

Transplant news

Official newsletter of the
South African Transplant Society

Vol 12 No 4 Issue 45 - November 2013

Editorial

Professor Jerome Loveland
Editor

This edition of Transplant News fills me with hope, and at the same time I despair!!!

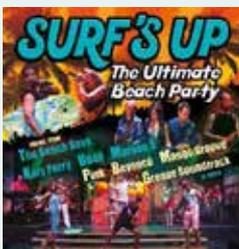
Last week Sky News ran a story about utilising a 2-week old baby's kidneys to transplant an adult recipient. It is a very interesting article, not only focusing on the technical challenges around the procedure but far more importantly on organ availability and optimising donor availability and utilisation. <http://news.sky.com/story/1153798/baby-kidney-donor-is-britains-youngest>

A stark difference between the United Kingdom and South Africa is that almost 20 million people are registered in the UK as potential organ donors! This would equate to almost half of South Africa's population, and should we attain such numbers, would revolutionise transplantation in South Africa!

What gives me hope for Transplantation in South Africa is the technical expertise that we have available: there is no doubt that we can confidently say that we are the equals of ANY international transplant unit when it comes to the ability of our

healthcare providers. Whether from a "medical" perspective, or if you consider the technical skill necessary to perform the procedure described by Sky News, we can confidently do the same, as clearly born out by Craig Joseph's article in August's edition and by Jacques Boshoff's transplant and subsequent success at the World Transplant Games as detailed on page 8. Amongst numerous aspects of transplantation in South Africa, these stories clearly define our success, something to be immensely proud of!

A "tendency to despair" sets in on reading the article on page 7 in this edition by Anna Sparaco. This pens a situation depicting the majority of transplantation occurring in the "Private" Sector, with significantly less happening in the "State" Sector. To a large extent this statement is true and unfortunately is a phenomenon not isolated to transplantation, occurring in many other facets of medicine too. This is a travesty and it really is incumbent on us to see that this situation is reversed. Whilst numerous stakeholders are responsible, one feels that it really is the Department of Health's responsibility (Government) to see that their patients receive an equal opportunity to access transplantation as a right.



Transplant News Diary: Cape Kidney Association's Barnyard Theatre Celebration

In celebration of their 35th Anniversary, the Cape Kidney Association will be hosting a fundraising afternoon on Sunday 24th November at the Barnyard Theatre, Willowbridge, Tygervalley at 2pm. Tickets are R135 p.p. and tables of 8/10/12/14 or individuals can be booked. It promises to be a wonderful afternoon to enjoy with colleagues, families and friends. Please call Molly at: 021 761 1326 for more information.

Production Editors:

Ann Lake Publications:
Ann Lake/Helen Gonçalves
Design:
Jane Gouveia
Sponsor:
Astellas Pharma
Enquiries:
Ann Lake Publications
Tel: (011) 802 8847
Fax: 086 671 9397
Email: lakeann@mweb.co.za;
www.annlakepublications.co.za



Editorial Board



Professor Jerome Loveland
Head, Dept of Paediatric Surgery
Chris Hani Baragwanath Academic
Hospital, University of the Witwatersrand
and Transplant Surgeon, Wits Donald
Gordon Medical Centre, Johannesburg



Professor Russell Britz
General Vascular
Surgeon
Wits Donald Gordon
Medical Centre
Johannesburg

The views expressed by the editor or authors in this newsletter do not necessarily reflect those of the sponsors and publishers.
The South African Transplant Society Website: www.sats.org.za

This newsletter was made possible by an unconditional grant from

TRANSPLANTATION
UROLOGY
DERMATOLOGY
ANTI-INFECTIVES

 **astellas**
Leading Light for Life

Preparing for your transplant



Alexia Michaelides
Regional Transplant Manager
Netcare
Western/Eastern Cape

Each person's journey to transplant is unique. Some people wait for extended periods of time, hoping for the day when they will be called for a transplant. For others the wait is short, as they are fortunate that a living related donor is compatible. These patients move quickly to surgery and life with their new organ. No matter the circumstances, nearly everyone finds it difficult to completely absorb that they have an end-stage disease that can best be treated by transplantation.

The fear and anxiety that nearly every transplant candidate feels are further compounded by the complex system for transplant evaluation and organ matching.

