

Transplant News

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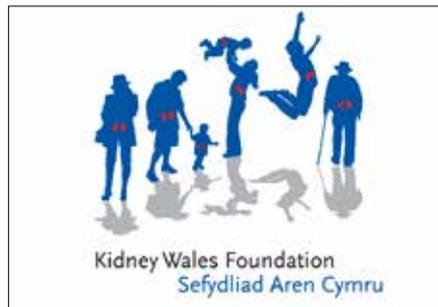
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Editorial

Professor Jerome Loveland
Editor



This August marked the 50th anniversary of Johannesburg's first kidney transplant, a year shared with Kidney Wales <http://www.kidneywales.com>

and various other transplant centres around the world. It is good to know that transplantation in South Africa was born at the same time as in the rest of the world, and lead the field in heart transplantation through Chris Barnard, Groote Schuur Hospital and the University of Cape Town. It is also comforting that although facing challenges at some levels, we remain recognised at an international level from numerous perspectives. Certainly from a local perspective, transplant units are gearing up to celebrate the last 50 years, this from many different perspectives.

Whilst the historical perspective is always important, and adds so much insight into the nuances of how transplantation has developed in South Africa, numerous organisations have chosen to focus on

the challenges that we currently face, in addition to the successes. The 2 big issues that must be at the forefront of this discussion remain availability of donor organs, as well as equitable access to transplantation services. Two organisations focussed on these initiatives during the month of August, these being the Organ Donor Foundation as well as the ChancePlant Initiative, <http://www.chanceplant.org.za>.

The **ChancePlant** Initiative
giving a second chance at life

As ever, the ODF are forging ahead with efforts to increase organ donation, and as part of their drive, launched their "Organ and Tissue Donor Awareness Month" at the beginning of August. In addition, the ChancePlant Initiative, a local NGO started by university students, held their 2nd annual debate around organ donation, on Thursday, the 4th of August. The topic was "This House would use an Opt Out system for Organ Donation" and was held at the School of Public Health Auditorium, Wits University.

So as ever, enjoy the informative read that this edition provides, and where feasible, support the wonderful work that these two initiatives are doing!

Lung Transplantation in South Africa

*Dr P G Williams MBBCh, FCP(SA), DTM&H, FCCP
Specialist Physician/Critical Care Specialist
Heart and Lung Transplant Unit
Milpark Hospital
Johannesburg*



Successful transplantation of the human lung has proved to be one of the more challenging arenas in the field of transplantation. This is largely due to the complexity and length of the operation, the fact that most of the huge surface area of the lung is separated from the environment by a mere layer of cells a few microns thick and the fact that the lung with its associated lymph nodes and specialised alveolar macrophage system is one of the body's largest immune organs capable of eliciting a brisk and robust immune response to antigen challenge. These factors make the transplanted lung particularly vulnerable to ischemic damage before transplant and infectious agents and immune damage post transplant.

The intensity of immunosuppression that needs to be maintained higher and longer further increasing the risks of infection and also lowering of immune surveillance leading to a high risk of neoplasia higher incidence of skin cancers to virally mediated pre-malignant lesions such as post transplant lymphoproliferative disorder to frank malignancy e.g. lymphoma.

Non the less the enthusiasm for lung transplantation has continued to grow exponentially and has been accompanied by associated improve outcomes

History of lung transplantation

The first successful human lung transplant was preformed by Hardy in 1963 - before the first human heart transplant was done. Technical issues and poor immunosuppression tempered the enthusiasm for human lung transplants until after the introduction of cyclosporine which heralded a new era of success from the late 1980's onward. Transplant numbers worldwide dramatically increased during the 1990's.

A few isolated cases were performed in South Africa with some success, but the numbers only really improved after 1999 with the formal establishment of the Milpark Thoracic Transplant Unit. There has been sustained enthusiasm despite grave donor shortages. Nevertheless this unit has transplanted just in excess of 80 patients in this period with results being submitted to the ISHLT Registry and appear to compare favourably with similar size matched units in the rest of the world.

Indications for Lung Transplantation

The very important decision as to who to list actively and the timing of active listing is a complex decision made by each local transplant unit considering local supply and demand as well as with guidance from the ISHLT Guidelines as to suitability.

