

Transplant news

Official newsletter of the
South African Transplant Society

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Editorial

Professor Jerome Loveland
Editor

2015 seems to have only just begun, yet January is behind us. Hence my editorial is late! Apologies. This year brings some change to Transplant News, fortunately with no impact on the high quality articles that come your way.

It is with much sadness that we say goodbye to Astellas with this issue. Astellas have sponsored Transplant News since 2009 and without their dedicated support and commitment it would have been absolutely impossible to publish this journal on a quarterly basis, if at all. There is no doubt in my mind that Transplant News offers a wonderful service to our transplant patients and their families and friends, giving them clear insights into their condition, educating them around their expectations, and providing clear direction into all of the medical and allied medical support that they are going to require. Transplantation is not without its challenges, and hearing first hand reports from the numerous patients that publish their experiences can only aid in motivating our precious patients.

Thus, from all of us involved in Transplant News, editors, publishers and contributors, but most of all the patients, we would like to express our extreme gratitude to Richelle Fouche and her team from Astellas for the wonderful support that they have provided to us over the years. Thank you for your most generous contribution, and we wish you well in your further endeavours in support of the transplant community.

Despair not, however, we have secured a new sponsor, and Transplant News will live on! Which brings us to another wonderful, the 1st of 4 in 2015!!!

I particularly like this edition. It is a superb example of much of what I have discussed above, providing insightful patient perspectives. Three separate transplant stories demonstrate the inspirational drive that successful transplantation provides, including Prenola's recent liver transplant, the establishment of the Open-Eye Foundation by a kidney recipient, culminating in the ever heart warming stories that originate from the transplant games. Challenges faced with respect to organ shortages and those that transplantation faces in the government sector are well addressed, keeping us in touch with the ever present challenges that the entire transplant community face on an ongoing basis.



World Kidney Day

SUNSET 5KM WALK

IN PARTNERSHIP WITH THE CITY OF CAPE TOWN

SEA POINT PROMENADE ON THURSDAY 12TH MARCH 2015

For more information, please contact Molly Fabé at the Cape Kidney Association on: 021 7611326 or 083 265 7490

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Take charge of your life



Reuben Mosa Mphore
Founder and CEO of Open-Eye Foundation
Johannesburg



Being diagnosed with an acute illness and placed on a waiting list for a life-saving organ can be extremely distressing, especially when one is confronted with the frightening reality of organ donation (or the lack thereof) in the country. If you are lucky enough to be receiving a transplant from a living donor, your wait will be relatively short but those awaiting a cadaver donor have a longer wait, sometimes up to three years or longer. There is no way of telling when a suitable donor will become available and the only thing that one can do is to be patient and keep the faith.

I had been on dialysis for just two years when I received the call from the hospital for my kidney transplant. Walking into the hospital that day knowing that my life was about to change for the better felt absolutely surreal. I couldn't believe how fortunate I was to be receiving this transplant in what I consider a very short time.

The thought of having to just wait for a miracle, not knowing from where or when it would come, can be truly disheartening and even more so when that miracle depends on others. There are three paramount decision-makers involved in organ procurement – the dedicated multi-disciplinary transplant teams, the selfless donor families, lastly and most importantly, you – the recipient. Truthfully, it all starts with you.

The transplant team does everything in its power to ensure that enough organs are procured and that the procedures run smoothly; the donor families (God Bless Them) are taking selfless decisions to donate during very difficult times to ensure that those who need a second chance in life receive it. The rest of it is really up to you. What can you do to play your part in receiving this miracle?

“TAKING THE BULL BY ITS HORNS”

Understandably, it might not seem possible to do anything but try to survive during the time of your illness. It can also be very stressful to not be in control of your life but it can also be an opportunity to look for the fighter that's in you and “take the bull by its horns”, so to speak.

There are a few steps you can take to accomplish this. Firstly, you need to understand your own needs and take charge of your health-related responsibilities as this can help you feel in control of your life. This will also help in offsetting feelings of helplessness. Here are a few of my suggestions on how you can take control of your health:

Think positively and strive to be happy!

It's so easy to fall into a depressive state when living with an acute/chronic illness but the best thing you can do for yourself and your health is to start thinking positively.



The Giving Tree

UAB'S KIDNEY TRANSPLANT CHAIN

To be a part of this unique living donor transplant list, a recipient needs someone in their life willing to donate a kidney to a stranger in their honor. With 21 recipients to date, University of Alabama at Birmingham Medical Center's chain is the longest, on-going, single-institution chain in the country. It can continue indefinitely as long as there are willing donors.

