



Transplant News

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Editorial

Professor Jerome Loveland
Editor

I believe that this first edition of Transplant News for 2017 really epitomises the focus of what this publication is about: that being the patient and their immediate support structure, as well as the general public. As ever the greatest challenge that the transplant community faces is the availability of solid organs, as well as other tissue (skin, bone and corneas are good examples!) used on a daily basis to save lives and treat progressive, otherwise non-curable diseases.

Dr Rose Richards, a long-standing transplant recipient, provides wonderful insights into life post-transplant, this with the benefit of 25 years of hindsight. She certainly has the insight to know exactly how precious a gift she received. An enormous amount of work is done on a daily basis to promote organ and tissue donation, this in an ongoing effort to increase rates of organ donation. This, in conjunction with the potential for legislative changes, has the ability to significantly increase donation rates.

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Thus, from a medical perspective Dr Errol Gottlich gives sage advice on compliance to treatment, this having an enormous impact, initially, in delaying or even preventing the need for transplant, and then obviously post transplant. Having received an organ, management priorities undergo a complete change, this from a dietary perspective, as well as the obvious medications. Strict adherence to all of these will undoubtedly prolong the transplanted organ's life span. Together, preventing the need for transplant, and prolonging the durability of the transplant, both have a massive impact in reducing the pressure on transplant waiting lists.

There is no doubt that collaboration yields significantly better results than isolated organisations working independently, and it is very gratifying to see that various of these entities, for example the South African Transplant Society, Organ Donor Foundation, South African Tissue Bank Association and Love Life: Gift Life are growing their collaborations with the endpoint of achieving a common goal.

The articles below provide wonderful insights and inspirational stories into how these organisations and individuals, work towards making transplantation a reality.

This newsletter is also available to
download on the following sites:
Organ Donor Foundation website:

www.odf.org.za
www.transplantsports.org.za
www.lovelifegiftlife.co.za
www.facebook.com/lovelifegiftlife/
www.openeyefoundation.co.za

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It's not easy being a patient with chronic kidney disease and it is especially difficult for children.

In the progression from mild to severe stages of kidney disease patients become exposed to the rigours of management and high expectations that are asked of them from their doctors.

Often in the milder stages there are only a few medications, such as for high blood pressure and high phosphate. Diet might include a low salt and low phosphate component but nothing too hectic. Sadly, as kidney disease advances, it starts affecting all organs in the body. If one tablet existed that managed all these effects then it would be an ideal world. However, the reality is that it is necessary to continually add specific medications for a whole range of treatment requirements. Dietary modification becomes increasingly necessary and often fluid restriction creeps in when reduced urine output occurs.

Dialysis then increases the exposure to drugs, dietary modification, fluid restriction, blood tests, X-rays, consultations with other specialists and lifestyle changes to a far greater level. For those fortunate enough to be transplanted, another whole change occurs, especially with respect to diet, fluid intake and range of medication. Where we have asked patients to restrict fluids we now ask them to take as much as wanted. The chalky tasting TUMS are happily thrown away in preference for a diet now free of most food type restrictions.

In the above journey, compliance to management becomes critical as prescribed treatment needs to be taken to achieve the best outcomes. Unfortunately compliance to treatment, understandably, is difficult for a whole range of reasons. (Table 1)

Table 1 - Barriers to compliance

- Number of drugs taken
- Tablets or capsules in young children
- Taste of medications
- Frequency of medication
- Medical aid co-payments
- Children falling asleep before night medication given
- Vomiting of medications
- Side effects
- Bland tasting modified diet
- Fluid intake restriction
- Limited parental responsibility

The consequences of poor compliance are severe and, in many cases, life threatening. In a diabetic child who does not get their insulin, the parent clearly understands that the child may go into coma and need admission to hospital. The consequence of poor compliance is often immediate and very visible. In kidney disease, this is often not the case except if fluid restriction is not managed. Patients who skip an occasional blood pressure pill or don't take their TUMS often don't feel any different and think they can "get away with it."

