Dr Elmin Steyn, a past President of the South African Transplant Society and Surgeon at the Christian Barnard Memorial Hospital in Cape Town provides a sombre overview of transplant activity in South Africa. There are not nearly enough transplants being performed to meet the present needs. South Africa has one of the lowest organ donation rates in the world (around 2-3/ million as opposed to 13/million in the UK and over 30/ million in Spain, the most successful country. What is also worrying is the relatively low numbers of transplants being done in the public sector. Considering that only approximately 18% of the population are covered by medical aid yet less than 30% of organ transplants occur in the public sector. In Natal the proportion is less than 10% public patients. Doctors need to lobby very hard as advocates for their patients for more resources to be allocated, so that more are accepted onto dialysis programmes and are ultimately transplant candidates. Dr Steyn makes a strong plea for more education of the public regarding donation, for more resources to be allocated to transplant care and for a state sponsored organisation to oversee all transplant activity in the RSA.

Dr. Sarala Naicker and a Nigerian Nephrology Fellow Dr. Christina Amira tell us how a transplant patient should behave to get the very best from their new ‘gift of life’. Avoid dehydration, take your medicine and just have some common sense is the strong message to all transplant patients! Also, all must be aware that any medication has the potential to have some cross reaction with the immunosuppressive medication they have to take, thus care must be taken when introducing any new medication.

Jenna tells her story of childhood kidney disease leading to complete kidney failure in adult life and the wonderful privilege and feeling of vitality on receiving her brother’s kidney by living donation. Living donation is now becoming an increasing method of acquiring a graft because of the dearth of deceased donor organs.

Pregnancy before and after transplantation in patients with organ failure is risky for the mother. Surprisingly there is no increased incidence of congenital anomalies in infants born to mothers on immunosuppressive medication; but they are at risk for deterioration in graft function. Dr Mike Pascoe, for many years head of the renal unit at Groote Schuur Hospital tells potential mothers how to survive their pregnancy and yet have both a beautiful child and a healthy organ at the time of birth.

Finally, for all of us in transplantation, we should take note of the August organ donor week publicised and sponsored by the Organ Donor Foundation, which does so much in raising public awareness and providing educational material.
Transplantation in South Africa, 2011

Transplantation well recognised to be the most cost-effective therapy for many life threatening conditions involving end-stage organ failure that may affect any age group, race or gender. Transplantation does not necessarily require super-expensive technology and although the post-surgery anti-rejection therapy is costly, it is still less expensive than treatment for other life-threatening conditions such as cancer, heart attacks and serious injuries. Post transplant therapy continues for life, but this has to be seen in the context of a functional person returning to work and fulfilling a role in the family and community, versus a disabled person on costly permanent dialysis or other forms of long-term treatment for end-stage organ failure. All over the world transplantation is accepted as an essential specialist medical service for the population.

For transplantation to succeed, many different systems need to be in place, ranging from adequately trained healthcare personnel, operating and high care facilities, medication, dialysis facilities, laboratory and radiological facilities, referral systems, transport systems, legal and ethical governance, and most important of all: donor organs.

The aspects of transplantation in South Africa that warrant review in 2011 are those that reflect the performance and quality of the healthcare system, the attitudes and education of the people, and the skills and capabilities of the medical services. This can be done by examining various parameters such as waiting lists, waiting times, organ donation rates, transplants performed and short- and long-term outcomes after transplantation.

Healthcare Systems
The South African constitution in Chapter 2 Section 28 guarantees the right to healthcare for all. The Department of Health aims to provide equitable access to appropriate care. Many patients however, especially in rural areas, are unable to attend dialysis or other specialised medical care on a regular basis. Specialised medical care is essential to ensure survival until a suitable organ can be found, consequently many sufferers of end-stage organ failure will lose their lives before being listed on a waiting list. Some Academic hospitals have well established transplantation programmes that continue to grow, others do not. Certain private hospital groups provide comprehensive transplant services which include specialised medical teams, co-ordinators and donor referral systems, and a growing percentage of transplants are done at these hospitals.