- Set small goals for each day (such as to smile and be happy) and strive to achieve them as best as you can. Have intentions to achieve your ultimate goal (finding a donor), set your mind to it and it will happen. William Shakespeare has a saying: "It is not in the stars to hold our destiny but in ourselves". Go out there and do the most you can to (legally) achieve your goal.
- Use what you are good at to do this. I believe that I have been blessed with the ability to express myself and have been using this skill throughout my illness to create positive change. I never pass up the opportunity to tell my story and find it not only therapeutic for myself but helpful to others as well.

Don't be afraid

Find it within yourself to seek assistance from family, friends or even strangers; they actually want to help. While doing my research on altruistic donations, I came across many, very inspiring stories about acts of kindness from total strangers offering kidneys to other strangers who needed them. Two particular stories caught my attention:

- One story was of the Alabama UAB Medical Centre's Kidney Transplant Chain called The Giving Tree initiative. The chain was started when one lady - Paula Kok of Alabama - decided to donate one of her kidneys because she believed that she was "someone's stranger". Paula's deed started an intricate living donor transplant chain where living donors who don't match their recipients donated their kidneys to other recipients who did match in their recipient's honour, allowing them to receive a matching kidney in return. With 21 recipients to date, the chain is the longest, most successful, single-institute transplant chain in the United States and will continue indefinitely as long as there are willing living donors out there.
- Another story was of a long-time Georgia police officer (diagnosed with stage 5 kidney failure) receiving a kidney after his family posted a photo of themselves holding a sign that read "Our Daddy Needs A Kidney". Soon after this, a Texas man came across the story and was so moved by it that he immediately called his wife to tell her that he wanted to donate one of his kidneys. As if this wasn't amazing enough, the two men were found to be a match and are now both recovering from post-transplant surgery. The two families are now posting new photos with each member holding a sign that reads "We Found A Kidney For Daddy". "We feel very blessed to be part of this miracle, we're all family now" said the Texas family ☺

Remember, asking for help is not a sign of weakness, but of your desire to do well. Out there is a person who has a kidney for you, they just need you to let them know it.

For more information on Open-Eye Foundation:
"like" our page on Facebook - www.facebook.com/OpenEyeFoundation
Follow us on Twitter @OpenEyeFoundation



11th National Transplant Games - 10 - 11 October 2014



Mrs Heilie Uys
SATSA Secretary
St. Francis Bay

It was truly a Celebration of Life by all the athletes who participated and the supporters who attended the 11th National Transplant Games 2014 in Cape Town!

The main aim for participating in these Games was to qualify in different sports items to come into contention for selection to the National Team to participate in the World Transplant Games (WTG) that will be hosted in Argentina from 23rd till 20th Augusts 2015. Another objective was to promote organ donation and transplantation by the living examples of these athletes and their quest to live a healthy life after transplantation. In this quest the Organ Donor Foundation and Sun Flower Fund were part of the Games not only through marketing stands but also by celebrating Bandana Day with bone marrow recipients.

The excitement ran high when "old" and new athletes met on Thursday 9th October during registration and the Welcome function. New athletes and their families were welcomed with open arms and soon felt part of the Transplant Sports family.

It was not just fun and celebration as the Annual General Meeting of the South African Transplant Sports Association (SATSA) took place on that evening. The members not only welcomed the new National Chairman, Stan Henkeman and his new team, but were sad to say good bye to Willie, former National Chairman, and Heilie Uys, former National Secretary. This was also the opportunity to bestow Life membership to Jan de Kock, Lourens Schultz, Henri van Aswegen and Heilie Uys. They have been members of SATSA for 10 consecutive years. Honorary Life Membership was awarded to Willie and Heilie Uys and Bill Rosenberg in recognition of their active interest in and service to SATSA over many years.

On Friday 10th October the road runners were the first to participate at the Rondebosch Common area while the cyclist

participated in a 20km road race in the beautiful Atlantic Beach Estate area.

What a great atmosphere was created at the Pearl Valley Estate when the golfers teed off, the Petanque players drew a crowd at the club house and the tennis players enjoyed the beautiful scenery at the tennis courts while playing serious tennis.