This behaviour unfortunately often creeps into the rigours required of more important medications, especially anti-rejection therapy after transplantation. This often occurs a few years after transplant when the patient has been well for a long time and feels that a few missed doses are not important. Tragically, the consequence is often irreversible rejection of the transplant organ, resumption of chronic dialysis and a limited opportunity to get a second transplant.

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What bigger a consequence of poor compliance is the loss of a precious transplanted organ and a reversal to a chronic organ failure state? At the Morningside Children's Kidney Treatment Centre, in partnership with the KidneyBeanz Trust, we apply a number of measures to maintain compliance. (Table 2, 3)

Conclusion

Compliance to treatment will ensure best clinical response associated with an improved quality of life, reduced complications, and fewer hospital admissions.

Knowing and understanding the *dire consequence* of poor compliance in chronic kidney is critically important. Parents and caregivers need to fully accept the responsibility of ensuring that children in their care need to be fully, and at all times, supervised and assisted in the difficult field of compliance to treatment (medication, follow up, diet, fluid intake, lifestyle).

Table 2 - Medication
<ul style="list-style-type: none"> • Explanation for treatment • Written clear instructions • Restrict number of medications • Restrict frequency of administration • Omit lunchtime medications if possible • Managing side effects • Suitable formulations • Discard old or unused medications

Table 3 - Taking of medication
<ol style="list-style-type: none"> 1. Absolute supervision by parents or care givers 2. Pill boxes 3. Electronic alarm reminders – watch, cellphone alarms and apps 4. Medicine diary 5. Star charts 6. Constant reminders and reinforcement

Child RJ *				
Medicine	Function	Morning 8am	Lunch 12am	Supper 8pm
Tacrolimus	Anti-rejection	2 capsules (2mg)		2 capsules (2mg)
Mycophenolate mofetil	Anti-rejection	500mg		500mg
Prednisone	Anti-rejection	7.5mg (1½ tablets)		
Disprin	Anti-clotting	1/8th tablet (37.5mg)		
Atenolol	Anti- hypertensive	50mg		
Cotrimoxazole (6 months)	Antibiotic			½ tablet (240mg)
Pantoprazole	Anti-acid			½ tablet (10mg)
Nystatin (6 weeks)	Anti-fungal	2ml		2ml
Valganciclovir suspension	Anti-viral			6.6ml (330mg)

* Some of those regimens may constitute off-label use and this remains at the discretion of the treating physician

Losing and finding gratitude: The first 25 years of a transplant journey

Dr Rose Richards
Transplant Recipient
Stellenbosch



Last year in October, I celebrated my 25th transversary. I had my kidney transplant in 1991, at the age of 22, after a lifetime of chronic kidney disease. My kidneys had been damaged by haemolytic uremic syndrome when I was eight months old. Although I hadn't needed dialysis until I was 20, my health was impaired and I became progressively more frail as I grew up. My illness had relegated me to the sidelines often and I spent the first 22 years of my life observing other people living life and for this reason, contemplation has always been very important to me. Because of this, I found it easy to feel grateful after transplant, because I could all too easily imagine what might have happened had I not received a kidney and I could appreciate how large my donor's gift to me had been. But that changed.

You see, over the last 15 years, I have got used to waking up in the morning with functioning kidneys and not being surprised by it. Friends tell me that that is what being healthy is. Nonetheless it troubles me. For the first ten years after transplant, every morning, I awoke immensely grateful. Every morning as I

opened my eyes, I would take a few minutes to think about how lucky I was to receive a kidney and how selfless my donor and his family had been. I would reflect on my second chance at life and on all the things I could do and experience. As I closed my eyes at night I would go to sleep with the same thought in my mind.

