deep at the centre and covering a surface area of 89 acres. It is disappointing when one looks at it because it looks like a big parking lot but the surface is very soft. The natives say the water flowing is good for virtually anything that ails you. We picked up a couple of bottles of the water but I did not find any change in me. It was a very relaxing and enjoyable vacation.



Roy pulling a few taffy strings from the lake

Cancun, Mexico

The next year Sandra and Roy wanted to go on a vacation to Cancun, Mexico. Sandra took care of all the planning with dialysis and daily caregiver first. The trip was to be all inclusive which included the flight, all meals and drinks (both alcoholic and non-alcoholic).

We booked the Riu Caribe hotel which is an elegant 5 star hotel that has a spectacular view, beautiful facilities and is wheelchair accessible. The flight to Cancun was uneventful and I was now used to the transfers. However, when we arrived at Cancun airport I had to be carried in an aisle chair down the stairs to the tarmac and carried up on the way back as the planes did not dock at the terminal of the airport. I was very appreciative of the extremely strong men that were able to do this for me.

The weather and vegetation in Cancun is very similar to Mangalore during the Christmas Season so it was a nostalgic vacation for me especially when I was able to drink water from the fresh coconuts. The dialysis clinic was about a 10 minute drive and as we did not rent a vehicle we used taxis which were reasonably priced. The dialysis treatment in Hospiten Cancun cost was



I am being carried down the stairs

\$400.00 U.S. with the Eprex being provided by us. The dialysis clinic, as it has been for all my trips, was clean and the staff very pleasant and professional.

We visited Tulum and Chichen Itza; two of the ruins from the Mayan civilization. Tulum's greatest attraction is its location on a bluff facing the rising sun looking out on the Caribbean Sea. "Tulum" means wall in Mayan and is aptly named as it is a walled city. The Castillo, sometimes referred to as the lighthouse, is the tallest building at Tulum and the most famous.



El Castillo in Chichen Itza

Chichen Itza is a Mayan City with the giant Pyramid of Kukulcan in the centre. It was called El Castillo by the early Spanish visitors and is the first building one sees when one enters.

It was an interesting, educational vacation and broke up the doldrums of the winter with the nice warm, sunny weather.

Ottawa, the Capital of Canada

Although I have lived in Canada for over 30 years I had never visited Ottawa, the capital of Canada. Roy was to come to visit from San Francisco and Sandra made arrangements for us to go. Jerry Pinto, the brother of my childhood friend, Fr. Theo Pinto, accompanied us as his sister-in-law lives in Ottawa and he wanted to visit her. This trip was relatively easy to organize as we just had to find a wheelchair accessible hotel and a caregiver. We were going for the weekend so I would not require dialysis and we were taking our own transportation.

We made a reservation at the Lord Elgin Hotel which is located in the heart of downtown. After checking in, we did some sightseeing around the hotel. With my power wheelchair it was easy to get around. Some of what we saw included the Rideau Canal, Ottawa Congress Centre, various Parliament buildings and the Ottawa Rideau Centre.



Parliament Hill

We were lucky to see the changing of the guard at the tomb of the Unknown Soldier.



The tomb of the Unknown Soldier

That night we had dinner with Jerry and his in-laws at a nice Italian restaurant. The next day was Canada Day and the city was abuzz with celebrations. We were fortunate to have an up close view of the Royal Canadian Mounted Police on their way to Parliament Hill for their performance.

We drove around Ottawa and saw the architecturally beautiful buildings. At Rideau Canal, we saw the locks in operation moving the boats upstream. For dinner, we drove to the neighbouring Province of Quebec (a 15 minute drive) to a nice Steak restaurant. After dinner, near our hotel, we watched the amazing fire works display for Canada Day. We drove back Monday morning and I was taken directly to Sunnybrook Hospital for dialysis. A nice way to spend the long weekend!

Book Signing

When we returned I finished writing my biography. I had started it when I was in A.J. Hospital having my leg amputated. The Labour Day week was when I distributed the book, called *Villager to Banker*. We had a book signing party which was attended by many of my family and friends. I took the book to my friends at the congregating dining as well. Many wanted to pay for the book but I asked that the money be donated to the Kidney Foundation of Canada. We collected over \$1,200 in donations.



