

# Transplant News

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Official newsletter of the  
South African Transplant Society

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## Editorial

Professor Jerome Loveland  
Editor

W e as the medical practitioners involved in transplantation deal with this complex aspect of medicine on a daily basis. Whilst every patient is important to us, and we strive for the best possible outcome, this is our job, and I guess that to a certain extent it does become "routine". However, each and every patient that we treat remains an individual, a single person who has been thrust into the unknown, to travel an extremely tough, and often long, frustrating journey during their diagnosis and supportive care, their transplant itself, and their care post transplant. As a medically naïve person, this is an extremely daunting proposition, and whilst you are encouraged to educate yourself as comprehensively as possible, you are extremely dependent on your doctors to advocate for you in the best possible manner, ultimately with your best interests at heart.

A close relative with chronic kidney disease has recently reached the point of end stage renal disease, is on the precipice of requiring dialysis, and is being worked up for a pre-emptive transplant. I was devastated as to the manner in which she has been cared for in the last 18 months, with very little communication, and certainly no discussion and education around the potential for transplantation. Fortunately we as a family were in

the position (for obvious reasons) to intervene, and have now moved to an alternate practitioner and put in place the care and treatment plan that is required.

Obviously we are fortunate. I tell this story though as a lesson to each and every patient: empower yourselves with as much knowledge around your disease as possible. Ask your doctor everything that you can, and without second-guessing them, interrogate each and every aspect of your treatment plan. Remember that you are the most important person in your care: if you are not happy, you are absolutely entitled to a second opinion.

Remaining with the patient: chronic organ failure is difficult enough to come to terms with, can you imagine how much more tough things must be when a person in the epitome of health is catapulted into transplantation on account of acute organ failure, often facing death if not transplanted. Difficult to comprehend. I was amazed by the article by Henk Goris when editing this edition. A 22 year old varsity student in the prime of his life, this is exactly what Henk faced. His insights into his experience, emphasis on, and gratitude to his donor, and contribution to education are exemplary. I encourage all patients to adopt his positivity and energy!!! Enjoy the read.

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**I went from a healthy student to a young guy fighting for his life in ICU, within a couple of days, not knowing what caused it but being given the diagnosis of organ failure.**

**R**eceiving a donor kidney has not only meant that I have returned to a normal lifestyle, being blessed with the gift of life means that I now have a new perspective on life, and the best part is having the energy and zest to put this into practice. My donor family has not only given me an organ that has saved me from Chronic Renal Failure, they have given me a new life full of opportunities.

Not being exposed to renal failure before my own illness meant that I didn't know what kidney failure or haemodialysis meant until the age of 22 when my life changed dramatically. Within a couple of days, I went from a healthy student to a young guy fighting for his life in ICU. The causes were unknown but I was given the diagnosis of organ failure. I had lost the function in both my kidneys and as a result my heart function was deteriorating. This just illustrates how quickly something like this can happen, as my whole condition started with a sore throat.

After a lengthy stay in hospital including various tests and scans, I returned to a stable condition as my heart had recovered, but my kidneys unfortunately didn't and I was told that I had to dialyse as an outpatient. It was a process of accepting that this had happened to me, and as many things - this took time, but once making peace with the situation, I realised that the

only thing I could change was my attitude. Months went by and various reasons meant that I couldn't receive a living donor kidney, and I was placed on the Transplant Waiting List with the hope of being blessed with a kidney one day.

Going from reading the Transplant News at Renal Care Umhlanga on a haemodialysis machine, I am privileged, blessed and proud to be writing this article as a kidney transplant recipient. My life changed in May 2015, when I got a call at 2am saying that there was a beautiful kidney waiting for me and after making sure it wasn't a dream, I was just trying to picture myself leading a normal lifestyle again. Words cannot explain the difference that an organ transplant has brought to my life. The strength in my body compared to being on dialysis is indescribable, and along with that came the sense of freedom that everybody living their life has. This is only realised when no longer being restricted by the effects organ failure has on a patient waiting for a transplant. This is appreciated every second of every day, as you can live your life to the fullest knowing that every day is a gift and presents you with opportunities to make a difference.