In the mean time the swimmers enjoyed the wonderful facilities of the Coetzenburg swimming pool in Stellenbosch where swimmers from 8 years to 67 years old competed.

The badminton players were not only competing against each other, but were treated with an excellent exhibition of badminton by Johan Kleingeld and provincial players.

Friday afternoon the squash players enjoyed the courts of the Virgin Active club while the atmosphere at the ten pin bowling competition in the Grand West Casino facility was contagious.

On Saturday 11th October all athletes (102 of them) and supporters gathered at the Coetzenburg Athletic Stadium in Stellenbosch to enjoy a day of track and field events. The weather was perfect and the competition of high standard. A permanent highlight of this day is the children participating in the sprint, long jump and ball throw events. We thank Megan Frye and her team from Kidney Beanz for their sponsorship allowing 11 children to join with other from over the country to Celebrate their New Lives.

All athletes were rewarded with participation medals at the Gala evening on Saturday. It was clear that new athletes and their families, who arrived on Thursday, became friends and "family" members during three days of competition and Celebration.





The shortage of organs... a challenge to recipients



Fiona McCurdie
Transplant Co-ordinator
Groote Schuur Hospital
Cape Town

Two questions that transplant co-ordinators frequently get asked are why most patients wait so long for transplants and why there are so few organs available for transplant when there are so many traumatic deaths in South Africa. Many people reading this article have probably already received their precious transplant and will hopefully never have to go through the waiting process again but for those who are waiting these answers may help explain the situation.

Despite the fact that there are many traumatic deaths in SA as well as deaths due to brain haemorrhages and other causes, many of those patients are either not organ donors, or do not become donors due to a variety of reasons – their deaths occur outside of a hospital, they have medical or surgical complications that preclude organ donation, their death occurs in an isolated location, or there is a lack of resources to support the donation process.

An organ donor is a patient who is declared brain dead and is on a ventilator in an ICU or Emergency Unit in a hospital. The doctors treating the patient need to refer the patient to the transplant team and then the transplant co-ordinator approaches the family for consent for organ donation (if the transplant team agrees that the patient has no other injuries

or medical problems that cause him/her to be an unsuitable donor). Unfortunately a number of brain dead patients are medically unsuitable as donors, many brain dead patients are not referred to transplant teams by treating doctors and many families do not give consent for organ donation due to emotional, cultural, educational and religious reasons. The net result is that very few organs eventually become available for transplantation.

This all leads to another question - what can be done about the situation? And then a challenge! The transplant co-ordinators and the transplant teams around the country together with the Organ Donor Foundation are involved on an on-going basis with education programmes and events for colleagues and the public. An effort is made to make colleagues more aware of the need to refer all brain dead patients to transplant teams and to encourage families to discuss their wishes about organ donation with each other.

I would like to challenge the transplant recipients reading this article to consider assisting the transplant teams and the Organ Donor Foundation. When the public and members of the medical profession meet recipients and hear of their experiences, the need for organs becomes more real.

So please - contact the ODF or your Transplant Team/Co-ordinator and offer your help with their education programmes or ask for their advice or help about setting up an awareness talk/ function about organ donation and transplantation at your workplace or church or community centre or nearby school. In this way you can show your community how grateful and fortunate you are and how they can help others who are in the position you were in.

The privilege of transplantation

Dr David Brittain

Clinical Haematologist, Director

Alberts Cellular Therapy

Drs Thomson, Brittain and partners incorporated

Netcare Pretoria East Hospital

Pretoria East

A few weeks ago a young man said to me "I am so privileged to be able to have this transplant". "What do you mean?" I asked. "I am privileged to have access to a team of specialists who can do this"

To put this in context, he is 32 and previously had never been ill. He had just completed his induction chemotherapy for Acute Lymphoblastic Leukaemia and was at his final planning session for a matched, unrelated donor, bone marrow transplant to consolidate his therapy.

After preening a bit in the glow of this compliment (even transplant physicians are human) I got to thinking, what this "privilege" entailed. The more I thought about it, the more I realized we are all privileged to be part of this. The complexity of the science and technology blended with the goodwill of the donor required to transcend international borders is nothing short of miraculous.