It is very important to realise that **Referral for assessment** is quite different from actual **Listing for transplantation** and should really occur much earlier than is unfortunately often the case. It is far better to have a patient assessed too early and then followed up than as a last ditch attempt to help a desperately ill patient who cannot benefit from neither the second opinion of the Transplant Unit nor from transplantation.



Lung transplantation should be considered as a potential form of therapy for any patient with end stage lung disease that is not related to malignancy.

Eligibility for Transplantation

Lung Transplantation should be considered as a potential form of therapy for any patient with end stage lung disease that is not related to malignancy with the proviso that the patient is otherwise well and not likely to demise from an unrelated medical illness in the ensuing period and is expected to survive at least 5 years post transplantation.

In order to see a realistic survival benefit from lung transplantation the lung disease should be severe enough to make survival without a transplant beyond 2 years unlikely. This determination should be made by the transplant unit and thus patients should be referred for initial assessment long before this point is reached.

This is obviously difficult to predict for many slowly progressive diseases such as COPD but is much easier to predict in the more rapidly progressive diseases such as the more aggressive

interstitial lung diseases such as idiopathic pulmonary fibrosis (IPF). Predictive Survival Scores may have a limited role in cystic fibrosis.

As our local recipient pool is small and the donor pool even more of a challenge we do not make use of any form of lung allocation score which has ensured the more equitable distribution of lungs to those recipients expected to die sooner and benefit the most from a lung in the USA.

We thus rely on the physician judgement of the transplant panel to fairly allocate organs using the broad lessons learnt from abroad and informed by the Lung Allocation Score principles.

Diseases of the Lung that can be treated with Transplantation

Potentially any non-malignant, progressive disorder of the lung that results in end stage.

Respiratory failure may be treated with transplantation. Those best suited are those disease processes that follow a predictable decline and include the following:

- 1. Interstitial lung diseases** comprise a range of rare disorders of the lung tissue itself. These occasionally respond well to medical therapy such as corticosteroids but more often do not. Idiopathic pulmonary fibrosis (IPF) is usually relentlessly progressive and most patients demise within 3 years of diagnosis. These patients should thus ideally be referred for assessment for potential transplantation at the time of diagnosis in order to allow the transplant unit adequate time to optimise the patient and not miss the window of opportunity. These patients are frequently well suited to a single lung transplantation.
- 2. Cystic fibrosis.** These patients usually have a very long history of mainly lower respiratory infections leading to lung tissue destruction and colonisation with bacterial organisms such as *pseudomonas* and *Staphylococcus aureus* which further damage the lungs. The prognosis is continuing to improve due to medical advances directed against the defective chloride membrane transporter protein that causes abnormal mucus secretion as well as better overall treatment for the condition. Despite this the course may still be slowly progressive and there is then a fairly narrow window of opportunity to offer these patients lung transplantation before the medical condition of the patient is too far advanced to withstand transplantation. Once again this is a difficult judgment call made by the
- 3. COPD and other forms of obstructive airways disease.** The clinical course of most patients with COPD is more difficult to predict as many patients may live a fairly long length of time in acceptable health (i.e. in excess of 2 years transplant free). The risk benefit ratio is thus more difficult to gauge and many patients have reached a point of unacceptable frailty due to associated medical co-morbidities. A younger subpopulation of patients with advanced disease such as occurs with alpha-1 anti-trypsin deficiency or bronchiolitis obliterans may be more ideally suited to transplantation and the short and long-term results in our unit with these conditions is good
- 4. Pulmonary artery hypertension.** Patients with idiopathic pulmonary hypertension and related subgroups of patients such as in connective tissue disease associated pulmonary hypertension (PH) may also progress to the point where lung transplantation offers the best long term outcome. The experience abroad has however suggested that many of these patients respond favourably to the many new PH specific therapies now becoming available. Although most of these drugs are not yet registered in South Africa it would seem medically inappropriate to offer transplantation before a trial of these therapies in combination and I believe all means possible to access these drugs must precede the drastic option of transplantation.
- 5. Congenital heart associated pulmonary hypertension.** Patients may present with severe PHT with or without cardiac shunt or Eisenmenger's Syndrome and may even occur months to years after successful repair of congenital defect. It is very difficult to predict the clinical course in these patients and they often do very well medium to long term, especially in the presence of a shunt. Timing is thus a challenge and combination medical therapy should be the first option. Should this fail these patients may be suitable for bilateral lung transplant or in very rare situations may need heart-lung transplantation although this is very infrequently needed.