My passion to contribute to organ awareness and education in South Africa, was ignited by a family that selflessly made a decision on the hardest day of their lives, and provides us with reason to educate and create awareness wherever we go so that people are at peace when being approached with the opportunity to potentially save seven lives.

My donor family did not only save my life, they gave me a new life with a perspective and mind-set that I wish I could share with everyone. Realising how important it is to keep your mind clear of hindrances and not to allow emotions to destroy your destiny. We are all more than conquerors and living with the attitude of always wanting to achieve more has been ignited by my kidney transplant.

I am excited to take part in the National Transplant Games to hopefully qualify to represent my country - an opportunity I wasn't exposed to before, to promote a healthy lifestyle under recipients, contribute to the evidence of the positive results of organ donation and to encourage those waiting for a transplant.

I have such respect for patients fighting a battle with the aim of being blessed with a transplant one day. It is a difference in society we can all contribute to, to educate and raise awareness about organ donation and how it saves lives and empowers people with new opportunities they are thankful for daily.



**D** diabetes accounts for almost half of all patients in the world today who have end stage kidney failure. The great majority of these would have so called “Type 2 diabetes”, that is, adult onset diabetes. These patients have a large burden of cardiovascular disease and can often develop complicated problems around the time of transplantation. In addition, many of the antirejection drugs used can aggravate the cardiovascular risk profile and can often worsen sugar control. The latter can cause a more rapid recurrence of diabetic kidney disease in the transplanted organ. In spite of this, research has shown that those patients who are lucky enough to receive a transplant do better than those who remain on dialysis, both in terms of quality AND quantity of life. It is also clear that those patients who are transplanted prior to the commencement of dialysis also do better than those who start dialysis first. Thus it is preferable to refer patients to transplant centres once their degree of filtration (or glomerular filtration rate (GFR)) falls below 20-30% of normal. Unfortunately, in South Africa, where the rates of transplantation are rather low, this is not always possible in the major transplant centers.

Prior to being placed onto the transplant list, many tests need to be carried out to ensure that it is safe to undergo the operation as well as take the required medication. I would like to go through the evaluation process in this article as it can often be a confusing and lengthy process for the patient.

## Cardiovascular screening

Diabetics with kidney failure not only have all the traditional risk factors for coronary artery disease, but they also have a whole host of “non-traditional” risk factors. It is estimated that as many as 33-50% of asymptomatic diabetics with kidney failure will have serious coronary artery disease. These patients are at high risk for both mortality and morbidity in the post operative period.

Thus the cardiovascular evaluation of diabetics on a transplant list is rather thorough and would include:

- **History:** this would include information on the patients, age, family history, time with diabetes, smoking history and any experiences of chest pain
- **Examination:** preferably carried out by a cardiologist
- **Chest X-ray and ECG**
- **Exercise stress testing:** this can be difficult in kidney failure patients who often have a low exercise tolerance because of their illness. The exercise stress test can be mimicked with a “dobutamine stress test” which results in an

increased pulse rate and cardiac output

- **Coronary angiogram:** although this test is invasive and carries with it some risks, most transplant centres will want a coronary angiogram in a diabetic patient prior to listing that person on a transplant list. Unfortunately, in those who are not yet on dialysis, it can cause the further deterioration of kidney function and even the premature commencement of dialysis. For this reason, this test may not always be appropriate. In those patients with established coronary artery disease, the exact method of revascularisation remains controversial but may include formal coronary artery bypass grafting.
- **Peripheral vascular disease:** this is important particularly with regards the femoral arteries which are used to attach the new kidney to. Assessment of these vessels is frequently carried out using non invasive Doppler studies with an ultrasound probe.

## Urinary tract assessment

- **Voiding cysto urethrogram:** this test is rather uncomfortable as it consists of a catheter being placed in the bladder which is then filled with dye. Following this the patient is asked to empty the bladder. Diabetics frequently have floppy dysfunctional bladders which are unable to completely void. This makes recurrent infection more likely post transplantation and thus the detection of the “diabetic bladder” is important pre-surgery.