THE TRANSPLANT PROCESS

- You are evaluated for a transplant by the medical team at a transplant centre.
- If accepted as a transplant candidate, you are registered on the Deceased Donor waiting list.
- In addition, a living donor may be identified and evaluated for living donations.
- Begin organising your support system.
- Organise your financial strategy with your medical aid scheme
- Your waiting period begins.
- Your transplant takes place.
- Your medical team manages your post transplant care.

The transplant centre is a hospital that has staff that specialises in transplant medicine. Your primary doctor will refer you to a transplant centre that specialises in your medical situation.

The transplant evaluation process involves long days of tests and clinic visits and can be stressful. The transplant team will test every major organ system in your body. It's perfectly normal to feel anxious or vulnerable. You will likely receive a huge amount of information during your evaluation. Afterwards, spend some time alone and let it all sink in. It may also be helpful to talk with others who have had a transplant. This is a good way to spend your time as you wait for test results and medical aid scheme approval.

It is normal to feel unsure as to whether you want a transplant, even though you may need one. You may doubt your ability to get through the process, or you may be frozen with fear of one or other aspect of the process. Your transplant team is there for you and will support you through all of these stressful moments.

It is okay if you decide that a transplant is not for you – it is your decision to make.

CONGRATULATIONS! The evaluation is over and you are on the organ transplant waiting list. Now the waiting for a donor organ begins. This can be extremely stressful, since you do not know how long that wait will be. Now is the time to mobilise your resources so that you are ready when the call comes.

While you wait, others may get their transplant quickly. Unfortunately organ allocation is not a first-come, first-served process and is based on many criteria. Severity of disease often allows sicker patients to receive an organ in a very short time. Each patient is unique and is handled as such. Being on the waiting list simply means that your transplant team found you to be a good candidate for transplantation – unfortunately it does not guarantee that every patient receives an organ.

There are two quotes by transplant patients that I always remember. One patient who was waiting for a heart transplant said "You want to be sick enough to be listed, but well enough to survive the transplant". The other quote also came from a heart transplant recipient who had undergone two heart transplants. He simply said "Transplantation is not for wimps!"

Waiting times for transplants vary widely. Not everyone who needs a transplant will get one. Because of the shortage of organs, some patients can wait up to 7 years for a transplant. But while you are waiting, it is important to work closely with your transplant team. Keep all scheduled appointments; build a solid support system of family, friends and medical professionals. Let people know what's going on in your life. Take care of your health!

- Follow diet and exercise guidelines!
- Make sure you are available!
- Complete medical tests and procedures!
- Stay organised! Inform the transplant team if your address or phone number changes!

If you are well prepared physically, then your emotional and practical preparedness will follow. Your transplant team should be the main source of information about your care. Ensure you have a transportation plan in place for when the call comes in, especially if you live far from your transplant centre. Create a support network and find people to help you. Ask your social worker and transplant psychologist for advice. But remember: answer your phone at all times of the day and night! One day it will be the call you have been waiting for!

2013 World Transplant Games – A victory for organ donation and transplantation

The week-long 19th World Transplant Summer Games, held in Durban, South Africa, from the 29th July to the 3rd of August were deemed a resounding success by the athletes and organisers alike!

President of the World Transplant Games Federation, Mr Olivier Coustere, commented: "The South African event rates as one of the best in the history of the Games, which have been running every second year since 1978. The organisation of the event plus the warmth of the Zulu welcome, the culture, the food and the music, will leave lasting impressions on all of us."

Top five teams	Medal count
Great Britain and Northern Ireland	124 gold, 79 silver, 58 bronze
USA	47 gold, 33 silver, 29 bronze
South Africa	42 gold, 32 silver, 33 bronze
Hungary	38 gold, 19 silver, 26 bronze
Australia	27 gold, 14 silver, 12 bronze

Team South Africa finished in third position in the final medal count and moved up six places since the 2011 Games in Sweden. Overall winners were Team Great Britain and Northern Ireland, who competed as one team.

870 athletes from 49 countries enjoyed Durban's warm winter sunshine in weather conditions that were hotter than the last Summer Games held in Sweden in 2011. In addition to the competitors, approximately 1000 supporters from all over the world flocked to South Africa to cheer on their athletes

Heilie Uys, Team Manager, said at the beginning of the Games that each one of the 81 athletes in the South African Team were "Medal Winners", irrespective of whether or not they received a medal on a podium at the Games. They are winners of "survival" and true examples of how to celebrate their New Life after Transplantation.

Our champion Badminton player, Johannes Kleingeld, won a gold medal and Nora Lombaard won silver medals in the 5km and 20km cycling events in the 18-29 year age group. Robert Laubscher won gold in his 5km cycling event in the 9-11 year age category.