Some of the new things I loved were big things such as being able to travel, hold down a job or complete my Master's degree. Every birthday or achievement was a milestone. By 1991, when I had my transplant, I had come to accept, after many years of poor health, that I would be lucky to see my next birthday. I had got a chest cold that winter that had become a nasty bronchitis I couldn't seem to shake off and afterwards I was different. I was weaker and I knew in my bones that I wouldn't survive another winter. Fortunately, I got my transplant the following spring. So, instead of dreading winter in 1992, I was happy to see it. I found it fun and invigorating. (I had also gained weight and was much less anaemic, which helped.)

Other things I appreciated would be seen as small by some, but they were big for me. For instance, the first time I ate lettuce after transplant and could actually taste it. It was as if a festival of tiny green fireworks had gone off in my mouth. It was astonishing. Did other people experience this? To this day, I have a soft spot for lettuce; I associate it with being alive. Less pleasant was the sensation of hunger. I hadn't felt it in years and at first I thought my stomach was reacting to my new medications.

My new energy levels were astonishing and so was my physical strength. Having a successful transplant is like being reborn as superhuman. I swore I would never get used to it. But I did. My full-time job was demanding and I was involved in lot of activities outside of work. So, after a decade, I got caught up in the daily business of living and I forgot to be grateful. I got out of the habit of reflecting.

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Then some years later I applied for a mortgage. I got the mortgage, but I didn't get the health insurance that the bank wanted me to have – because of my medical condition. I was stunned. I was normal. My blood results said so. I could do anything and live a normal life. And I had for 16 years. But the insurance company didn't think I was normal. They even made me go for more blood tests without telling me why—a terrible thing to do to a transplant recipient.

Nothing I could do would make them change their minds that I was abnormal. That gave me pause for thought. So much so that I started writing about it. What I wrote started out as a letter. It grew into an article and then finally became a PhD. For the first time in years I had a chance to think deeply about what my transplant meant to me and what it was like living as a transplant recipient many years after the surgery.

What I found was that research about the stories of kidney disease is not as plentiful as you may expect. The voices of people with kidney disease and insights into how we see ourselves and understand our lives and post-transplant need to be heard more. This made me more determined to tell my own story.

So I undertook an autoethnographic study of my own experience of life with kidney disease, with a particular focus on life after transplant. Many transplant stories seem to stop a year or so after transplant, as if a transplant was an operation and not also how one adjusts to living with a transplanted organ or how one returns to mainstream life. For someone like me who was never previously part of mainstream life, joining it isn't simple. These were some of the questions I considered: Can my story change? How do I describe myself: The well, the ill, the impaired, the disabled, the afflicted? Do I describe myself living in no man's

land? In my narrative, do I oscillate between being well and ill, or do I occupy another territory entirely? And if I do, what is it?

At the time I started writing, the idea of liminality was big in research about the experience of chronic illness. However, this is an idea borrowed from the experience of acute illness. From experience, I don't find transferring the concept of liminality to chronic illness very helpful because liminality is supposed to be a shortish period of "in-between" time, where one withdraws from society to undergo an identity change—and then returns. In health narratives, this means that you start out well, fall ill, undergo treatment and then return to health. I was never healthy until after transplant and my health requires that I manage an incurable condition. My experience has been less about overcoming illness and moving on than about coming to terms with an identity that is not damaged so much as different.

In conducting my research, I hoped to find an alternate way of telling the story of kidney disease and life after transplant. I found so much more. One of the things I found was my own recognition of what my illness journey had been and what it is now. Possibly this was because I now had more life experience and the point of reference of good health. Maybe it was because I finally was strong enough to think about it deeply and the crises were now far enough away not to be threatening anymore. Maybe it was simply because I gave myself the luxury of really thinking about it properly. Doing this took a long time, partly because I found the idea to be more complex than I had realised, partly because identities are complex and partly because I had to overcome some emotional hurdles to do it.

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I found my experience of doctoral research cathartic. After I had submitted my dissertation and had been examined, I went on a trip to Greece for two weeks and after that to England. When I returned my gratitude returned as well. I haven't yet returned to my first decade's morning reflections on my good fortune, but every morning I awake I feel really glad to be alive. Long ago, I used to fall asleep at night with my hand over my new kidney to protect it. I find myself doing that again now. This year, for the first time in many years, my transversary seemed like a real milestone.