The prevalence of end-stage organ failure such as renal failure is increasing worldwide. This is also true in South Africa where diabetes, hypertension and HIV/AIDS contribute to rapidly growing numbers of renal failure patients requiring dialysis. Unfortunately government hospital dialysis facilities have not expanded to accommodate this need, and doctors are forced to apply strict selection criteria for acceptance onto a dialysis programme. Only those who are suitable for transplantation will be allowed to have life-saving dialysis, as once they receive a transplant, the dialysis slot is available for someone else.

There are 16 hospitals in SA where transplants are performed. Kidney transplants can be done at almost all transplant centres, liver transplants are done at Johannesburg Academic Hospital as well as Donald Gordon Medical Centre and in Cape Town at Groote Schuur and Red Cross War Memorial Children’s hospitals. Heart and lung transplants are offered at Groote Schuur and Christiaan Barnard Memorial Hospitals in Cape Town as well as Milpark in Johannesburg and Ethekwini Hospital in Durban. Pancreatic transplants are currently available only in Johannesburg.

Medical professionals caring for transplant patients in South Africa are on par with the best in the world.

Attitudes and education of the population
The average citizen has very little insight into the plight of patients with end-stage organ failure, and knows even less about organ donation. Organ donation rates in SA are among the worst in the world, despite our constitution that defines brain death and our pioneering heart transplant history. The socio-political environment has not encouraged altruism towards strangers such as required to be an organ donor. Among the 14000 road deaths in SA each year there are potentially more than enough donors: if not beating heart donors of solid organs, then at least donors for corneas and skin. Education of the public is a never ending task, currently bravely performed by the (not for profit) Organ Donor Foundation, which can only be truly successful if governmental support is provided. Medical personnel are often reluctant to approach families of brain dead patients for permission to refer to transplant centres, but organ procurement and donor management training courses have been offered annually at all the main centres.

Data Collection
The Organ Donor Foundation collects accurate annual statistics on donors and transplants at all facilities in SA. This tells us how many transplants are done and where the organs are from, but nothing about the successes and failures after transplantation. Unfortunately very little standardised comparable annual outcomes information is immediately available and in the public domain. Until 1994 the SA Dialysis and Transplantation Registry provided reliable information, however there is currently no central data collection system that tracks long-term survival rates for all the transplant recipients in the country.
Waiting lists
Waiting lists are adjusted all the time as new candidates are added and those at the top of the list receive their organs. Patients are accepted onto waiting lists for organ transplants based on internationally recognised criteria. Every transplant team and region keeps track of their own waiting lists and organ allocation within that region. Allocation of organs to persons on the waiting lists is regionally coordinated and is based on blood group match, time on the list, age, gender, size and urgency. As distribution and allocation of organs is a sensitive issue, the lack of central (national) governance and support places clinicians in a vulnerable position, and may certainly be to the detriment of certain patients. Waiting times are long; kidneys patients usually wait 2-3 years, shorter for hearts and lungs and livers, where lists are shorter and waiting times depend on the nature and urgency of the disease, as very serious cases get preference over those who can keep going a little bit longer.

Waiting lists alone do not really reflect the total national need for organs, as it is well known that many patients who would be deemed suitable for transplantation by international standards, never reach the transplant waiting lists for various reasons. One reason is the shortage of dialysis facilities, in addition, many patients suitable for heart, liver or pancreatic transplants, may never be identified or referred to transplant centres by their medical practitioners due to obstacles in the referral system or simple lack of knowledge.

Transplants performed
During 2010, a total of 342 solid organ transplants and 256 corneal transplants were performed in the various transplant centres in South Africa, according to information released by the Organ Donor Foundation. Table 1 reflects the total transplants done at each centre, which may include several different organs.

63% of all transplants (217 of 342) were performed in private hospitals on funded patients. In Cape Town 85 state hospital patients received organs, 32 in Johannesburg, 3 in Pretoria, 2 in Durban and 3 in Bloemfontein: 125 of 342 solid organ transplants were done for state patients. In all provinces the majority of people with end-stage organ failure are likely to be in the population seeking healthcare at the government hospitals, and the same can be said about potential deceased donors. Why are so few transplants performed on state patients in certain regions? It is always said that at any given time over 2000 patients are waiting for transplants. The number of transplants performed each year varies, but has not reached 400 in the past 7 years.