Referral of a patient for assessment for possible transplant listing implies referral to a multi-disciplinary unit responsible for review.

- 6. Miscellaneous conditions.** Other rarer lung conditions may progress to end stage lung disease and may be considered for lung transplantation. Sarcoidosis, pulmonary histiocytosis of the Langerhans Cell-type, and lymphangioleiomyomatosis (LAM) are rare disorders we have encountered and successfully transplanted.

The Multi-Disciplinary Transplant Team

Referral of a patient for assessment for possible transplant listing implies referral to a multi-disciplinary unit responsible for review of and ultimately care for the patient. The initial contact is usually a pulmonologist who then activates the review process should initial assessment be even potentially positive. Every referral is regarded as having at least potential for listing for transplantation. The role of the transplant unit is not to merely screen patients according to a check list but to actively intervene in all areas of deficiency and “convert” as many referrals as possible into ideally suitable transplant listed candidates.

The multi-disciplinary team comprises all medical and paramedical staff involved with transplantation. These usually means pulmonologist, cardiothoracic surgeon and anaesthetist as well cardiology and intensive care. The transplant recipient co-ordinators are the vital link that ensures swift communication between all and also arrange logistical issues as well as ensuring strict record collection and liaison with the funders. Also pivotal to the success of the team is input for transplant psychologist

who also often acts as councillor and social worker to recipients, their families and also valued support to the team members themselves who also need de-briefing and assistance at times.

The physiotherapist and biokineticist also evaluate and actively work on maintaining and improving functionality at optimum fitness level possible pre-op and work to further rehabilitate post-operatively.

Nutritional status is a key area of concern and much effort is spent optimising goal weight and good nutrition pre and post surgery.

All the above team members meet on a formal basis once a month to discuss the listing status of all proposed recipients. This meeting is unfortunately frequently misunderstood by our patients who are often very anxious to be given a positive answer regarding their listing status. The emphasis of this meeting is rather to decide which patients are at an appropriate stage in their disease process to be actively listed which formalises the process, but also most importantly to discuss what further needs to be done by the team to ensure appropriate listing of those not yet on the active list. Thus the emphasis is on treating as well as listing of patients for whom therapy and follow-up are ongoing till transplantation.

Availability and outcomes in South Africa

Milpark Hospital is unfortunately the only large multi-disciplinary Lung Transplant Unit in South Africa with a smaller yet successful programme in Kwa-Zulu Natal as part of a cardiothoracic transplant unit. Unfortunately there is no formal transplant programme available to Non-medical aid and state patients; a situation that has arisen despite efforts to make our services available to all. None of the current team at Milpark are comfortable with this inequitable situation and we remain willing to provide care to all. It remains for the medical politicians to sort out the details.

Outcomes

84 patients have received lung transplants since the unit's inception in 2000. Broadly speaking the results appear in line with those from similar sized units elsewhere in the developed world, and our statistics are in turn reported to the International Society for Heart and lung transplantation database.

We report a 67% 1 year survival, 65% 2 year survival and a 44% 5 year survival. Given our relatively low numbers these along with a 31% 10 year survival are in our opinion clear evidence of a positive signal to continue and to expand this program to all South Africans.

The role of the transplant co-ordinator: challenging but rewarding

Fiona McCurdie
Transplant Co-ordinator
Groote Schuur Hospital
Cape Town



“As a co-ordinator I can be everything. I get to practice the different sides of nursing – clinical, educational, research. There is an opportunity to be an Intensive Care Unit, Emergency Room and Operating Room nurse, all at the same time. Even more, I get to do what I love to do – writing and teaching. Simply put, being a transplant co-ordinator is having a little of everything. I could not do any better than that.”

*Kristine Chang Deyto, Registered Nurse, Transplant Co-ordinator.
Manila, Philippines 2009*

Organ Donation and Transplantation involves close networking of medical, nursing, paramedical and other personnel with the transplant co-ordinators at the centre of this network.

Transplant co-ordinators are employed either in a donor (procurement) or a recipient role and the systems that co-ordinators work in vary from country to country. Some countries have independent Organ Procurement Organisations (OPO's) which provide organs for a large number of transplant centres in a region (eg USA) while in other countries, donor (procurement) co-ordinators are employed in each and every hospital in the country and organs are allocated through a central office (eg Spain). Recipient co-ordinators are generally attached to each transplant centre – with a co-ordinator dealing only with recipients of a specific organ.