The golf team excelled and bagged 5 medals:

- Heilie Uys – gold and best lady golfer

- Wikus Esterhuyzen and Dick Kruger – silver
 - Derrick Pillay and Anton Roux – bronze
- Derrick Pillay and Johnny Da Silva also won gold in the Golf Team event

The SA Lawn Bowls Team ended strongly against world class competition where Robyn Emslie and her doubles partner, Marion Oldfield won bronze medals. In the singles division Robyn and Pat Dicks won gold, Anton Grobler won silver and Marion Oldfield won bronze.

Petanque (boules) as a new event on the SA sports list, saw our players excel amongst the best in the international field when Marion Oldfield and Marion Skaffer both won silver medals.

All the SA Road Runners (5km) won medals with Zanelle Britz surprising herself with gold as she only took up running the past year! In addition, in the men's events, Daniel Matsoso won gold, Derick Lategan silver and Morokwane Itumeleng bronze.

Lloyd Perry, our SA tennis champion, won silver in the singles event and together with Stephan van den Berg, won silver in the doubles section. Stephan went on to win bronze in his single division while our junior players, Jacques Boshoff and Joshua Francis won gold and bronze respectively. Johan de Jager joined his fellow juniors by winning bronze in the Ten Pin Bowling event. Other medal results are listed in the tables in the following pages.

At the gala dinner on the Saturday evening Heilie Uys was also awarded the Most Outstanding Female Athlete of the Games. In her comments after the award ceremony, she said that she felt very humble as this award was made possible by her donor who made a decision many years ago to donate his/her organs so that others might live.

A first for any World Transplant Games was the unveiling of a special set of stamps designed and printed by the SA Postal Services illustrating athletes who had organ transplants. This was the initiative of Willie Uys who worked for two years with the SA Postal Services to make this dream a reality.

Linking onto the Games was a very successful Save Seven Lives Beach Walk on Sunday 29th July as well as an inter-religious Donor Recognition Service to honour all donors. Thanks to Samantha Volschenck, Jooste Vermeulen and Alison Reddi of the Organ Donor Foundation for organising these events.

What made the 2013 World Transplant Games unique was the South African Transplantation Society's congress that was held concurrent with the Games in the Elangeni Hotel. Many of the doctors and nurses attending the congress also attended some of the sports and social events and could see how their patients excelled! The Local Organising Committee thanks Prof. Elmi Muller and her Team for supporting the Games.

All of this couldn't happen without the leadership and skills of a Team of persons who worked very hard over the past three years, namely:

- Willie Uys – Chairman of the WTG 2013 LOC and all the LOC members
- Kim Renyard – General Manager
- Donna Rodriguez – Accommodation and Transport Manager
- Vusi Ncobo and Ryan van Rensburg – Sports Directors
- All the Sports Coordinators and volunteers
- Mande Toubkin, Prof. Kramer and their Netcare Team who delivered an excellent medical service during the Games
- Team Physiotherapist Andri Smit and her assistant Jolene Kleinschmidt

**For more information on the South African Transplant Sports Association – please visit www.transplantsports.org.za.
For more information on organ donation and transplantation – please visit www.odf.org.za**

Event	Name	Age	Gold	Silver	Bronze	World record
SQUASH	Cathy de Beer	18-29	1			
	Alice Vogt	18-29		1		
	Edward Ormond	18-29			1	
	Kevin Vicars	18-29	1			
	Kobus Weideman	18-29			1	
	Johan Kleingeld	40-49	1			
	Sean Adriaanse	40-49			1	
	Sakkie vd Westhuizen	40-49			1	
	Glen Spolander	60-69	1			
SWIMMING						
100 Freestyle	Cathy de Beer	18-29	1			
	Tersia Smit	50-59		1		
200 Freestyle	Harold Moore	50-59		1		
200 Ind Medley	Koenraad Pretorius	18-29		1		
25 Backstroke	Robert Laubscher	9-11			1	
25 Breaststroke	Kyle Southworth	6-8	1			
	Joshua Laurenz	9-11			1	
25 Butterfly	Robert Laubscher	9-11	1			
25 Freestyle	Robert Laubscher	9-11	1			
400 Freestyle	Harold Moore	50-59	1			
	Tersia Smit	50-59	1			1
50 Backstroke	Koenraad Pretorius	18-29	1			1
	Tersia Smit	50-59		1		
50 Butterfly	Koenraad Pretorius	18-29		1		
	Harold Moore	50-59		1		
50 Freestyle	Cathy de Beer	18-29		1		
	Tersia Smit	50-59		1		
	Robert Laubscher	9-11	1			
	Luke Dawson	12-14			1	
	Koenraad Pretorius	18-29		1		
Relay 4x50 Freestyle	Men's Team				1	
Relay 4x50 Medley	Men's Team				1	