A bone marrow transplant performs two essential functions:

- Rescue/replacement of the diseased or damaged bone marrow by healthy stem (seed) cells to allow recovery of the marrow to its function of making blood cells. This permits the administration of whole body irradiation or intensive chemotherapy to treat cancers, especially those of the blood forming organs
- It replaces the patient's immune system allowing recovery of immune function in inherited disorders but also facilitating an immune response against some cancers to help eradicate them

Because the blood circulates through all tissues and the transplanted marrow is immune-competent the tissue-typing match needs to be very rigorous. The human tissue type/group (Human Leukocyte Antigen) is enormously

diverse and complex to allow us to fight a diversity of infections. And since only a third of people have a tissue group matched sibling this means we need a very large pool of volunteer donors. There are over ten million registered donors in the world donor data banks and current efforts to expand this are focused on ethnic minorities and rare tissue types or associations.

So consider this, to get a tissue matched unrelated donor needs a huge international system of scientific co-operation and emotional commitment balanced by strong ethical considerations.



The training and commitment from harvesting, laboratory testing, pharmacy support, radiology, nursing and para-medical services is intricate and necessary.

The donor volunteers to give some of their bone marrow stem cells to help an unknown person anywhere in the world. They trust the donor clinic to look after their interests and ensure they come to no harm and are medically, psychologically prepared and harvested.

The patient and his team trust the donor centre to accurately type the donor, ensure the product is clear from transmissible diseases, is adequate for the transplant and the donor's commitment is ensured to allow intensive preparatory treatment for the transplant.

This trust is earned again and again on a daily basis by demonstrating adherence to standards, double and triple checking every step of the way from harvest, transport and transplant. The actual transplant is a small step in a long series of necessary processes that are performed on a very high standard. The training and commitment from harvesting, laboratory testing, pharmacy support, radiology, nursing and para-medical services is intricate and necessary.

This is the miracle and this is what makes it a privilege to be part of transplantation. The good will, co-operation and collaboration on so many levels.

Perception of transplantation from government sector



Dr Sanjay Lala MBBCh (Wits), DCH (SA), DTM&H (Wits), FCPaed (SA), MMed (Wits), PhD (London)
Department of Paediatrics
Chris Hani Baragwanath Academic Hospital
Johannesburg

The Department of Paediatrics at the Chris Hani Baragwanath Academic Hospital (CHBAH) offers a gastroenterology, hepatology and nutrition service and sees about 650 patients per year. Our clinic runs on a weekly basis and is staffed by three paediatric gastroenterologists, all of whom have major clinical responsibilities in the general paediatric wards.

Most of our patient's families come from impoverished backgrounds and are reliant on our services to provide medical care for their children. Each year, we see scores of children with chronic liver disease, mostly biliary atresia. Sadly, only a handful of children undergo liver transplantation and choosing which children are suitable for liver transplantation is perhaps the greatest ethical and moral dilemma that confronts paediatricians working in the government sector.

What are major difficulties of treating children with chronic liver disease at government hospitals?

The steady deterioration of services at government hospitals is well documented and CHBAH, despite being a major academic teaching hospital in South Africa, is no different. There are no full-time paediatric gastroenterologists or nursing staff needed to cope with the medical needs of the hundreds of children who attend our clinic. Our children have to share over-crowded and under-staffed outpatient and inpatient facilities (in particular, we have no isolation facilities to prevent exposure to highly infectious pathogens such as respiratory viruses and tuberculosis). There are also perennial problems with the regular provision of essential medications and we do not have a highly reliable laboratory service. The hospital cannot afford to provide nutritional supplementation to most of our children and most parents cannot afford to purchase additional nutritional supplements.

How do we approach transplantation?

In the past, so-called 'state patients' were referred to the Red Cross War Memorial Children's Hospital (RCWMCH) in Cape Town, which was the only centre performing paediatric liver transplantation. However, there is very limited capacity at RCWMCH to offer liver transplantation to the vast majority of children managed at government facilities, and only a handful of paediatric liver transplants are performed per year. In recent years, the development of a world-class transplant facility and the availability of living-related donor transplantation at the Wits Donald Gordon Medical

Centre (WDGMC) have significantly improved the numbers of children who receive liver transplants. This development has, however, increasingly placed pressure on paediatric gastroenterologists working in the government hospitals to refer children for liver transplantation. Nonetheless, despite the availability of this surgical expertise, there is no capacity to provide adequate life-long medical care at CHBAH following transplantation and the paediatric nephrology service at the Charlotte Maxeke Johannesburg Academic Hospital can only provide post-transplant follow-up care for a restricted number of children.

How then do we approach the issue of liver transplantation for children who are treated in government hospitals?

