



# Transplant News

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Official newsletter of the  
South African Transplant Society

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## Editorial

**Professor Jerome Loveland**  
Editor

Welcome to the 1st edition of Transplant News in 2018! To me it seems a longish gap since the last edition of 2017, and being such a well received publication, I am sure that you are all excited to see what this edition holds!

Medicine is extremely dynamic, with progress being made on a daily basis, the positive impact of which translates into how patients are treated, often enhancing their care and recovery. Transplantation is not exempt from this, and whilst extremely well established in South Africa, with results comparable to centres in developed countries, we have continued to advance in leaps and bounds, both surgically where laparoscopic donor nephrectomy and living donor liver transplantation have been introduced and are well established and now routine, as well as medically, where advances in immunosuppression, prevention of infection, and ICU care continue to improve.

As is experienced worldwide, and so often highlighted locally, our low rates of organ donation continue to limit the rate at which we transplant, this despite extremely committed transplant units around the country. Through the **South African Transplant Society (SATS)**, an additional society i.e. the **Transplant Coordinators' Society of South Africa** was formed. This new

society will provide a unified platform for transplant coordinators throughout the country, regardless of where they are employed or of their specific area of expertise. The group has made great strides over the last 6 months, have planned their 3rd meeting for July of this year, and hope to positively impact donation rates across South Africa.

I am always so positively influenced and impressed by the articles in Transplant News. The need is so great, with so much highly relevant information to share. For me this could easily be a monthly publication! This edition reminds me of just how much transplantation in South Africa has contributed to the field on an international basis, this on many levels.

Heart transplantation was initiated in South Africa, and Dr Graham Cassel provides wonderful insights into Johannesburg's experience, whereafter Dr Elmi Muller, the world's leader in HIV-to-HIV kidney transplantation tells us about how these transplants happen, providing massive hope where there was none before. Alison Lang then provides essential information on how to look after your diet, and then it is over to the patients, their experiences, journeys and involvement in so many facets of life after their life giving experience.

Enjoy the read!



# Life before and after transplantation

**Dr Graham Cassel**  
Cardiologist  
Milpark Heart Transplant Team  
Milpark, Johannesburg



**S**olid organ transplantation has become an every day operation and for those of us in the field, it has taken the mantle of the mundane... we see patients with end organ damage, meet with the patient and family and tell them transplantation will change their lives forever. That is usually true but is it always for the better for the patient and importantly for his/her family?

Family life for people with one member suffering from a terminal illness is a daunting and emotionally and usually financially a very difficult situation. The sick member usually can't work, is dependent financially as well as physically on the family and in general life is extremely difficult for all. There often are young children who are too scared to bring their friends home to play for fear of disturbing the sick parent so their lives are badly affected too. Does anyone spare a moment to think of these poor young members of the family? The situation is even more stressful when the sick family member is a child. This has a devastating effect on the family, often with parents fighting and blaming each other for the plight of their child. No family outings or holidays, only visits to the clinic or hospital. The healthy children bear the brunt of lack of love or money or attention as it is all spent on the sick family member.

The transplant team tries to address all these issues before the big day of the life changing transplant. The coordinator makes the call that a donor is available and please rush to the hospital for the operation. Often no time to spend with the family, thanking them for all the support in the months and years leading up to this big day. Will I survive the transplant and will I return to my loved ones? What goes through the mind of a patient about to undergo the biggest day of their life since falling sick... Do we ever think of this?

The big day arrives and the patient is taken to theatre. The family sit outside the operating room with fear but excitement. Will the operation succeed and will all the stress of the waiting be worthwhile? They must have faith and trust in G-D and the medical team.

Later in the day or night our family member returns to the ICU. Lots of activity but we are not allowed in the cubicle. Through the glass he looks OK but all those machines! The long wait is finally over but are we prepared for the tough road ahead? Some patients sail through the operation and are home in no time. Others are less fortunate and spend weeks and occasionally months in the ICU. Daily visits are arduous and very difficult for the young members of the family.