I don't think our fast, technology-driven lives are really suited to reflection, but, without reflection, gratitude and understanding are impossible. For me the chance to honour my transplant, my donor and my own struggle for survival took the form of doing doctoral research. For another it might take the form of prayer, meditation or art. But spending time being mindful of our journeys is important. Our journeys change us and our understanding of them helps us to change them too.

Increasing organ donation: Is presumed consent the answer?

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Solid organ transplantation saves life. Furthermore, it has been repeatedly shown that to transplant a patient with end-stage organ failure is more cost effective for health services, than to maintain and support their organ failure until their demise. However, the biggest limitation globally is the lack of organs to transplant. There are two ways to donate, either as a living donor or after death (cadaveric donation).

The majority of organs are from people who have suffered brain death. In this situation, the family is approached for consent to use the organs of the demised loved one. This is the opt-in system. Needless to say, it is the exception that consent is given.

What if all people are donors unless they specify that they are not? This is the opt-out or presumed consent system.

The question then arose: But what if all people are donors unless they specify that they are not? This is the opt-out or presumed consent system. France is the latest country to adopt this system with effect from January 2017. To date 150 000 people have registered as non-donors. When Wales adopted the system in 2016, the number of transplants rose by one third. A study comparing countries with the opt-in versus the opt-out system were compared and showed that the opt-out system increased organ donation by about 20%. Spain is the most successful organ donor country with a donation rate of 36 per million population. (The donor rate for Gauteng alone is less than 1 per million). This was achieved by implementing a comprehensive donor awareness program that included the opt-out (or automatic organ donation) system in the early 1990's. Every hospital in Spain has a transplant co-ordinator who educates public and professional and identifies donors early. Importantly to note, Spain exercise a "soft opt-out" system i.e. family consent is still sought prior to donation. Should the family refuse, the donation does not take place. And in fact, it is believed that the Spanish success is due to the additional support, resources and education that have been put into organ donation and in fact very little to do with the opt-out system.

Implementation of an opt-out system does not always have the expected effect. The Chilean experience, showed a dramatic decline in donation when the opt-out system was implemented. The Chileans were not comfortable with the

notion that the state owned their organs and that they had no say in what happened to their bodies after death. This negative response has been experienced in a number of countries.

It would be a safe to assume that with the fresh history in South Africa of disempowerment that the implementation of an opt-out system may have a negative effect on organ donation.

There are about 6000 people awaiting kidney transplants alone in South Africa. This has got to be an underestimate as awareness of transplantation is still very low and there must be a myriad of eligible people with organ failure who would benefit from a transplant and yet are not on the lists. Yet the most common scenario is that the question arises when there is a family loss and the benefits of transplant are hard to digest amid the deep emotions of the loss.

As South Africans, it must be queried, is transplantation really supported in our society, is the information readily available? Is the public optimally educated? When next of kin deny donation are they really giving informed denial. Are the medical professionals optimally educated? Are there enough co-ordinators? Is there a co-ordinator team that is valued, cohesive and supported? Is the state invested in providing this life saving service? Is transplantation fairly accessible to all?

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It is believed that transplant speaks to the philosophy of Ubuntu. However, the lack of awareness of the possible can be addressed to a large extent by appropriate education and support of the body that gives this education – the coordinators. The development of an independent non-profit organ-procuring agency must surely be part of the answer. Unless these measures are optimised, the risk of the fall out by imposing a system that may be perceived as disempowering is too great.

More success at the Proud 2B an Organ & Tissue Donor walks around the country!

Gillian Walker
National Liaison Officer
The Organ Donor Foundation, Cape Town



Year on year the Organ Donor Foundation has hit the end of the year on a high, and 2016 was no different. The second half of 2016 was busy and exciting with various activities, amongst which were our ever popular "Proud 2B an Organ & Tissue Donor" walks and the Telkom 947 Cycle Challenge.