My cousin Amrith came for the book signing

Doha, Qatar

In October, we received an invitation for a roce on December 27, 2007 and a wedding on January 3, 2008 for Priya Pinto (daughter of Jerry Pinto) in Doha, Qatar. We were not able to stay for the wedding but decided to go for the roce. Jerry was amazing making all the arrangements for the trip. He dealt with the dialysis clinic, made the reservations for our accommodations at the Marriott, rented a wheelchair accessible van and scheduled a caregiver for the mornings and evenings. This was a blessing as the 9 hour time difference made calling the various people difficult. Qatar is a very small but rich country. Doha is in the process of being built up and we found cranes everywhere. The buildings that are built have beautiful structures.

We were very fortunate to be able to attend the camel races as it is one of the most popular sports among all the sports in Qatar. Since the abolition of children as jockeys, the sport has gained a better reputation worldwide. Thanks to a Swiss invention, we saw robot jockeys trying to guide the camels to run in a straight line and prod them to go faster. The experience of watching camel racing is a truly unforgettable experience!



Camel racing with robot jockeys



Grace before meal "May Allah be praised and our bellies be raised!"

This was a Christmas vacation with lots of food, drinks and socializing. Priya's roce brought back many memories of home for me. On our flight back to Toronto we came first class on Qatar Airways. The crew on the airline provided exceptional service and it was a wonderful way to end a very enjoyable trip.

Sandra's Engagement and Roce

A couple months after we returned I was delighted to hear that Sandra had become engaged to Claude Tieche. The engagement ceremony was held on May 24, 2008 with about 90 people in attendance. This was held in the party room in our condominium building with family and friends from far and wide including Roy from San Francisco, Marina from Trinidad and Amrith and her family from Philadelphia. The hall was beautifully decorated, there was lots of food and drinks and our D.J. Ryan kept everyone dancing.



Some of the guests

Everyone enjoyed themselves especially the entertainment - the “Mahi, Mahi Dance Troupe”.



Our “imported” entertainment!

This was followed by a traditional roce in the same party room on December 27, 2008. The tradition calls for some family jewellery, a bunch of bananas, ash pumpkin, coconuts, rice and live chicken given as gifts to the bride with a time-honoured procession. We had everything but the live chicken!

The bride is anointed with coconut milk and oil by the elders present. As her father, I had the honour of anointing Sandra first.



Starting the anointing

A traditional meal was served after the anointing ceremony which included mutton curry, pork sorpatel (curry made with pork meat and various other organs like the liver, intestines, heart and tongue), channas (a type of lentil with coconut), sunnas (steamed rice flour cakes) and Vorn (a sweet made of coconut milk, jaggery, lentils and rice flour). There was dancing to the wee hours to the music of Ryan.

Los Cabos, Mexico Sandra's Wedding

Sandra, like me, has the travel bug and wanted to have a wedding abroad. After looking at various destinations, it was decided that the wedding would be on the beach in Los Cabos, in western Mexico on the shores of the Pacific Ocean. The wedding would take place on January 24, 2009. The plans were made not just for the wedding but for me with the dialysis and caregiver. We were to stay at the all-inclusive Riu Palace which is a wheelchair accessible hotel. Dialysis was at the AmeriMed Hospital which was a short distance away. We were pleasantly surprised to find out that round trip transportation was provided for me as well as Roy and Claude so they could assist in transferring me to the bed from the wheelchair and back. The cost for dialysis was \$450.00 U.S. per treatment with us bringing the Eprex.

The wedding ceremony took place on the beach. However, as there was no path for the wheelchair, the wedding planner made arrangements to have me carried on my wheelchair with Sandra who was riding on a horse with me. It was quite an experience with all the on-lookers watching and cheering as we went by.



"Walking down the aisle"

The surroundings for the wedding was perfect between the Sea of Cortez and the Pacific, surrounded by the sun, the sea and family and friends.