Finally, our patient comes home. Great excitement but equally great anxiety. Will we give him the right pills, be sure no-one with



**Can we go on holiday and when can the patient return to work? How do the children react to a parent who was too sick to kick a ball but now can run a mile? How do we integrate a previously sick child into a family of only healthy people?**

an infection comes close, am I cooking the correct food and what about our personal relationship. The doctors and nurses avoid the subject and we are too scared to ask! The weeks pass by and we are doing well. Can we go on holiday and when can the patient return to work? How do the children react to a parent who was too sick to kick a ball but now can run a mile? How do we integrate a previously sick child into a family of only healthy people? We are not trained for this and need to feel our own way. The role of a therapist is extremely important in this time of the transplant patient's life to help heal the family that has been so badly scarred for so long.

With time, everything heals and life in the family returns to normal. Back to work; family dynamics are normal and finally we say thank you for the gift of life.

The transplant team is a special group of people, selflessly helping to restore the family together, forgetting the tough times and only remembering the good times ahead. Mothers raising children they thought they would never see grow up, fathers walking their daughter down the aisle and the ultimate, holding the grandchild I thought I would never live to see.

Transplantation is a tough road but when successful is truly "the gift of life".

# Kidney transplants a viable option for some HIV-positive patients

**Dr Elmi Muller**  
Transplant Surgeon, Head of the Transplant Unit  
Groote Schuur Hospital, Cape Town



In 2015 we published an article in the New England Journal of Medicine showing that kidney transplants from HIV-positive deceased donors is a viable additional treatment option for selected HIV-infected patients (on antiretroviral treatment) who need renal replacement therapy.

Between September 2008 and February 2018, 49 HIV-positive patients underwent kidney transplants at Groote Schuur Hospital. In the study group 5 patients lost their graft due to various issues, which makes the graft survival at 3 years 84%. HIV infection remained well controlled, with undetectable viral loads in blood after the transplant.

The South African study has demonstrated that the outcome of kidney transplantation in HIV-positive patients with HIV positive donors is just as good as in patients without HIV infection.

Lead author Prof Elmi Muller is based at UCT's Department of Surgery and at Groote Schuur Hospital. In October 2008 she became the first surgeon in the world to transplant a kidney from an HIV-positive donor to an HIV-positive recipient.

The findings are significant as South Africa has one of the highest incidences of HIV infection in Africa. The rollout of antiretrovirals has been very successful in extending the lives of those with HIV.

Groote Schuur Hospital has an active kidney transplant programme; each year 50 to 70 kidneys are transplanted, 30% of these are from living donors.

South Africa has many HIV-positive patients with end-stage renal failure. With the biggest HIV population in the world, there are an increasing amount of HIV-positive deceased donors. A major concern, said Muller, was the risk of transmission of a new and possibly resistant strain of HIV from donor to recipient. This is when a strain or subtype of HIV triggers a more rapid progression of HIV in the transplant recipient. However, the patients in this study did not show any clinical evidence of this happening. Viral loads remained undetectable in all patients. New data looking at the virus in more detail is underway and will hopefully confirm the safety of these procedures.

Rejection rates among HIV-positive recipients were reported to be approximately three times as high as those among HIV-negative recipients. These results correspond with rejection

rates found in the large NIH study that was done in the USA using HIV negative kidneys into HIV positive recipients. The reason for this is still unknown, but there are two possible reasons: Immune dysregulation and the challenge of managing the drug interactions between the antiretroviral agents and the immunosuppressants used to lower the body's ability to reject the transplanted organ.

**When the study started HIV positive patients were not able to access dialysis or receive a HIV negative kidney transplant, leaving them with no other option than a HIV positive kidney transplant. This situation changed in 2010 when dialysis and general transplantation became available to HIV positive patients.**

The proposal to perform transplantations from an HIV-positive donor to an HIV-positive recipient also raised several ethical issues, the first being the validity of the informed consent. When the study started HIV positive patients were not able to access dialysis or receive a HIV negative kidney transplant, leaving them with no other option than a HIV positive kidney transplant. This situation changed in 2010 when dialysis and general transplantation became available to HIV positive patients.

And although HIV-positive patients became eligible for dialysis after the first year of the study, this is still a very limited resource and many patients with stage-5 chronic kidney disease, regardless of HIV status, do not qualify for dialysis.