## Gastrointestinal assessment

- **Gastroscopy:** this test, which consists of a camera being placed in the stomach is important to detect any occult ulcers which may be adversely affected under the influence of steroids.
- **Barium meal:** diabetics often develop autonomic nervous dysfunction. In the gastro intestinal tract this can manifest with severe nausea and vomiting, which may well interfere with adequate absorption of anti-rejection and other medication.

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# Immunosuppression: side effects and sound advice

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**D**ear patient  
Congratulations on your transplant! This is truly a live-saving event, and we hope that you will grasp the opportunity that comes with it for a long and healthy life. You will be faced with taking handfuls of immunosuppressants - and this may be scaring you. So many drugs, so many potential side-effects...

What, still awaiting transplantation, or in the process of being worked up for a living related transplant soon? All the better. Grab the opportunity to discuss your medications in detail with your doctor.

Prior to the introduction of cyclosporin in the late '70s by Sir Roy Calne, the only drugs showing benefit in terms of reduced acute rejection were corticosteroids and azathioprine. Since then, we have seen the introduction of tacrolimus, sirolimus, mycophenolate mofetil, everolimus, and new developments on drugs for induction of immunosuppression prior to transplantation as well. The days of one-size-fits-all therapy are long gone. Compare your immunosuppression regimen with buying a suit. You no longer have to buy it off the shelf; it can be specifically tailor-made for you based on your history, your illnesses, and risk factors including diseases common to your family, your own antibody profile, and your response to the various components. For brevity's sake, here's a very basic classification of the various groups of drugs you may be given:

**Induction therapy:** e.g. basiliximab or thymoglobulin

**Corticosteroids:** Most units use several days' worth of intravenous induction followed by oral medication, for various lengths of time. Some units may have protocols that avoid or minimise its use as soon as possible.

**Calcineurin inhibitors:** cyclosporin or tacrolimus.

**mTOR- Inhibitors:** sirolimus or everolimus

**Anti-proliferative agents:** azathioprine, mycophenolate Mofetil or mycophenolic acid

The aim of immunosuppressive medication is to preserve the function of your transplanted organ for as long as possible by preventing and minimising acute rejection. The biggest risk for rejection is in the first six months after transplantation, therefore during this period the cocktail of drugs offered to you will be at its most intense. For some organ transplants the risk of rejection decreases significantly thereafter. With others, such as the kidney, a substantial risk may remain – this too will play a role in the selection of the drugs you need to take in

the long term. But let's get back to the side effects, as you've asked. Side effects are a risk of all medication. Before I frighten you off, have you ever read the pamphlet insert in a box of paracetamol? Scary, isn't it? Yet how often have you or anyone you know of taken paracetamol, and how many people do you know that have come to any harm? Very, very few. Though immunosuppressants are more dangerous and have more side effects, with careful attention to detail and communication between you and your doctors the risks can be minimised. There's not enough space to discuss each and every problem, so for convenience sake I will divide the side effects in two groups and briefly mention some in each:

## Side effects that scare or worry patients the most

### Cosmetic

Weight gain, acne, striae, excessive facial hair, gum hypertrophy and overgrowth – many of these are temporary effects in the first months, and can be managed with changes in medication dose or corrected surgically in the case of gum hypertrophy. Unfortunately, many patients see this as the major problem after transplantation. Do not change ANY of your medications without discussing it with your doctor, please.

**Gout** is a common and painful side effect of the CNI's, cyclosporine in particular. To treat this effectively you may need several changes in your immunosuppression prescription as well as extra medication to control uric acid levels.

**Diarrhoea** is a common complaint in up to a third of patients using mycophenolate mofetil or mycophenolic acid, especially when starting on these medications. It usually improves drastically on transient lowering of the dose of medication and with gradual re-introduction.

## Side effects that scare or worry doctors the most

**Nephrotoxicity** - The CNIs in particular can cause acute deterioration in kidney function with doses that are too high, and have been linked to chronic renal impairment in kidney transplantation as well as in patients with other organ transplants.