The happy couple

There was a lot I was able to do in Los Cabos other than at the hotel. The highlights being a city tour during which I was able to drink fresh water from a coconut as the weather at the time we went was very similar to Mangalore and a whale watching tour. During our whale watching tour, we noticed



Whale watching

that of all the other tour boats our boat was the smallest and none of us had any life jackets on! However, we had a great day out and saw a mother and baby whale quite close up. Unfortunately, we were only able to get photographs of the tails of whales which were very prominent!

Upon my return, I was hospitalized for 2 weeks because my dialysis lines were infected. When I returned home I had lost some weight. After a couple of weeks I was admitted to the hospital again as my lungs were filling up with fluid. The only sign I had exhibited that this was happening was a cough in the mornings with no cold or flu symptoms. I was in the hospital again for a couple of weeks. People say that things happen in 3's. I was home again for a couple of weeks when I started throwing up blood. Apparently, there were holes in my oesophagus that had to be cauterized. After a couple of weeks in the hospital, I came home. This had been a very difficult six weeks but I was well again and back to my routine.



The airport staff carrying me in an aisle chair from the tarmac up the stairs to the aircraft

San Francisco, California

Roy's Wedding

On May 16, we had some friends over for a Swiss raclette party²⁶ and Roy called to say that he was engaged to Olga Kazakova and the wedding was planned to be in San Francisco on July 17, 2009. He asked if I, as well as Sandra and Claude, would be able to attend the wedding ceremony. As Roy is my only son, I was overwhelmed with joy that my son had finally decided to settle down. We would be delighted to attend as long as we could make all the arrangements and Claude could get vacation time for that time frame. I was delighted both my children were married and in the same year! We were surprised to find so many more options for dialysis in San Francisco but the cost was the same \$450.00 U.S. We were able to rent a wheelchair accessible van from Wheelchair Getaway for the same price as before. We hired a caregiver from Professional Health Care for an hour in the morning and an hour at night. With the requirements complete, we were very fortunate to book our business class flights and accommodation using our frequent flyer points. This saved us a bundle of money as San Francisco is a very expensive city. The hotel we reserved was the Westin St. Francis in Union Square. The hotel is a 10 to 15 minute wheelchair ride from the DaVita Dialysis Clinic in Chinatown so it was very convenient. We arrived on Thursday and the wedding was on Friday. The dialysis clinic was very accommodating and allowed me to have dialysis on the Saturday, Monday, Wednesday and Friday.

The wedding ceremony was held at the San Francisco City Hall which is a very beautiful building both outside and inside. The dome is the fifth largest in the world. This building was used as the model for the Capitol Building in Washington D.C.

The reception was held at the Top of the Mark, in the InterContinental Mark Hopkins Hotel, downtown San Francisco, with its gorgeous panoramic view.

²⁶ Raclette is a type of cheese from Switzerland that is prepared with vegetables on a special raclette grill. The grill heats numerous small pans in which each guest melts the raclette with vegetables and other toppings of his or her choice.



City Hall in San Francisco



The trip to San Francisco was a blend of new and old sights bringing back lovely memories of my previous trip. This included a visit to the Golden Gate Park which has the California Academy of Sciences that houses the Steinhart Aquarium and Morrison Planetarium, with an exhibit of stuffed animals as well as live penguins; the de Young Museum; the Japanese Tea Garden; and the Conservatory of Flowers with species from all around the world. Some of the flora at the Conservatory included banana plants, mango, papaya, jackfruit, breadfruit and coconut trees which I had around me during my boyhood days.



The happy couple



San Francisco skyline

Another highlight of the trip was a drive down I95 of the picturesque West Coast of California to the Apple Computer Headquarters at 1 Infinite Loop in Silicon Valley. One of the shows we attended was the Teatro Zinzanni which had a cast of jugglers, magicians, acrobats, contortionists and musicians and was very entertaining.