The programme now receives NIH funding to do viral sequencing on both donors and recipients. The study is also expanded to look at some of the immunological reasons why these patients have such high rejection rates. We are hoping to enrol more recipients into the study as well as to increase the number of brain-dead donor referrals from HIV positive patients.

# Nutrition in paediatric liver disease

**Alison Campbell Lang**  
Dietitian - Special Interest in Paediatrics  
Wits Donald Gordon Medical Centre  
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Infants and children with liver disease are at severe risk of malnutrition. The liver has two main functions in supporting nutrition. It produces bile that helps us digest and absorb fat that is in our food, and it also helps convert nutrients in the diet into other substances that support growth. When the liver starts to fail this results in fat malabsorption, poor metabolism of protein and consequently poor growth.

Good nutrition is important for the growth and development of all children. It is especially important for those who have liver disease.

Studies have shown that malnutrition can adversely affect the outcomes of liver transplantation. The malnourished child may have increased length of hospital stay post transplant and is more at risk of serious complications.

Paediatric dietitians and gastroenterologists need to be involved in close monitoring of the nutritional status of these children and intervene with nutritional support that is appropriate and affordable to the individual child.



The liver metabolises protein, carbohydrate and fat

## Nutrition in Infants with Liver Disease

- Babies with a reduced bile flow are not able to digest the fat from their milk feeds, which causes them to still feel hungry. This is why babies who are jaundiced may drink large volumes of milk or formula or be very demanding breast feeders.
- These babies have higher requirements for energy (calories) and protein due to the poor synthesis of these nutrients.
- Some babies with liver disease may have poor appetites in times when they are acutely ill.

- Ascites and an enlarged liver and spleen may decrease the space in the abdomen for food and cause poor intake and/or vomiting

These infants should be referred to a dietitian who specialises in paediatrics for a full nutritional review. They may need to start a special milk formula with a source of pre-digested fat called MCT (medium chain triglycerides) if they are jaundiced. If babies are not taking sufficient volumes a high calorie infant formula should also be prescribed to maximum nutrition into the volume tolerated.

If a breast fed baby is failing to thrive they may need to be topped up with an energy dense infant formula with some MCT.

Some babies may require nasogastric feeding if they are too unwell to drink the amount of formula they need to grow.

Babies should not be offered tea, juice, water. It is more important for them to drink their high calorie formula.

## Weaning a baby with liver disease

- There are no specific foods that need to be avoided because a baby has liver disease. Solid foods should be started between 4-6 months of age, and introduced in the same way as for any infant.
- High calorie, high protein foods should be encouraged to promote growth e.g. full fat yoghurt, baby cereals mixed with high energy formula soft cheeses, vegetables with butter, nut butters, fruit with cream, avocado, meat, chicken and fish.

## High Calorie Weaning foods

- Baby cereals mixed with formula
- Egg
- Nut butters
- Avocado
- Double cream yoghurt
- Full fat cream cheeses
- Inkomasi
- Fish
- Chicken livers
- Vegetables with butter and cheese
- Chicken thigh and meats





- Even if one is worried about a baby's growth it is very important never to force feed them as this may result in food aversion and increasing feeding difficulties.
- Salt should not be added to any weaning foods as it may exacerbate ascites (fluid build-up in the abdomen).

#### Nutritional intake in children with liver disease

Children with liver disease can eat normally. Fatty foods may cause some discomfort but can be eaten as long as they are tolerated. Protein should not be restricted as it is important for growth. Protein restriction is only needed when a child is acutely encephalopathic and should not be restricted for long periods of time. Children with ascites should watch their intake of salty foods.

These children often need high calorie nutritional supplements to support their oral intake. There are many supplements on the market. When choosing a supplement taste factors, tolerability, religious factors and dietary factors e.g. vegetarianism must be taken into consideration.

Children may need to be admitted for a period of tube feeding to build them up before their liver transplant. Some families are happy to tube feed at home if they have the suitable resources.

#### Vitamins

Fat soluble vitamins need to be routinely supplemented in all patients with cholestasis. Blood levels of the fat soluble vitamins (A, D, E and K) are monitored by the paediatric gastroenterologists and supplements are prescribed by the doctors as required.