Event	Name	Age	Gold	Silver	Bronze	World record
TRACK						
100m	Suretha Maartens	18-29	1			
	Nombeko Rwaxa	50-59		1		
	Fidel Nkadimeng	12-14			1	
	Brett Howburg	15-17			1	
	Johannes Lombaard	15-17		1		
1500m	Daniel Matsoso	30-39	1			
200m	Suretha Maartens	18-29	1			
	Johannes Lombaard	15-17	1			
	Andre Murphy	50-59			1	
3km Race Walk	Alice Vogt	18-29	1			
	Constance Sithebe	30-39	1			
	Sannie Liebenberg	60-69		1		
50m	Phamela Mavundza	9-11			1	
	Kyle Southworth	6-8		1		
	Joshua Silber	9-11	1			
	Jacques Boshoff	9-11			1	
800m	Derick Lategan	60-69	1			
Ball Throw	Kyle Southworth	6-8	1			
	Jacques Boshoff	9-11		1		
	Johan de Jager	9-11			1	
	Luke Dawson	12-14		1		
	Fidel Nkadimeng	12-14	1			
	Johannes Lombaard	15-17			1	
	Emile Honiball	18-29		1		
	Constance Sithebe	30-39			1	
	Nombeko Rwaxa	50-59	1			
	Heilie Uys	60-69	1			1



Event	Name	Age	Gold	Silver	Bronze	World record
Discus	Heilie Uys	60-69	1			1
	Lourens Schultz	50-59			1	
	Gawie du Toit	60-69			1	
High Jump	Herculaas Lamprecht	15-17			1	
	Johannes Lombaard	15-17	1			1
	Sakkie vd Westhuizen	40-49			1	
Javelin	Heilie Uys	60-69	1			1
	Stephan vd Berg	30-39			1	
	Lourens Schultz	50-59		1		
	Gawie du Toit	60-69			1	
	Kosie Laubscher	60-69	1			1
Long jump	Kyle Southworth	6-8	1			
	Jacques Boshoff	9-11		1		
	Johan de Jager	9-11			1	
	Johannes Lombaard	15-17		1		
	Philimon Mogotsi	15-17	1			1
	Suretha Maartens	18-29	1			
Shot put	Kuhlula Shilubane	15-17	1			
	Heilie Uys	60-69	1			
	Brett Howburg	15-17			1	
	Herculaas Lamprecht	15-17		1		
	Kosie Laubscher	60-69		1		



The state of public sector solid organ transplantation



Dr Anna Sparaco
HPB and Transplant Surgeon
Charlotte Maxeke Johannesburg Academic Hospital
Wits Donald Gordon Medical Centre
Johannesburg

Is transplantation a right or a privilege? Should access to this therapy be sector dependent? The “haves” can have it and the “haves not” cannot. Clearly this poses an ethical dilemma. According to the organ donor foundation statistics there are 4300 South African adults and children awaiting a solid organ transplant that will be life saving or life enhancing. The statistics show that 573 organs including corneas were transplanted in 2012.

The UNOS statistics reported at 1:59am on the 25 June 2013 that in the USA there were 118 608 people awaiting solid organ transplants and in 2012 a total of 28 051 transplants were done. So if we look at the figures and extrapolate from a population basis, the USA has a population of 500 million and South Africa of 50 million, so if we just reduced the transplant statistics by a factor of 10 then South Africa is under-performing.

If we go back to population statistics there are about 10 million people with medical insurance and 40 million without. Again, suggesting simply from extrapolation, there should be a 1:4 insured vs uninsured patients requiring transplantation in South Africa. So why are there fewer public transplants done?

In terms of public sector transplant units we have 7 kidneys transplant centres, 1 pancreas, 2 heart and 2 liver centres. There are no public lung transplant centres listed. **Table 1** shows the distribution of centres between the sectors.