**Diabetes** - Several drugs are culprits here - corticosteroids, mTOR inhibitors; but tacrolimus is the biggest contributor. Developing diabetes after transplantation brings with it a long list of further potential complications which increase mortality and morbidity. Discuss your risk profile for developing diabetes

with your doctor, and together look for options to minimise the risk.

**Bone marrow suppression** is a common side effect of the combination of immunosuppressive medications you may take, especially in the first 6 months after surgery. Your blood cell counts will be monitored carefully, and medication may be omitted or changed as needed particularly if your white cell count falls to below acceptable levels.

**Opportunistic infections** may arise as a consequence of impaired protection from your immune system. Of particular concern, again, is the first 6 months after surgery. You may be given antibiotics such as bactrim, isoniazid and/or anti-viral drugs to assist in protecting you, but it is wise to avoid big gatherings for the first couple of months. Make sure your immunisations are up to date prior to transplantation.

**Malignancies** occur much more frequently in transplant patients. The most common is skin malignancies, but in general the risk of getting cancer is 3-3.5 times that of the general population. Breast, lung and prostate cancer are not more common in the transplant population while colon cancer is. Viral infections, decreased immunosurveillance against cancerous cells and other factors may play a role. The risk for malignancy increases the further along you are from your transplant – if you have any worrying symptoms please discuss this with your doctor.

**Cardiovascular disease** i.e. strokes and heart attacks are one of the commonest reasons for death after transplantation, and the immunosuppression you use may contribute to risk. Your risk profile (hypertension, diabetes, high cholesterol and other risk factors) should be monitored regularly. Your doctor can help by offering advice on modifying your lifestyle choices.

In order to make sure that you have the best and safest possible care, as well as the least possible problems from your immunosuppressive medication, here's some really good advice.

- Know your medications, their doses, the times that they are supposed to be taken. It may be a lot to remember, so perhaps write all the information down on a card and keep a copy in your wallet or purse. Give a copy to a family member as well, in case you are too ill to explain them yourself.
- Take your medication at the correct time of day, and at the same time of every day. If you struggle with this, pack your tablets over into a weekly pill-holder, and set the necessary reminders/alarms on your cell phone to remind you. Calcineurin inhibitor levels are measured as trough levels, and it is vital that the timing of the test is correct otherwise your dose-adjustment may be wrong.
- Read from reliable sources about your medication, not just internet-gossip. Keep on discussing any side effect that you are concerned about with your doctor. We truly do have your best interests at heart and need you to talk to us about side effects you experience or worry about.
- Do not under any circumstances skip or stop any medication without discussing it with your doctor first. Missing even one dose of medication can lead to rejection. If you do feel strongly about stopping or changing, make sure that you will be safe or will start with an alternative medication as is deemed appropriate.
- Do not take any other over-the-counter medication or medicines prescribed by other doctors without having it cleared with your transplant doctor. Drug interactions can cause very high or very low levels of transplant medication, which could be severely damaging to you and lead to toxicity or rejection.
- Take care of yourself. Always use sunscreen. Eat prudently and exercise. Watch for signs of an infection, especially in the first 6-12 months, and see someone as quickly as possible. Keep your blood pressure in check, and undergo regular screening for cardiovascular disease and malignancy as you grow older. Above all, cherish the chance you have been given.

#### References & further reading:

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# Where do donors come from?

**A van Heerden & C du Plessis**  
Procurement Co-ordinators  
Netcare Transplant Division, Johannesburg

**O**rgan donors come from the community. Patients waiting for an organ or tissue transplant have to rely on the community to find it in their hearts to donate 'the **GIFT of LIFE**'

## Organ donation is from the community to the community

The number of organ donor referrals has been steadily declining over the last couple of years. This has been attributed to numerous factors i.e. 'not wanting to cause further trauma to the family', cultural and religious beliefs, gatekeeping in the hospitals and bizarre beliefs about the process. Despite this adversity, the number of patients requiring life-saving operations continues to spiral and patients are frequently dying while waiting for a donor.

Throughout South Africa there is a dedicated team of Procurement Co-ordinators that continually do training and education in our hospitals in an attempt to promote organ donation and educate staff on the process of organ donation.