In South Africa there is a network of about 35 transplant co-ordinators who work together ensuring that precious organs from deceased donors are utilised optimally, live donor transplants are carried out when possible and important information is shared. The Public and Private Sectors both employ co-ordinators who are attached to specific transplant centres around the country with the majority of co-ordinators in the private sector. Within South Africa, the precise job descriptions of the donor and recipient co-ordinators vary depending on the needs of their specific transplant team and centre.

Donor (procurement) co-ordinators

- Management of potential donors in ICU's and Emergency Units
- Counselling of families and requesting consent for organ donation
- Comprehensive clinical assessment of donors once consent has been given – blood tests, radiology, bedside monitoring
- Referral of organs to relevant transplant teams while maintaining donor stability

- Arranging theatre for organ procurement as well as distribution of organs safely to colleagues (Emergency flights may need to be arranged)
- Administrative responsibilities ensuring that all donor and transplant records are accurately maintained, all relevant legal requirements are met and transplant centre policies adhered to.
- Follow up with donor families

Recipient Co-ordinators

- Part of the team that assesses the suitability of a patient in end stage organ failure for the transplant programme
- Supports and educates the patients and their families from the time they are accepted as transplant candidates. Ongoing psychosocial and clinical support while the patient is on the waiting list. (Also deals with Medical Aid issues in private sector)
- In some transplant centres the recipient co-ordinator is involved in calling the patient in when an organ becomes available and assists in getting the patient prepared for theatre
- Long term psychological and clinical support after discharge from hospital
- Administrative responsibilities ensuring that all patient records are accurately maintained, all relevant legal requirements are met and transplant centre policies adhered to.

Most co-ordinators have a nursing background – donor co-ordinators usually have ICU or Emergency Unit training or experience while recipient co-ordinators may have a dialysis background.

Recipient and donor co-ordinators work on a rotational 24 hour call basis with their respective colleagues and need to be available for emergency donor and transplant calls as well as keep up to date with their day to day administrative, research and education responsibilities.

The number of both living donor kidney and liver transplants being performed has increased dramatically in recent years, internationally and in South Africa. This has increased the work load of the co-ordinators as the counselling and testing of the potential donors is carried out by them (the donor co-ordinators in some transplant centres and recipient co-ordinators in others). Ensuring the physical and mental wellbeing of the donors is of paramount importance and the co-ordinators are primarily responsible for this. Co-ordinators from different teams work closely together to arrange testing and counselling should the

potential donor and recipient be in different cities. Liaising with the Ministerial Advisory Committee and the Department of Health when arranging an unrelated living donor transplant is also the responsibility of the co-ordinator.

Co-ordinators have to be prepared, willing and able, at all times, to deal with the emotional and physical needs of patients (and their families) who are waiting for a transplant if recipient co-ordinators, or to deal with the grief of the family of a deceased donor if procurement co-ordinators. This can be tiring, stressful and emotionally draining and the support of the rest of the transplant team as well as other co-ordinators is vital.

Two ongoing challenges face transplant co-ordinators and the rest of the transplant community:

1. Continually having to encourage colleagues in ICUs and Emergency units to refer ALL brain dead patients (ie potential donors) to the transplant team
2. The need to increase the public's awareness of the

importance of making a decision about becoming an organ donor and then to communicate this decision to their family.

To address these challenges the co-ordinators work closely with the Organ Donor Foundation on donor awareness projects, arrange press coverage of transplants and give regular talks and lectures to colleagues and the public.

To summarise the role of the transplant co-ordinator, I would like to quote our colleague in the Philippines again:

"Nobody ever said that being a co-ordinator would be easy... Difficult? Yes. Challenging? Definitely. Rewarding? Absolutely"

On a personal note, I would like to conclude by saying that even though I have been a procurement co-ordinator for 25 years, the satisfaction and excitement of having a donor referral result in successful transplants, as well as my gratitude to the families who donate their loved ones, organs have not waned at all.

Patient's Journey - Cystic Fibrosis to lung transplantation



I was born with a genetic condition called cystic fibrosis ('CF'). I was diagnosed in 1989, at the age of three, when the gene for cystic fibrosis had only just been discovered. At the time of my diagnosis, my life expectancy was estimated to be around seventeen years.