Table 1: Transplant centres that have been listed as public or private transplant centres on the ODF site

Transplant	Public	Private
kidney	7	9
pancreas	1	3
heart	1	5
liver	2	2
lung	0	2

The Johannesburg group has taken an innovative approach to address this discrepancy by suggesting a private-public partnership. This to a large extent addresses the emigration of the skills from the state sector by creating one unit that services both sectors and the private practitioners that wish

to be part of the transplant unit must make themselves available to service the public sector as well. This works very well in the surgical group and it is hoped that this model will be adopted more widely. Also, the listing process is the same for both sectors and both public and private patients are listed on one list. The organ goes to the most appropriate recipient regardless of sector.

The Johannesburg center has now expanded its transplant repertoire by starting a living donor liver program. So now it is possible to not only donate your organs upon your death but also to entertain the idea that either a kidney or a segment of your liver can be donated as a living donation.

Further reasons for the low rate of transplantation are the fact that there are fewer referrals from the public sector. So the ability to provide most transplants is available. The belief that transplantation is an expensive egalitarian luxury procedure implies that our people are not worthy of the same sophistication of medical treatment as elsewhere. All people should have the right to all levels of medical care available in our society. It should not be a case of survival of the richest! The question should not be of “should certain patients have access and others not” but that all patients should have access. It is incumbent on the medical profession, administrators and government to ensure that this is done equitably and fairly. Access to most of the types of organ transplantation is now available for the public sector patients and the public sector doctors should now be assured that this modality of treatment is available for their patients. The public should be aware of transplantation and if they suffer from an organ failure, they should ask, “Can I have a transplant?” The electorate should be asking what systems are there to ensure equal and fair distribution of transplants. The people should be saying not “whether I can be a donor” but “how can I be a donor – dead or alive.”

Transplantation is available, it is here to stay and it is incumbent on us all to ensure that this valuable therapy be distributed to all fairly and quickly. All provinces should have a transplant centre, but until then we should optimize and fairly distribute what we have. Innovative models of health delivery should be explored. The duplication of facilities in close proximity should be avoided by collaboration and sharing of resources to deliver transplants to all who need it.

A dream comes true - Jacques' story

Jacques Boshoff is an eleven year old boy from Pretoria who never thought that his quality of life would turn out in such a positive way, only 10 months after he received a kidney transplant from his mom, Linda, in November 2012.

Jacques was born with hydronephrosis which caused his chronic renal disease and eventually caused renal failure. He has been a fighter from the start and received his first operation when he was only six days old. Since birth Jacques struggled with the normal symptoms such as chronic infections and growth restriction. In spite of all the needles and hospital experiences, Jacques stayed positive and was so lucky to always have the best medical advice and doctors who looked after him. He knows that with God's grace and family support he was and still is in very good Hands.

Jacques is so grateful to be a patient of Dr Gottlich from Morningside Clinic who diagnosed him with end-stage renal failure in June last year. Soon after his mom started the work up for being the donor and was so thankful that she was tested to be the perfect match.

The transplant was performed at Donald Gordon Medical Centre by Prof. R Britz and Dr Craig Joseph. Linda said: "Although it was a difficult and stressful time, we were so impressed with everyone involved in the operation and aftercare. We experienced and still realise that these health professionals live out their passion to participate in this wonderful gift of life for so many people in need of transplants. Thank you so much!" Jacques still realises that he should never take his good health for granted and loves to tell everyone that after only two days, his new kidney was functioning perfectly normal.

Since then, Jacques who is a very sporty person, received the news that he might be well enough to participate in the World Transplant Games held in Durban this year. He started to develop a new dream which became a reality in August this year. With the excitement of meeting



new people who went through the same as he did, he participated in three track and field events and the single tennis event. He won a gold medal in the 9-11 year old tennis event, two silvers for the ball throw and long jump and a bronze on the 50m track where he also managed to break the world transplant record. Jacques is so thankful that he could be a part of the South African team to raise awareness that people can save so many lives by being a donor. He is definitely living proof of new energy and improved quality of life after transplantation. "I believe that I must enjoy life and do as much as I can and always be thankful for every day!" Jacques said. Jacques is playing tennis and cricket for his school's under 11-A team and enjoys cycling, golf and swimming.



Kaidyn Blair (Canada) first, Jacques second and Johan de Jager (also South Africa) third.

He is already dreaming about the next World Transplant Games which will be hosted in Argentina during 2015.

The spirit of the World Transplant Games was certainly one of determination of the transplanted athletes to never

give up hope and to be grateful for every moment that they can do their sport. It is important not only to aim to win, but to being able to participate alone, is the best gift after transplantation. Never give up your dreams!