The role of the Organ Donor foundation (ODF) is to educate the community about organ donor awareness and needs to be a continual process throughout the year, covering all regions and provinces of the country.

Having said this, there is a large group of the population that are extremely skeptical of organ donation and for reasons stated above, are reluctant to consider organ donation. The graph below indicates this clearly.

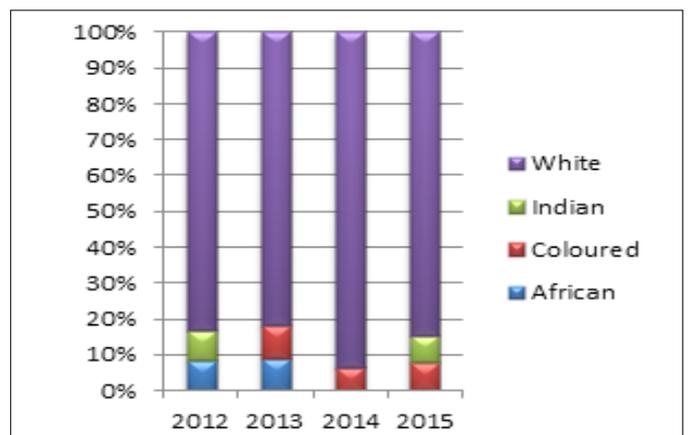
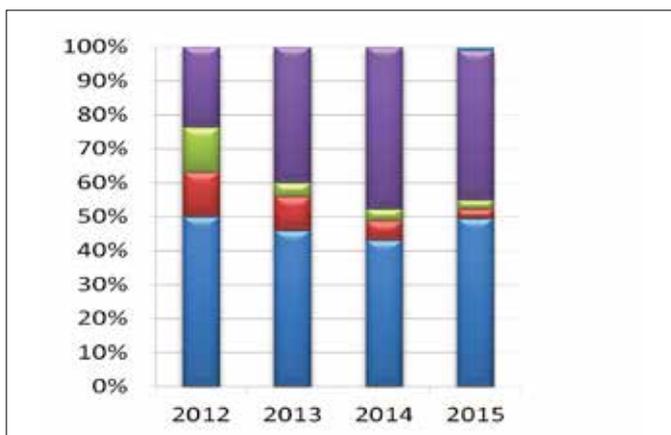


Figure1: Demographics of referrals from Netcare JHB versus the actual donors from Netcare Johannesburg