Durban jumps on board

The Organ Donor Foundation had yet another successful season of walks around the country. The season started off with the Durban walk during Organ Donor Month, the first time a walk of this size has been held in Durban, and it proved to be a wonderful day! The event was organised by Janet Legemaate who put in a huge amount of effort and many, many long hours; getting sponsors on board, organising lucky draw prizes, kids entertainment and a fun and safe walk, not to mention the free T-shirts and refreshments along the way. In addition to the large number of participants, there were also a huge number of organ donor registrations on the day!

A massive thank you, also, to the various sponsors who made the event possible. Without Kloosterboer, Megazone Hit Radio, Eire Construction and the many other sponsors the event would not have happened.

Next up, Johannesburg...

The Johannesburg Proud 2B an Organ & Tissue Donor Walk, held at the Joburg Zoo in October, hosted almost 1000 people, who all turned up bright and early despite the heavy rains through the night. This year all participants were again given a Proud 2B an Organ & Tissue Donor T-shirt as well as a bottle of water, which was generously sponsored by Aquella. The water was very well received as what was a chilly morning very quickly turned out to be a very hot day!



The walk took participants on a beautiful route around the Zoo and ended up back at the Centenary Lawn where there was a fantastic atmosphere with music, refreshments as well as the opportunity to sign up as an organ donor. There was also a lucky draw with some amazing prizes.

The grand finale in Cape Town

Cape Town hosted the third and final walk of 2016. The Cape Town Proud 2B an Organ & Tissue Donor Walk was held on 5th November at Mouille Point. Participants, who were also given a T-shirt and sponsored water brought an amazing vibe to the event and just like the Durban and Johannesburg walks there were a number of patients, family and friends of those waiting for transplants as well as those who have received transplants.

We are sincerely grateful to Henk van der Steenhoven who arranged sponsorship for the Cape Town and Joburg Walks. The generous contributions of our sponsors helped to make these events an amazing success.

Volunteers, our unsung heroes

Every year our volunteers and our own family and friends come out on the day to make the events happen. A massive thank-you to all of you in Durban, Johannesburg and Cape Town; we are sincerely grateful! Time and time again you are there for us and we wouldn't be able to do it without you.



Our Cyclists hit the road again

The ODF Cycle Team now has another 947 Cycle Challenge under their belt as they joined thousands of other cyclists at the race in November 2016 in Johannesburg.

The 2016 team was bigger than ever with 186 cyclists competing across the three events being the Kiddies Ride on 12th November, the Mountain Bike Challenge on 13th November and the Cycle Challenge on 20th November. This year the team was sponsored by Profmed who were wonderful in providing the funds for the cycle jerseys, amazing goodie bags, an Expo stand, refreshments along the ride and our stand at the charity

village. Thank you Profmed for your generosity and your time in helping us to create an awesome team with an awesome vibe!

As part of preparation for the race, but mostly as a bit of fun, the team got together at the Cradle of Humankind on 12th November for a training ride. There were 2 distance options leaving from Riverstone Lodge to cater for the more casual riders as well as the more eager trainers! The pelotons were seconded by some of our ever-enthusiastic volunteers who followed the cyclists with Coke, water and snacks. Our volunteers also had a gazebo set up at the finish for cyclists' supporters to sign up as organ donors.

The Expo stand was also a great success and provided invaluable exposure for organ & tissue donor awareness. The Telkom 947 Cycle Challenge Expo was held at the Ticketpro Dome over 3 days from 17th November until 19th November. Having a stand at the Expo was terrific as in addition to our cyclists being able to collect their goodie bags with ease other cyclists were given the

chance to sign up as donors. Our volunteers signed up over 200 new organ & tissue donors and provided information on organ donation to many other members of the public.

Not only were our cyclists amazing for getting out onto the road and completing 94.7 kilometres but they were also able to use the event as a platform to raise funds for the Organ Donor Foundation and we are proud to say that over R30,000 was raised. These funds will go towards future sporting events, which are a wonderful opportunity for creating awareness. Thank you so much to all of you.