Although we consider each child on an individual basis, we use the following general approach:

- If there are no medical or psycho-social contra-indications to transplantation, we refer the child to the WDGMC and/or Red Cross Hospital. If the family has medical insurance, we tend to refer the child to WDGMC because of the greater likelihood of obtaining a transplant (either living related donor or deceased donor)
- If there are medical or psycho-social contra-indications to transplantation, we manage the medical complications attributable to chronic liver disease as best we can, and we aim to provide as much holistic care as possible, taking into account the limited resources available in the state sector. During this time, we continuously re-assess the medical or psycho-social circumstances, and if these have improved or stabilised, we will consider referring the child for transplantation.

In general, most of our children are not referred for transplantation because of adverse social circumstances, and the inadequate resources available in government hospitals to deal with these problems.

What is our relationship with the Donald Gordon Medical Centre?

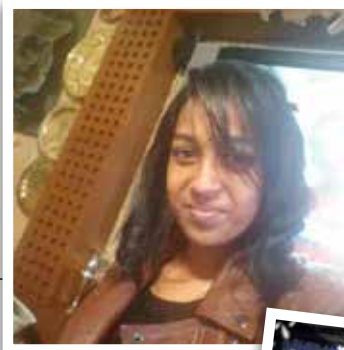
In the past couple of years, we are pleased because several of our children have received liver transplantation at the WDGMC and, if more resources are made available to children requiring liver transplantation at government hospitals, many more children would be referred for this life saving procedure.

Patient interview: Prenola Govender's journey

Kevin Govender shares his 15 year old daughter's story of her lifesaving liver transplant



Mr Kevin Govender
Durban
KwaZulu-Natal
Father of liver transplant recipient, Prenola



Family:

Has very close family ties: Father - Balkie, mother - Priscilla and brother Nico.

Hobbies:

Dancing, listening to music, baking, watching series and Indian movies.

Interests:

Music, her favourite artist is John Legend. A Manchester United supporter, her hero is David Beckham.

Prenola's Likes: Fashion, sea food, being with friends especially NIKSHA AJODHA who has been a sister in her difficult times. She also likes being called "MY BABY GIRL" by her DR GHILA

Prenola's Dislikes: Needles and drips, boiled veggies. The thing she dislikes the most is when her father treats her like a four year old!

When did Prenola have her liver transplant?

She had a transplant in 2013 which was made possible by her donor. Prenola is indebted to her donor's family for the rest of her life and they are indeed always in her prayer.

How did Prenola come to have a liver transplant?

To be honest if you believe in miracles then you would understand our situation. It all started with Prenola not feeling well. We took her to the trauma unit where she was diagnosed with having built up fluid in the lung. She was immediately admitted to ICU, where she remained there for a few weeks before being discharged. Prenola remained home for a few weeks before being re-admitted and it was here through the miraculous work of her doctors that Prenola was diagnosed with liver disease. Because of her condition Prenola was air lifted to the Wits Donald Gordon Medical Centre where she was stabilized, placed on a waiting list and sent back home. Almost a month later we received a call informing us that Prenola had a willing donor.

How has having a transplant changed your daughter's life?

We are grateful to GOD that she is okay and doing well. We keep to our regular checkups. She is active and enjoys a healthy life style like any other normal 15 year old.

Have you found an improvement in your daughter's quality of lifestyle?

Most definitely, as a parent or any other parent it is hard to see your child go through this, you can do nothing and we therefore want to thank all the doctors, nurses and every single person who have supported us. God bless you all!

What are the challenges of your daughter's lifestyle as a transplant patient?

Not many, we just abide by what is expected of us in terms of taking certain precautionary measures, the adaptation of taking her medication on time every day and eating and staying healthy.

What advice would you give to those who have been newly transplanted?

Firstly thank GOD for his marvelous work and the only way to make GOD happy is to do good and be good. Do as your doctor's request. Eat well and lead a healthy life style.

What resources have helped you and your daughter cope with transplantation?

Books, websites and most of all support from the doctors, nurses and staff at Mount Edgecombe Private Hospital and the Wits Donald Gordon Medical Centre.

What advice would you give to potential donors?

Being able to give the "gift of life" is something that words cannot explain. Becoming a potential donor would be the greatest one can achieve to see the happiness one brings to others.

Anything else you would like to add?

Live life to the full as you never know what tomorrow might bring. Become a donor as there is someone out there that needs your help.