Again many factors play a role. Shortage of specialists, shortage of ICU beds, theatre time, funds and organs. Most of all when compared to other countries there is a shortage of support from government health structures. There is no nationally funded and supported organ donation and procurement programme. There is a vast shortage of transplant co-ordinators in the state hospitals. There is no national policy to educate the public and promote organ donation.

The shortage of donors can be attributed as much to ignorance and apathy on the side of healthcare practitioners as to ignorance among the general public. Many referred donors that are not utilised as there are often no intensive care facilities available to sustain brain dead donors who need mechanical ventilation – artificial life support requiring technology and specialised nursing care.

Due to the shortage of cadaver donors over the years, more and more living donor transplants have been done. Heart transplant numbers have remained fairly stable, but lung, liver, pancreas and kidney transplants have shown an upward trend.

Corneal transplants have dropped significantly over the years as corneas have become more difficult to source. Corneas are currently being imported from the US.

Conclusions
Transplantation in SA has much potential as medical facilities are more than adequate, potential brain dead donors are plentiful and the population of patients with end-stage organ failure is constantly growing. All that is required is education of the public and the healthcare profession, and support from the Health Department. Good transplant system governance requires a central agency, financially and strategically supported by the state, to gather data, oversee implementation of jointly designed protocols and promote organ donation.

State hospitals in SA need the support of the Health Department to employ transplant co-ordinators, identify donors and educate the public, in order to do more transplants for the needy people from that region.
Kidney transplantation is one form of treatment for chronic kidney failure and may offer the best chance of returning to a normal life. It is therefore important, as a kidney transplant recipient, to play an active role in the post transplant phase of treatment with the aim of maintaining good kidney function and thereby prolonging the survival of the transplanted kidney. The factors that depend on your active involvement are:

**Preventing dehydration**
Dehydration is a constant threat to patients with transplanted kidneys. Kidney function may deteriorate rapidly if episodes of vomiting, diarrhoea or inadequate water intake are not dealt with promptly. The transplanted kidney has no nerve supply of its own; therefore it cannot regulate its blood flow. It is therefore recommended to take plenty of fluids especially during bouts of diarrhoeal illness and vomiting and patients should report to their Physician where additional intravenous therapy may be given in cases of severe dehydration and blood levels of immunosuppressive drugs assessed.

**Compliance with treatment**
Non compliance with immunosuppressive medications can lead to the development of acute or chronic rejection and this could lead to failure of the transplant kidney. It is important to develop a routine and take the medication at the same times every day. Non compliance with clinic appointments, dosage adjustments and laboratory follow-up will hinder the early detection of acute rejection episodes and drug toxicity, which often present with an increase in serum creatinine levels. Monitoring of drug levels is also very important as drug toxicity (especially Cyclosporine and Tacrolimus) can cause kidney function to decline.

**Infections**
Infections are common and may occur with increased frequency as a consequence of immunosuppressive medication. The urinary tract is the commonest site of infection, which is often recurrent. They could result from bladder dysfunction caused by diabetes or from other anatomic urologic abnormalities. If you develop burning on passing urine, fever or pain in the lower part of the abdomen report to your doctor as you may have urinary tract infection (UTI). This may also be the case if the routine morning urine dipstick is positive for nitrite, leucocytes or proteinuria. Urine should be cultured and appropriate antibiotic treatment given by your attending physician. Some of the important ways of preventing UTI are: increasing your fluid intake to improve urine output, frequent micturition to avoid holding urine for a long time and avoiding constipation.

**Blood pressure control**
Blood pressure needs to be monitored periodically and high blood pressure should be controlled with low salt diet, prudent weight control and antihypertensive medications. Uncontrolled hypertension is associated with increased risk of transplant kidney failure and cardiovascular (heart) disease. It is very important to reach a blood pressure target, usually below 130/80, or in some instances 125/75. Cardiovascular disease is the leading cause of death in transplant patients and can also lead to late transplant kidney failure.