Toronto Blue Jays Gala Dinner

Upon our return from San Francisco, I had the opportunity to attend the Back2Back 92/93 World Series Reunion Gala Dinner at the Carlu on Saturday, August 8, 2009. I have been a fan of the Toronto Blue Jays since the inception of the team in April 1977. It was a very regal affair with the opportunity to meet and hear some of the players, relive the highlights of the World Series games and bid on Blue Jays memorabilia during live and silent auctions. I had the pleasure of meeting, getting autographs and pictures of many of the players and coaches including Joe Carter (my favourite player),



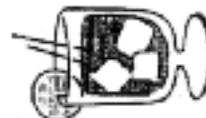
Sandra, Joe Carter, myself and our friend Helen

Tony Fernandes, Jimmy Key, Woody Williams, Devon White, Kelly Gruber, Pat Hentgen, Dave Stieb, Rance Mulliniks, Roberto Alomar, Cito Gaston and Nick Leva.

I thank God that if I was destined to have all these health problems that it happened in Canada where we have a health care system that has assisted me in maintaining a very good quality of life. Through all the trials I have experienced after my retirement, I had the choice to wallow in self-pity or ignore the ailments, persevere and relish my life - the power of positive thinking is very important as one's mind is very powerful. One must remember that dialysis is a necessary inconvenience to sustain life and not a deterrent to living your life to the fullest possible. As long as one follows the instructions for diet, fluid restrictions, medication and dialysis schedule one will have a happy and long life. The amputations were a harder pill to swallow but with the staunch support of my family, I have had a very enjoyable and fruitful retirement. My visions of much travel fulfilled as I had wanted for my retirement years. I hope I can help others to realize that their lives are "not over" and that these ailments or apparent limitations can be successfully overcome. "My Life with Dialysis" is now my gift to you. As we make plans to visit Las Vegas in November, our third trip this year, "Happy travels to you all"!

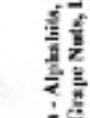
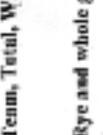
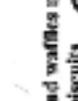
Appendix 1

Phosphorus level in foods

PHOSPHORUS	CHOOSE	AVOID
<p>FISH/ POULTRY/ MEAT/ EGGS</p> 	<p>Natural hard cheese: limit to 3oz./week</p> <p>Meat/fish/poultry</p> <p>Low sodium cold cuts (roast beef, turkey, chicken)</p> <p>natural hard cheese</p> <p>Heart, spleen, lungs</p> <p>Shrimp, lobster, crab</p> <p>Tofu</p> <p>Cottage cheese</p> <p>Limit to ___ oz. or g./day or week</p> <p>*Egg - Limit to 3 /week</p> 	<p>Caviar, fish roe</p> <p>Oyster, clams, mussels, scallops</p> <p>Bones (can appear canned sardines/tuna can)</p> <p>Liver, brain, kidney, pancreas</p> <p>All dried beans, peas and lentils (including fresh and canned) x 2</p> 
<p>FRUITS AND VEGETABLES</p> 	<p>All fruits and vegetables</p> <p>NOTE: Corn, raw mushroom, green peas and potato/ french fries must be limited to 1/2 cup, no more than 3 times per week</p>	
<p>ADDITIONAL ITEMS</p> 	<p>All soft drinks (example: gingerale, root beer) except colas</p> 	<p>Postum, Ovaltine, malted milk, Mycels, Horlicks, chocolate, chocolate milk</p> <p>Cola products, beer</p> <p>Nuts, nut butter, seeds</p> 

☛ if dietary potassium needs to be restricted, refer to your potassium list for the allowed fruits and vegetables.