#### Monitoring growth in infants and children with liver disease

It is important that these infants and children's growth is measured on a regular basis with appropriate equipment by a doctor or dietitian.

Weight alone is not a very good indicator of nutritional status due to enlarged liver and ascites. It is important also to monitor head circumference, length and mid upper arm circumference as part of nutritional screening.



#### High Calorie Snacks for children

- Nuts and Raisins
- Sausages
- Boiled eggs
- Nut butters on bread
- Avocado
- Double cream yoghurt
- Cheese
- Crackers with cheese and butter
- French toast
- Egg muffins
- Cold Meats

# Thriving 7 years later with a new heart

**Stanley Henkeman**  
Executive Director  
Institute of Justice and Reconciliation  
Cape Town



**M**y name is Stanley Henkeman and I had a heart transplant on 13 February 2007. I was a fit man who was doing what I enjoyed most – hiking, when I suffered a massive heart attack on 6 January 2001. In an instant my world came crashing down and changed from conquering a mountain to struggling to walk 5 steps without gasping for breath.

And so began 5 years of low quality and compromised health. At my lowest point I would think that it would be OK if I did not wake up because it was so frustrating to be saddled with a body that was so far behind my mind. Everything was an effort. When you are sick you are so self-absorbed that you often push away people who have your best interests at heart. I went through all the phases of mourning ranging from denial, anger, bargaining, depression and acceptance.

In April 2006 I was diagnosed with end-stage heart failure and I made the inevitable decision to go onto the waiting list for a heart transplant. At approximately 22H45 on Monday 12 February 2007 I received the call to come in to hospital and the transplant was performed at the Christiaan Barnard Hospital in Cape Town on 13 February 2007. I woke up on Valentine's Day with a new heart and for the first time in years I could breathe easily and deeply without coughing. Within two weeks of walking into the hospital with a "broken" heart I walked out with a "new" heart which signalled a new beginning and second chance to live again.

Any transplant recipient's biggest concern is the danger of rejection but I soon learnt that you have to make the most of

the second chance. I did this by accepting the heart as a gift from the donor and his family and in the process, I believe, the heart accepted my body as its new home. I undertook to faithfully adhere to my medication regime and to bring balance into my life.

One of the aspects of my life that was neglected during my illness was my physical well-being. I worked hard at getting fit and participated in the National Transplant Games in 2008 where I qualified for my first World Transplant Games in Australia in 2009. I was fortunate to represent South Africa in four subsequent World Transplant Games in Sweden (2011), Durban (2013), Argentina (2015) and Spain (2017). In the last three Games I enjoyed the distinct honour of being the national captain. The new heart had now created new opportunities as well.

I have always been a strong advocate for organ donation and wanted to show the world what is possible after transplantation. I have been fortunate to showcase the transformative nature of transplantation on many platforms and I am committed to do so whenever an opportunity presents itself. I am deeply indebted and grateful to the medical team at Christiaan Barnard Hospital who continue to amaze me with the level of care and support I still enjoy after 11 years. I am grateful to my family for their ongoing support and want to continue to make my mom, wife and sons proud.

My name is Stanley Henkeman and I am still living in the victory and wonder of my heart transplant.



# Transplant athletes head to Port Elizabeth

**Hermann Steyn**  
Executive Secretary  
South African Transplant Sports Association



**S**outh Africa's transplant athletes will descend on Port Elizabeth from 12th to 15th July to compete in the 13th National Transplant Games. This event is hosted by the South African Transplant Sports Association (SATSA). SATSA is recognised by the Department of Sport & Recreation and SASCOC and is a Member of the World Transplant Games Federation (WTGF), recognised by the IOC.

This is "Celebration of New Life" where athletes who have received organ and bone marrow transplants will compete in multi sports events.

It sets the stage to demonstrate the improved quality of life following transplantation and through that, promote awareness for organ donation and transplantation. This is also an opportunity to show their gratitude towards living donors and families of deceased donors.



**Some of the athletes who will be participating at the SA Transplant Games**

The picturesque setting of Port Elizabeth for this year's Games is sure to inspire athletes from ages 5 to 80 years in 13 sporting codes, to perform at their best in order to represent South Africa in the World Transplant Games 2019 in Newcastle, England.