**Hyperlipidaemia**
High cholesterol level is a risk factor for cardiovascular disease which as mentioned earlier could lead to transplant kidney failure and this should therefore be treated with low cholesterol diet, exercise and medications.

**Diabetic control**
Diabetic control is equally important to prevent cardiovascular disease. In addition to agents controlling blood glucose (insulin or oral hypoglycaemic agents), diet and exercise play an important role. Again, it is important to maintain targets for glycaemic control (blood glucose <7mmol/l; HbA1C<7).

**Avoid smoking**
Smoking damages the kidneys and is a risk factor for heart disease, kidney failure and cancer. The risk of cancer increases in the setting of immunosuppression and therefore kidney transplant recipients must make every effort to quit smoking.
Avoid the sun
Sun exposure must be avoided with use of effective sunscreens, to prevent skin cancer.

Use of analgesics
Non steroidal anti-inflammatory drugs (analgesics) used for the treatment of pain or arthritis may affect blood pressure control and the function of the transplanted kidney.

Drug interactions
Certain drugs can affect the levels of cyclosporine and tacrolimus by inducing or inhibiting the cytochrome P450 enzyme in the liver.

a. Cytochrome P450 inducers - result in reduced levels of cyclosporine, and possible rejection. These are:
   • Antituberculous drugs like rifampicin, rifabutin
   • Anticonvulsants - Barbiturates, Phenytoin (Epanutin), carbamazepine (tegretol)
   • Antibiotics - some antibiotics have been described to reduce levels of cyclosporine in small series, antibiotics like nafcillin, imipenem, cephalosporins, terbanine, intravenous trimethoprim, and intravenous sulfadimidine.

b. Cytochrome P450 inhibitors - result in increased levels of cyclosporine, and calcineurin toxicity:
   • Calcium channel blockers. These are used in the treatment of hypertension and heart disease, drugs like verapamil, and diltiazem. Careful monitoring of drug levels is very important in patients taking these medications.
   • Antifungal agents like ketoconazole, flucanazole and itraconazole.
   • Antibiotics: Erythromycin. You should check with your physician before taking any new medications.

c. Over the counter medication/ health supplements
   • Be wary of taking any over-the-counter medications/ health supplements, as there are many drug interactions e.g. St John’s wort taken together with Cyclosporine decrease cyclosporine levels and increase the risk of acute rejection.

It is important, as a kidney transplant recipient, to play an active role in the post transplant phase of treatment with the aim of maintaining good kidney function and thereby prolonging the survival of the transplanted kidney.

The Organ Donor Foundation (ODF) has renamed August “Orgust”, in honour of Organ Donor Month. Under the theme Save Seven Lives, Orgust will serve to highlight the statistic that one person saves seven lives when they register as an organ donor.

ODF Executive Director, Linda Peel, explains the rationale behind the change: “At any point, any person may find they need an organ transplant. When one person registers, they can potentially save seven lives because of the number of organs that can be transplanted. During Orgust we want every South African to think about and act on becoming an organ donor. It is free to register, but provides rich opportunities to change seven lives immeasurably.”

There are over 4300 people throughout South Africa currently awaiting an organ transplant operation. Many of them are children who are forced to put their childhood interests and dreams on hold, waiting for a suitable donor. Others are adults who could become fully functioning, economically active individuals, transforming their own lives and creating a lasting positive impact on their communities.

The ODF will also be unveiling its new logo, which was redesigned to represent the idea that all South Africans can be organ donors. The logo draws inspiration from the African concept of Ubuntu — the principle of interconnectedness between people. With one donor being able to save seven lives, organ donation creates the possibility that every South African can share in the real meaning of Ubuntu.

Orgust will be marked by a series of events and awareness programmes during the month. These include a one day radiothon by RadioSonderGrense, a national Corporate Civvies Day and Tribute Days for organ donor families.

For more information about the events, or to register as an organ donor, contact the ODF toll free on 0800 22 6611, or visit www.odf.org.za.
When my ‘kidney co-ordinator’, Kim, asked me to sit down and write my kidney transplant story, I was not sure where to start. Ultimately, my hope is that my story could help future transplant recipients and donors on their journey and my journey will be complete!