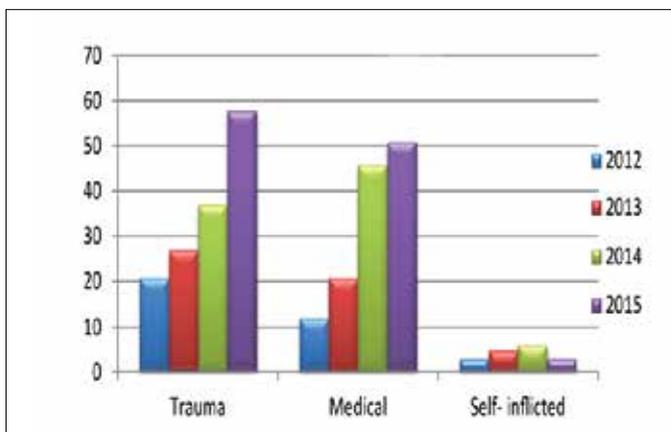


Figure 2: Type of injuries from the Netcare Johannesburg referral calls

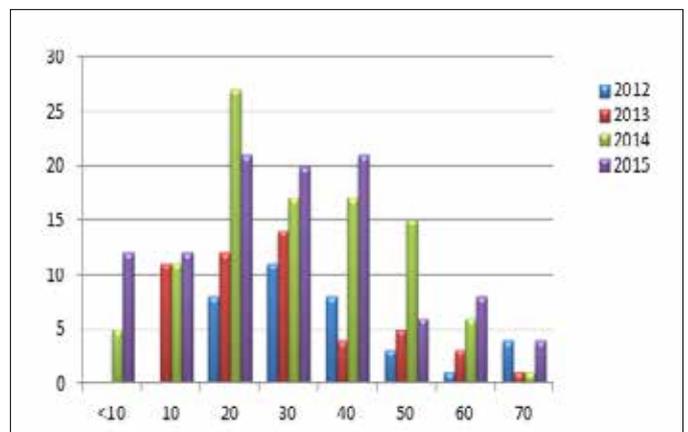


Figure 3: Ages of the referrals of the Netcare calls

Trauma cases used to be the main source of potential donors but figures have shown that medical cases are being utilised more and more. This would be patients that suffer from cerebral bleeds or incidents that may lead to brain death. The graph below indicates that more and more medical patients are being referred and used for organ donation. This makes the average age of donors increase, leading to older organs being transplanted and resulting in even longer waiting times for patients needing heart and lung transplants.

The dignity of the donor is maintained throughout the process with the procurement co-ordinator staying with the donor until the whole procedure is completed. **Figure 3** indicates that the age group demographics, with the 20-40 year age group being the largest percentage of donors, potential donors being the largest. This age group is very exposed to potential trauma from assaults, motor vehicle crashes (MVC), pedestrian crashes, assault and often their lifestyle carries more risk.

The other consideration is that motor vehicles are safer, seat belts are used and more people are becoming aware of 'drinking and driving'. This number is decreasing although the number of drivers that do drink and drive remains unacceptably high.

With the numbers of patients requiring lifesaving organ transplants there are a couple of points that people need to be aware of –

- Discuss your wish to become a donor with your family.
- Your family has the final say in this issue so it makes the

decision so much easier for them if they are aware of your wishes.

- The Organ Donor Foundation of South Africa is the body that registers potential organ donors but it is not essential to be registered with them to become a donor.
- No-one will be an organ donor without consent from your next of kin.
- The organ donor consent is a choice throughout the process.
- The dignity of the donor is maintained throughout the process with the procurement co-ordinator staying with the donor until the whole procedure is completed.
- If you require a kidney transplant, discuss the possibility of a family member or friend donating a kidney to you as the average waiting time for a kidney is 5-7 years.

Once patients are referred to the procurement teams and the patient has been assessed for suitability as a donor more factors come into play as to the suitability of the potential donor and a large percentage become unsuitable due to factors as indicated in **Figure 4** below.

**Figure 5** below indicates how many transplants were performed in 2015 in the Netcare Johannesburg Transplant Division and the urgent need of potential donors for life-saving treatment.

**PLEASE REGISTER AS AN ORGAN DONOR TODAY AND ASSIST SOMEONE IN DESPERATE NEED OF AN ORGAN TRANSPLANT. For further information on registering as an organ donor contact the Organ Donor Foundation at [www.odf.org](http://www.odf.org).**