My parents were defiant in ignoring my prognosis, and chose to raise me as if I would live until ninety. As a result of this, although my health issues were a big part of my life, I did not allow them to define me. I still accomplished many things, in spite of the challenges I faced being chronically ill.

My parents did their best to raise me as normally as possible. I have two healthy older brothers, and in order to prevent sibling jealousy, my parents avoided giving me any special treatment, except when absolutely necessary. I had to nebulise and do chest physio twice a day, take enzymes every time I ate, and also had to consume lots of nutritional supplements. I went to ballet, I swam competitively and I attended school. Although I would get chest infections, for the most part these were treated with oral antibiotics when I was younger, and so my health did not have a major impact on my life.

From about the age of twelve, my health started to deteriorate. I began requiring regular intravenous ('IV') antibiotic treatments, for two weeks at a time. In a good year, I could get away with IVs only once a year, but the older and unhealthier I became, the time period between IV treatments decreased. I avoided

hospital admission whenever I could, choosing to do my IV treatments at home so that I could continue going to school. I tried to remain very active and did lots of dancing to maintain my fitness. I would even go to my dancing classes with a drip in my arm, because I refused to let my health hold me back.

When I ran out of options

I matriculated from high school and went on to study at university, eventually qualifying as a chartered accountant, and then choosing to specialise in tax. Unfortunately, not long after this, my health began to deteriorate rapidly and I ran out of viable treatment options. A bi-lateral lung transplant was my only reasonable chance of long-term survival.

Waiting for a transplant is a particularly difficult time. It is incredibly challenging emotionally and there are physical and health challenges as well. Although being listed for a lung transplant comes with much hope for the future, at the same time, you have to deal with the fact that your health has deteriorated to the point where you need a transplant in the first place. This was possibly one of my biggest challenges, as I had an unhealthy quantity of denial keeping me going.

I was very underweight and infected with various highly antibiotic-resistant bacteria. I also had fungal infections – essentially a 'zoo of creatures' was living in my lungs. It was going to be a long road before I was even to be considered a reasonable candidate for transplant.

Good news - we have a donor!

When the coordinator told me that they had lungs for me, my stomach just dropped. I was in total shock. I started crying, but they were not necessarily tears of joy. I was absolutely terrified and didn't know what to do. In fact, I even asked the transplant co-ordinator if I could please have a little time to think about it. I called my CF specialist to ask her for some guidance. Although she couldn't tell me what to do, she explained to me that this was really my 'window of opportunity'. I was in relatively good shape at the time (although my lung function was 26%) but this is what gave me my best shot at survival. If I waited for another opportunity, I might be too sick by then and then I would be less likely to survive the transplant. I knew that if I didn't take my chance now, it was highly probable that another chance would not come my way again.

My surgery was particularly difficult as I have major venous problems. There were complications with my veins during surgery and at one point, my inferior vena cava (IVC) tore, and I bled out. I lost 6 litres of blood in 15 minutes, which is approximately 1.5 times my entire blood volume. They kept transfusing me with blood to replace what I had lost, and also kept pumping me with platelets, to get my IVC to clot. There was a risk of brain damage from all the blood loss, but the incredible anaesthetist induced hypothermia to try and prevent this from happening.

Recovery was extremely tough, I was still ventilated and ended up having a tracheotomy so that they could keep me vented more comfortably. I was in ICU for twenty-five days, involving around the clock care, with two nurses by my side 24/7. I would receive physio twice a day and had to try and regain my strength because after even just two weeks of inactivity my muscles had completely atrophied. Getting through that time in recovery was one of the hardest things I have ever had to do, physically and psychologically. I think if I had given up at any point mentally, it would have taken very little for my body to give up too.

My new life

Life has been completely different post transplant. I still have cystic fibrosis, and all the other complications that go with that, but the predominant issue, which was my lungs, is no longer a problem.

My new lungs have the DNA of my donor and so they do not carry the CF gene. As a result, they function like any normal person's lungs would function. Not only are they healthy and infection and damage free, they also don't produce the excess mucus that CF patients battle with. This means no more consistent lung infections, no more IV antibiotics every three months, no more chest physio or nebulising and no more supplementary oxygen.