Life as I knew it
I was born in 1985, a healthy baby, but soon became ill. By 18 months I underwent an operation to repair my abnormal ureters. However it was too late, the damage had been done and I only had 80% kidney function. My parents were informed that I would one day need to have a kidney transplant. Every 6 months throughout my life I would go for regular checkups and slowly but surely the kidney function began to drop and I suffered regular kidney infections. This was my life - the life I knew and we carried on as a normal, healthy and happy family. I did not even have to learn to “live with it” because this was the only life I knew and I adjusted accordingly.

My passion in life was to become a beautician; I gained my diploma in Beauty Therapy and opened my own little salon. I grew my salon and made a success of it and then was blessed to find the love of my life, Clinton.

An important aspect to any relationship is honesty and understanding, however I had an extra task of explaining my current life situation. Again, without letting my kidney situation define our relationship, we carried on and built a beautiful life together. We were married in March 2008, and after lengthy discussions with doctors; who admittedly told us it would not be the best idea, we fell pregnant in October 2008. This was a hard and emotional journey; a high-risk pregnancy and I was closely monitored by the doctors. Many a time the doctors wanted to terminate the pregnancy and I spent a few times in the hospital with some close scares. My kidney function did drop. As always, throughout my life, God was watching over us and our miracle baby, Layla Grace was delivered on the 4 June 2009.

And it all came tumbling down
And so there we were, our little family growing and loving together… I started to feel really ill, really tired, and really nauseous and generally “just not well”. I lost weight and developed numerous kidney infections over the next couple of weeks. By then I had only 19% kidney function and the giant white elephant in the room suddenly became visible! The next step was a kidney transplant! I had always known that one day I would need a transplant but the day that Dr Fabian actually said I would now need one; I felt an overwhelming sense of anger, hurt and fear! The fear of the unknown!

We started the steps towards the transplant. The research, testing and discussions began. The only matching family member was my brother, Tyrone, he was also O+. I had never actually asked him or anyone to donate or even be tested - it just happened. How do you ask someone to give something so big, so permanent of themselves?

Tyrone was adamant that this was something he wanted to do, one of his callings. I made sure that he knew that no matter what happened, whether he was a match or not or whether the kidney transplant was a success or not - I was and would be forever grateful. Besides the birth of our child, it would be one of the greatest gifts I could ever receive.

The surgeries
Tyrone was a good match, not the best but good and we began to move closer to D-day. However, I became sicker by the day and it was decided that I needed to go for a double nephrectomy but needed dialysis first. My kidneys were doing more harm than good and so it was time to say goodbye to them.

On the 5 October 2010 my kidneys were removed and my stent for dialysis was put into my chest, I was terrified! This operation catapulted us onto the road, although it would ultimately lead us closer to the transplant, it was a trying and awful experience. This part of my journey was by far the most painful and awful experience I have ever gone through. I wanted to give up! Dialysis was very difficult - no brochure could have prepared me for what I had to endure. My family

“I did not have to learn to ‘live with it’ because suffering regular kidney infections was the only life I knew.”

Jenna-Leigh and Tyrone today, 5 months after transplantation.
and friends were by my side, but no one could help. This was very difficult for everyone but Tyrone battled, he wanted to give me the kidney now - so that I did not have to endure this process.

I had never felt that ill in all my life, kidney failure was a lot better than this. Dr. Fabian told me that often people who had to endure dialysis would later appreciate the new kidney more. I could not even see that far into the future. This dark and painful road would later reveal the inner strength I never thought I had. I became a person I never thought I was - strong and brave!

I started living a life with dialysis and slowly learnt to live it - but I could not wait for transplant day; I was so excited! The transplant day was brought forward and on the 11 November 2010 my brother and I went in.

Tyrone was up first and harvested the most beautiful kidney I have ever seen. I was so nervous for him, undergoing surgery when he was not even ill; knowing that the operation would be more painful for him than for me and he was doing this for me!