"The National Transplant Games is always the highlight on the transplant calendar", Chairman SATSA Stan Henkeman explained, "It is the point in every transplant athlete's year where they strive to be at their best, ensuring they gradually improve their own performances, while keeping one eye on their goals to qualify for England."

"Port Elizabeth has always had superb facilities and is one of the most beautiful cities to compete in. We're sure this will help inspire our athletes to perform at their best. We welcome Nelson Mandela University and in particular the Faculty of

Health Sciences who are partnering with SATSA in organising an unforgettable event".

The National Transplant Games will open on 12th July with the arrival and registration of athletes followed by SATSA's Annual General Meeting. On 13th July all non-track and field events will take place namely cycling, road race, golf, swimming, lawn bowls, petanque, squash, table tennis, badminton, tennis, ten pin bowling and darts. One of the highlights on this day is a Fun Walk event that will take place on the beach front from 15:30 to promote awareness for organ donation and transplantation. The public is welcome to participate in this event.

As always, the athletics on Saturday 14th July remains the draw card not just for the athletes and supporters but is also open to the public. This will take place at the Madibaz Athletic Track of the Nelson Mandela University. The public is invited to come and experience the Celebration of Life which all athletes will display at these Games.

## Organ Donor and Transplantation STEPS Challenge 2018

The Regional Organising Committee is also very excited to announce the launch of the above initiative. It is planned that up to 125 teams of 4 participants will take part in this 90-day event during which the daily number of steps of each participant and the team will be registered.

This will start on Monday 9th April 2018 and is running until Saturday 7th July 2018. There will be a prize for the individual with the most steps and also a trophy for the team with the highest number of steps. The results will be announced at the Gala Dinner after the Games.

We are hoping that schools in the greater Port Elizabeth and even further afield will also enter a team and we will award a trophy for the school with the highest number of steps. The idea of the Steps Challenge is to promote an active life style and to get recipients, families and friends to promote organ donation and through that help to improve the transplantation rate in South Africa.

More detailed information will be available soon. Please help us to make this a huge success.

**To register on the Organ Donor Foundation, please go to [www.odf.org.za](http://www.odf.org.za) to register online. Most importantly, please discuss your wishes with your family and friends – thank you.**





# The Organ Donor Foundation's fantastic volunteer network is growing!

**Samantha Nicholls**  
Executive Director  
Organ Donor Foundation, Cape Town



**S**ince the inception of volunteer training in 2016, the Organ Donor Foundation has seen a phenomenal increase in the number of active ambassadors of our cause.

Volunteers help the Organ Donor Foundation tremendously with its objective to educate the public about organ donation. They play a vital role in encouraging all South Africans to register as organ & tissue donors. These kind people are also the face of the ODF and the link between the public and the Foundation. The ODF readily hosts training sessions in Johannesburg, Cape Town and Durban and will be shortly expanding to Eastern Cape and Free State during the course of 2018.

The informative training sessions not only cover the role of the Organ Donor Foundation but also are bolstered with very interesting and educational talks by the local transplant coordinator educating volunteers about the organ donation process. Also presenting is a specialist carefully explaining the exciting field of tissue donation.

Our current volunteers are a wonderfully diverse group, which includes patients awaiting transplants, recipients of organs or tissue as well as family and friends of those who are either waiting for a transplant or have received one. We also have a few special individuals who have decided to be volunteers for no reason other than that they believe in our cause.

Prior to 2010 we had less than 10 volunteers in the entire country. Today we have a network of over 300 volunteers who assist us in spreading awareness even further with stands at wellness days, expos, sporting events and talks at schools, corporates and other events.

We are extremely fortunate to have such a passionate network of volunteers who selflessly commit their time and efforts to our wonderful cause.

## Are you interested in becoming an ODF volunteer?

If you are interested in becoming an ODF volunteer, please visit our website where you can complete the form to become a volunteer - <https://www.odf.org.za/volunteer-registration> or contact Keith Weeder – [keith@odf.org.za](mailto:keith@odf.org.za) or call Toll Free: 08000 22 66 11.



*Volunteer training at Steve Biko Academic Hospital*



**PROUD!**



*One of our fantastic volunteers*



*Volunteers walk the talk*