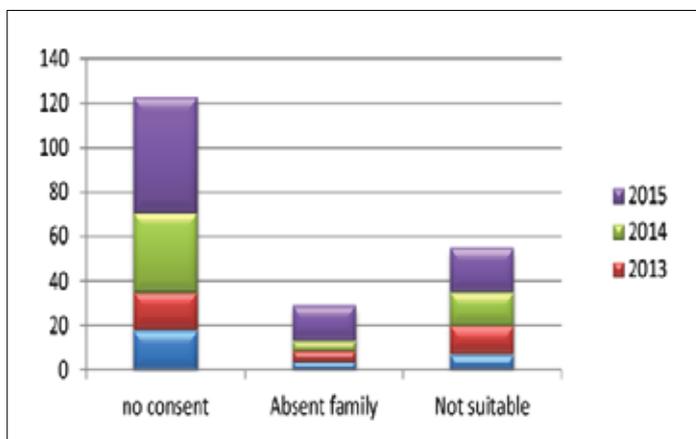


Figure 4: Dynamics of potential cases

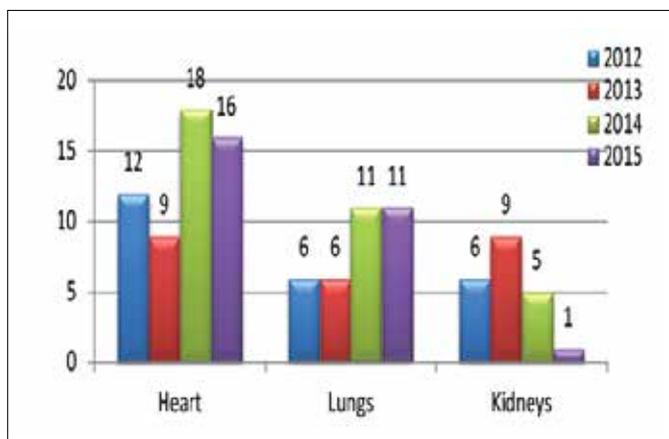


Figure 5: Number of Transplants of Netcare Johannesburg

# JOIN THE ODF VOLUNTEER NETWORK!

**Gillian Walker**  
National Liaison Officer  
The Organ Donor Foundation, Johannesburg



Last year the Organ Donor Foundation had their first volunteer training session in Johannesburg. Following the success of the training session we rolled this out to Durban and in 2016 we plan to roll it out to several more cities in the rest of the country.

Our volunteer network is extremely valuable to the Organ Donor Foundation and to organ donor awareness as it is the volunteers who go out into the community and speak directly to the public.

## What do our volunteers do?

The purpose of the ODF Volunteer Network is to communicate directly to the public about organ donation through awareness days, talks and other events. The Volunteer Network also assists with ODF events such as the annual Proud 2b an Organ Donor walks in both Johannesburg and Cape Town.

## What does the training involve?

We comprehensively cover the following aspects: the role of the Organ Donor Foundation, the transplant process, the role of an ODF Volunteer, questions frequently asked by members of the public and we end off with an open discussion and questions from volunteers. The training is delivered by ODF staff and transplant coordinators, and is interactive where possible.

## Why is training important?

Through our volunteer training sessions we aim to equip our volunteers with comprehensive training to give them the knowledge to confidently represent the ODF at a range of different events.

The training is especially important to ensure that the information that volunteers feed back to the public is in line with the ODF's messaging and that we all strive towards the same goals. The training also gives volunteers a good understanding of the challenges of transplantation in South Africa, the practices and protocols of transplantation in South Africa and

it will inform volunteers of how to correctly answer the medical related questions on transplantation that we are frequently asked. The ODF is not involved with procurement or allocation of organs. However, part of our role is to inform the general public of the challenges of transplantation and we frequently refer to relevant specialists in the field for assistance on this.

## Why do we need a volunteer network?

With a population of over 50 million in South Africa it is impossible for the ODF, as a small organization, to reach everyone with the importance of organ donation. Our volunteer network is a vital part of our organization and without our volunteers we won't be able to achieve our goal of registering 1% of the population in South Africa by the end of 2020.

## Who can be a volunteer?

Anyone! We encourage anyone of all ages. We currently have recipients and patients awaiting transplant as well family and friends of recipients and patients waiting. We also have volunteers who have no personal connection to transplants.

## How do I join?

Email [gillian@odf.org.za](mailto:gillian@odf.org.za) for a registration form and more details on the training session closest to you.

## Training dates?

Provisional dates for training in 2016 are as follows:

<b>Johannesburg</b>	27th February	<b>Bloemfontein</b>	May
<b>Cape Town</b>	12th Mar	<b>Nelspruit</b>	June
<b>Port Elizabeth</b>	April	<b>Durban</b>	October

Please note that dates are subject to change, so please confirm with Gillian before making arrangements to be at the training.

## How do I contribute?

To donate towards the volunteer programme please contact Gillian on [gillian@odf.org.za](mailto:gillian@odf.org.za) or on the toll free line 0800 22 66 11. Alternatively you can transfer money electronically directly to the ODF using the following bank details: Organ Donor Foundation ABSA Bank, Branch: Heerengracht Code: 506009, Account number: 01273580600, Ref: VOLUNTEERS + initials + surname

Please note that donations qualify you for a tax deduction in terms of Section 18A as we are a registered non-profit organisation.



All volunteers receive a volunteer pack at volunteer training