I remember waking up and feeling as if someone had turned a switch on. I felt alive in a way I had never felt before. I was overwhelmed with emotion, I was thankful and humbled; I had a piece of my brother inside of me. I could not wait to go and see him. My new anti-rejection medication made me feel a bit agitated and restless. I seemed to be suffering from some compulsive behaviour and just felt unsettled.

The experience of being able to meet up with Tyrone and heal with him, walk with him - made this experience that much more special and easy. Had it been another faceless donor - I would not have been able to experience this bond. It was like the cherry on top. Not only had Tyrone given me a new lease on life but we experienced this together and it just cemented our bond even more. I can never repay Tyrone and I am forever grateful. While he was healing, I had to see him go through some pain just like he watched me endure dialysis. I told him how I wished I could take his pain away, I remember him saying he would do it all over again just to see me so healthy and not suffer anymore. He is a truly beautiful and selfless person.

The beginning

It has been five months since the life changing operation - “life changing” sounds so miniscule compared to the overwhelming sensation I experience. The simple act of waking up each morning is a blessing and I feel truly alive, not just emotionally but physically. I never knew life could feel this good. I take medication everyday twice a day and the doses are lessening over time. There are side-effects that are not pleasant, and swallowing over 20 tablets at a time was something I had to get used to, but at the end of the day it is a very small life change for the most treasured gift one human can receive from another. Tyrone is doing really well; he is living a much healthier life and has a beautiful “battlewound” that he wears so proudly.

Tyrone and I have held hands while we walked a road together, but behind us; carrying our “luggage” were our ever supportive parents; my brave and solid husband Clinton and daughter Layla; Amanda, Tyrone’s courageous and unselfish wife; the love and support of our extended family and special friends; and the endless efforts, care and driving fight of our transplant doctors and team. Because alone, we would never have been able to walk this road.

by Jenna-Leigh Loxton
A fairly common question from young women after they have had a transplant is, "Is it safe for me to get pregnant?" Sometimes, of course, they just say, "I am pregnant." Pregnancy with all the physiological changes that it causes is not to be undertaken lightly in a person who has been in receipt of a kidney transplant.

During the phase of chronic kidney disease before dialysis is started and while on dialysis, pregnancy is unlikely to occur and if a woman does become pregnant during that phase of her illness the chances of a successful outcome - healthy mother and healthy baby - is very small. Only after a successful kidney transplant with normal or near normal kidney function can we answer the initial question.

Planning for a healthy post-transplant pregnancy
The best advice is that the patient should use an acceptable method of contraception for at least two years post transplant. During the first two years after the graft the doses of immunosuppressive drugs are steadily reduced and the kidney function, blood pressure and general health stabilise. Thus pregnancy during this first 24-month period post transplant is unwise. Thereafter for the patient who has a well-functioning kidney, well-controlled blood pressure and no other major problems a pregnancy becomes a possibility.

Precautions
There has been no reported increase risk of foetal abnormalities in post transplant pregnancies, although there is an increased risk of spontaneous abortion. There need thus be very little worry about the birth of an abnormal child, although this is possible as for any pregnancy, and the newer drugs used for immunosuppression have not been tested so extensively in this regard as the older agents. It is essential to remember that both the ACE-I drugs and the angiotensin receptor blockers are absolutely contra-indicated in pregnancy. If you are using these agents it is important to ensure that you avoid pregnancy and discuss and change to alternate drugs for your blood pressure before allowing yourself to become pregnant.

Rejection risk
Post transplant rejection may occur at any time and a number of studies have suggested that about 9-10% of pregnant transplant recipients will experience a rejection episode. This is as always treatable with the usual anti-rejection measures.

A further concern is in regard to any loss of kidney function during the pregnancy. A permanent decline in function has been reported in about 15% of post transplant pregnancies. This may be a modest decline in function but for some patients it may be total graft failure with the consequent return to dialysis.

Post-transplant fathers
Male patients after a successful graft are able to father children and fertility returns to normal.

Before starting on a pregnancy, it is only sensible to discuss the issue with your nephrologist or physician so that drugs can be altered if necessary and special close follow-up arrangements can be made, and referral to a suitable obstetrician can also be arranged.