PHOSPHORUS

CHOOSE		AVOID	
<p>BREADS AND CEREALS</p>   	<p>Breads: Plain bagels, brioché, challah, cracked wheat bread, croissant, crumpets, English muffin, French, Italian, Kaiser roll, matzoh, raisin bread, taco shell, white bread, white pizza</p> <p>Cereals: Corn bran, Corn Chex, corn flakes, cornmeal, cream of rice, cream of wheat, grits, puffed rice, rice krispies, Rice Chex, rice flakes</p> <p>Strengthened Cereals: Applejacks, Captain Crunch, Crispix, Frost Loops, Honeycomb, Trix</p> <p>Crackers: Melba toast, rusks, unsalted soda crackers, zwieback</p> <p>Angel food cake, arrowroot, fruit pies, pound cake, puff pastry, shortbread, social tea, sponge cake, white pasta, white rice, yeast donuts</p> <p>Cake, muffins, pancakes and waffles made with Baking Powder Substitute^{**}, tea biscuits</p>  	<p>Whole grain breads - bran, enriched, dark rye, multigrain, pumpernickel, rye, tortilla, whole wheat</p> <p>Whole grain cereals - Alphabet, bran, buckwheat, bulger, Chocitos, granola, Grape Nuts, Life, Muesli, oatmeal, puffed wheat, raisin bran, shredded wheat, Special K, Team, Total, Wheatnix</p> <p>Rye and whole grain crackers(example: Triscuit)</p> <p>Brown rice, barley, buckwheat, bulger, cake donuts, wild rice</p> <p>Pies or pastries made with nuts, chocolate, cream or custard; All commercial cookies except those listed on the CHOOSE side</p> <p>Food made with baking powder(tea biscuits, commercial cake, cookie mixes, muffins, pancakes, waffles)</p> <p>Processed cheese(example: single slices, Velveeta, cheese spread, macaroni cheese dinner)</p>	<p>MILK AND DAIRY PRODUCTS</p> 
<p>Milk and Dairy Products: Cream, custard, ice cream, milk and anything made with milk such as pudding and cream soup, sherbet, yogurt</p> <p>Limit to $\frac{1}{2}$ cup/day or week</p> <p>The following are equal to $\frac{1}{2}$cup or 4oz. of milk:</p> <ul style="list-style-type: none">  1 cup(8 oz. any milk)  4 Tbsp evaporated or condensed milk 	<p>Milk and Dairy Products: Cream, custard, ice cream, milk and anything made with milk such as pudding and cream soup, sherbet, yogurt</p> <p>Limit to $\frac{1}{2}$ cup/day or week</p> <p>The following are equal to $\frac{1}{2}$cup or 4oz. of milk:</p> <ul style="list-style-type: none">  1 cup(8 oz. any milk)  4 Tbsp evaporated or condensed milk 		

**Baking Powder Substitute Mix is 1/2 tsp cream of tartar with 3/4 tsp baking soda to replace 1 tsp baking powder in any recipe.

Appendix 3

Summary of Recourses for Assistance

- Social Worker at your hospital will help with doctor's referrals for home care assistance.
- Dietian at your hospital will assist with charts on foods that are high in potassium, phosphorus and other food requirements.
- Pharmacist will provide guidance for medications such as Eprex for travelling.
- Personal caregiver in the home
Community Care Access Centre
www.ccac-ont.ca/
- Personal caregiver in the home
Project Information Centre (PIC)
Centre for Independent Living In Toronto
www.cilt.ca
- Information about dialysis and world wide locations that offer dialysis.
www.globaldialysis.com/
- Out-of-Province, Out-of-Country Claims
www.gov.on.ca/health
- Assistance with wheelchairs and protheses
Assistive Devices Program (ADP)
www.health.gov.on.ca
- Funding for home and automobile modification
Ontario March of Dimes
www.marchofdimes.ca/dimes/
- Automobile modification
Kino Mobility
www.kinomobility.com
- Patient Assistance for medication
Sensipar Aid Program – talk to your local pharmacy

Appendix 4

Checklist Before Travelling

Once you have decided where you would like to travel

- Look for dialysis clinics or hospitals with dialysis units that accept patients from abroad or another province. Confirm what the price for dialysis includes (e.g. Eprex, other medication, doctor's visit).
- Locate accommodations close to where the dialysis will take place. If required, check wheelchair accessibility for the room as well as for the premises.
- Ensure communication between your dialysis clinic and the one you are to travel to at least two months prior to your travel date as the dialysis clinics have different requirements and often tests (e.g. X-rays, hepatitis) have to be done prior to acceptance.
- Letter from your dialysis clinic stating that you are carrying Eprex on board the airplane.
- Set up any airport and onboard assistance as required.
- Mode of transportation to and from the airport and dialysis unit.
- Travel Insurance should be obtained.
- Arrangement for a personal caregiver if required.