I am now able to do everything I wanted to do before, but was unable to do, due to my health. Already in the short time since my surgery, I have gone to live music concerts, 30th birthday parties, a friend's wedding in Cape Town, I have gone out with friends, I have got back into the dating world again, I have moved out of my parents' home into a flat with one of my good friends. I also went back to Flamenco dancing in January, which I hadn't been able to do for years. I see a biokineticist twice a week for pulmonary rehabilitation and can easily walk a distance of 5km. I climb the stairs now – just because I can.

Although life has been amazing this side of transplant, it is not without its complications. As a transplant patient I will need to be on immunosuppressants for the rest of my life in order to prevent the rejection of my lungs. I have to take these strictly every twelve hours, and cannot skip even one dose. There are also other pills that I need to take, such as prophylactic antibiotics, pills for the side effects of the drugs, as well as my other CF related medication.

Be cautious but not scared of living

The biggest complication arising out of the immunosuppressants is that because your immune system is suppressed, you are highly susceptible to infections. You do still have part of your immune system but transplant patients still need to be extremely precautious. I avoid sick people at all costs, and I frequently wash and disinfect my hands. Thus there is a fine balance between managing infection and rejection.

Advice for newly transplanted patients

I think my number one piece of advice to newly transplanted patients would be to listen to your doctor! The doctors definitely know best, and they will give you all the advice you need. Stay away from Google!

On a personal level, I think I would encourage recipients not to be scared to live their new lives. I initially struggled, because being sick had, in strange way, become a constant companion to me. I barely recognised my life without it and I was constantly anxious that at any point in time, my good health could all be taken away from me again. My anxiety is a constant battle, but I am being treated for it and I am slowly starting to trust my new good health. My life has barely been recognisable since then and I have never been this healthy in all my life. I am so happy and I am living every moment to the full. I cannot begin to express how grateful I am for my future, which has been gifted to me by my donor.

Raising awareness

Even before my transplant, and more so now that I have had a successful one, I have been extremely passionate about organ donation. Unfortunately, South Africa has one of the lowest donor registration rates in the world, and as a result, there is a dire need for organ donors. There are still thousands of other people waiting for organs (some of who I even know personally) and I feel a certain duty to try and address the problem, doing what I can to help raise awareness for organ donation in South Africa. I have been doing this on a volunteer basis with the ODF, and have even started an NPO called Love Life, Gift Life with a group of three other young women (all of whom have had successful lung transplants) in order to try and further the organ donor awareness initiative in the country.

Thank you

None of this would have been possible without the incredible heroism of my donor and my donor's family. They made the brave and selfless choice to donate their loved one's organs and I will be eternally grateful to them. I could never really put into words how thankful I am. Not a day goes by when I do not think of my donor and my donor's family.

**Patient's name withheld*

New unity between transplant stakeholders secures positive future in organ donor awareness

Samantha Nicholls
Executive Director

The Organ Donor Foundation, Cape Town



Successful relationship building and negotiations between the Organ Donor Foundation (ODF) and Tissue Banks have set in motion an ongoing collaboration guaranteed to escalate tissue and organ donor awareness in South Africa.

2014 and 2015 have been the most successful years for organ donor registrations and organisational growth to date. The ODF are proud to have employed the services of specialists addressing key issues related to organ donation. These including awareness drives specifically targeted around potential organ referral hospitals. Simultaneously, the ODF has strengthened its relationships with parallel organisations, specifically with the South African Transplantation Society, and are currently mapping out a working relationship and financial support for SATS towards establishing and improving medical education programmes.

The positive momentum the ODF has gained has resulted in stakeholders from the general public and transplantation joining forces with the ODF to build on its successful formula for organ donor awareness. Such an example is the relationship

developed with stakeholders in tissue transplantation who are generously investing record amounts into the ODF's awareness drives, not only demonstrating confidence but also buying into the vision of the ODF and its method of driving organ and tissue donor awareness.

In August, the ODF launched the Organ and Tissue Donor Awareness Month, a focused drive for tissue transplant awareness. In addition, the ODF has enhanced their registration process to indicate registration choices to include bone, skin, corneas and heart valves. Keeping this mind, the ODF's vision is to make the organ donor registry available to medical professionals to access the details of registered organ donors on a national level.

This synergy will escalate the ODF's awareness target to reach 1% of the population in a dramatically shorter period of time. The ODF are confident that more stakeholders in transplantation will support the Organ Donor Foundation in future, ensuring benefit not only to the ODF but to these stakeholders as well, and most importantly the patients receiving these life saving transplants.

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