Thank you to our fantastic cyclists and to Profmed!

Bring on 2017...

We are working hard to grow these events and we're looking forward to an even more exciting and successful 2017. Join us for the ride!

Reportback: Proud 2b an Organ Donor Mega Walk

Janet Legemaate
Organ Donor Foundation volunteer
KwaZulu-Natal



Photo credit: Manfred Poeper

At the beginning of 2016 a press session was held to bring focus on how poor organ donor registrations and referrals in KZN are. Even though it has the second highest population in the provinces the number of transplants is the lowest in South Africa. There had not been an Organ Donor Walk in Durban for a couple of years and it was decided that this should be held in August – which is Organ Donor Awareness month.

Therefore, on Sunday 14 August 2016 the Durban Promenade hosted the Organ Donor Foundation "Proud 2b an Organ

Donor Mega Walk". The event had a twofold focus – the walk itself aimed at raising awareness about organ donation but it was also intended to create an atmosphere where the topic of donation would be discussed. Awareness stands from the ODF, SANBS, the Sunflowers Fund, the Centre for Tissue Engineering, KZN Eye Bank and other related stands were present. After the approximately 1500 participants and volunteers enjoyed the walk, they were encouraged to visit the many stands and by doing so qualified to enter the competition for wonderful donated prizes. All who participated agreed it was a successful day.



Photo credit: Dianne Fick



Tell your family of your wishes to be an organ and tissue donor

Siobhan Scallan
Love Life; Gift Life Co-founder
Transplant Recipient



Love Life; Gift Life was established in April 2016 by four lung transplant recipients and is a registered Non Profit Organisation and Public Benefit Organisation. The founding members, having all personally gone through the transplant process, and having had to endure the seemingly endless wait, acknowledge just how lucky they have been to receive their life-saving transplants. As such, Love Life; Gift Life was launched in an effort to give back and to address the critical shortage of organ and tissue donors in South Africa by promoting awareness and education of the organ donor process.

The organisation aims to increase awareness of organ and tissue donation in South Africa through a variety of print, broadcast and internet media campaigns and events. Love Life; Gift Life has already in a few short months managed to run numerous successful viral internet campaigns, which have attracted both local and international media interest. Love Life; Gift Life's key message to the public is to encourage individuals to talk to their families about organ and tissue donation and to communicate their wishes to their next-of-kin. The majority of the public are not aware that their family members are the ones who ultimately have the final say and organs cannot be donated without the consent of their family.

In order to address this issue, Love Life; Gift Life have set up a facility on their website under the "How Can You Help?" tab, which enables individuals to send an e-mail to both family and friends to inform them of their wishes to be an organ and tissue donor. This unique feature only takes mere seconds to complete and allows people to communicate their wishes to as many friends and family members as they may choose.

Another way in which Love Life; Gift Life is trying to tackle the shortage of organ and tissue donors in South Africa is by putting a face to organ donation through the sharing of stories of real people. This includes the stories of transplant recipients and those waiting for a transplant, the stories of donors and their families, as well as the stories of the incredible team of medical practitioners who are making transplant possible in this country.

By attaching faces to the stories, Love Life; Gift Life hopes to add a personal element to transplant, which will resonate with the public. In particular, the hope is to connect with potential donors and their families, by giving them a chance to see how important and life-changing saying "Yes" to organ donation can be.

Love Life; Gift Life have recently started an online support group through Facebook which is exclusively for pre- and post- transplant patients. The primary purpose of the group

is to provide a platform for the patients of transplant to share any concerns, questions and experiences they may have, in a confidential and supportive environment.

Importantly, the group facilitates camaraderie amongst the members, boosting morale, and creating a support system for all those patients affected by transplant.

Love Life; Gift Life

Website: www.lovelifegiftlife.co.za

Facebook group: www.facebook.com/groups/LLGLTransplantSupportGroup/

Email: shaylene@lovelifegiftlife.co.za or alice@lovelifegiftlife.co.za



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