



Transplant News

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South African Transplant Society

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Editorial

Professor Russell Britz
Editor

Again, an informative and exciting edition of Transplant News that highlights the depth of work and dedication involved in the high-tech procedure of transplantation. This edition gives insight into the numerous aspects and the dedicated network of people who work for the benefit of patients.

Michael Pienaar touches on the paediatric need for liver transplantation and the availability of liver transplant for this group. With living donation for liver transplant now established in South Africa, new hope is provided for this group of families. An awareness of neonatal jaundice is stressed.

Jooste Vermeulen provides a heartfelt account of his family's anguish and journey that will, no doubt, resonate with and give encouragement to those who are experiencing similar difficulties.

The psychological aspects of transplantation are dealt with by Tina Sideris, a transplant psychologist, and will enlighten many patients who feel distressed by deterioration in mental wellbeing. Tina stresses that their condition is precipitated by the lack of organ function and that mental function and wellbeing can return once organ function is re-established.

Red Cross Hospital is to be congratulated in a sustained and productive transplant programme of 50 years duration and in continuing to provide a strong service to patients. This is a testament to their teaching programme, transmitting skills from one generation of medical personnel to the next.

The Organ Donor Foundation (ODF) again demonstrates its continuous efforts to promote transplantation in South Africa. An awareness of 80% of our population knowing about transplantation is a result of their consistent work in the past. Data is critical in directing education programmes.



An update on the Transplant Games provides assurance that there is a good, active life after transplantation. It will provide patients awaiting transplantation with reassurance and a light at the end of a tunnel from their current viewpoint. Many thanks to the contributors for their valuable contributions.

Neonatal Jaundice - A guide for parents

Dr Michael Pienaar
Paediatrician
Bloemfontein



The arrival of a newborn baby is the culmination of months or, for some couples, years of anticipation and excitement. This period is unique and is characterised by rapid development and adjustment to life outside the womb. The numerous changes during this period lead to a number of conditions that affect newborns (neonates). These range from benign variations and easily treated ailments to life threatening or debilitating disease.

Jaundice refers to a yellow discolouration of the skin and the whites of the eyes (sclerae). It is caused by accumulation of a chemical (bilirubin) in the skin. Bilirubin is the product of the breakdown of red blood cells. In newborns there is rapid turnover of red blood cells as they begin to adjust to life outside of the womb. Usually the bilirubin is removed by the liver and passed in the stool and urine. Newborns have not yet developed their livers enough to deal with this increased load and this is why many babies will develop a noticeable yellow discolouration. Very high levels of certain types of bilirubin may be toxic to the infant brain.



When not associated with other disease or complications we call this physiological jaundice. This is generally not associated with negative effects but may need to be treated by a paediatrician using specific wavelengths of blue light (phototherapy). It is, however, important that jaundice be taken seriously. Firstly, there are a number of other causes for jaundice that need treatment and

secondly, if the jaundice is severe it may lead to irreversible central nervous system injury (bilirubin induced neurological dysfunction – BIND). A number of the other causes of jaundice may lead to irreversible liver damage if untreated or be associated with other complications.

It is a common occurrence for babies with severe jaundice to only present to a paediatrician once they have been jaundiced for some time. While it is true that jaundice is, for most infants, a transient, mild and harmless phenomenon – many children with severe jaundice or jaundice associated with significant liver or systemic disease present with advanced disease after having

been reassured. This is unfortunate as many causes of liver disease in infancy are treatable if detected early but may progress to irreversible liver damage (cirrhosis) if not recognised timeously. This is especially true in the case of biliary atresia (a condition where the bile drainage ducts fail to develop normally), which is the most common cause for liver disease in childhood requiring liver transplantation.

It is important that babies be screened for jaundice during the first weeks of life. This should be done during your paediatrician's postnatal visit as well as at your follow-up either at your paediatrician or at the well baby clinic.

Bilirubin levels can be measured in different ways:

- Transcutaneous bilirubinometer – painless and quick but less accurate
- Blood sample sent to lab – may involve a blood draw and sample needs to be processed in a laboratory

Generally bilirubin levels can be measured by a doctor or nurse using a handheld device that is able to measure the bilirubin in the skin – transcutaneous bilirubinometer. It may, however, be necessary to draw a blood sample also to measure the bilirubin level accurately and so that other tests can be performed. It may also be necessary to repeat these measurements to evaluate the severity of the jaundice.

As mentioned before, any infant with jaundice should undergo careful evaluation by an experienced professional, but a number of specific symptoms warrant particular concern and should be brought to the attention of your doctor.

Any of the following are, however, worrying signs and should attract urgent attention:

- Pale stools
- Dark urine
- Distended belly (abdomen)
- Poor growth
- Lethargy, excessive irritability, reduced activity or poor feeding
- High pitched cry
- Jaundice lasting longer than two weeks.

In summary, many infants will be affected by a degree of jaundice, which will be a transient phenomenon, which does not lead to harm. It is however critical that infants with jaundice be evaluated by a health professional experienced in the care of newborns and infants and that they be investigated and treated timeously and appropriately.

Making sense of organ failure and organ transplantation: Psychological challenges pre transplant

Dr Tina Sideris (D. Litt et Phil)
Clinical Psychologist
Wits Donald Gordon Medical Centre
Parktown



“Shortly after my transplant people would often want to know what happened to me. I myself wanted to understand the extraordinary events that had so altered my life and so I told over and over the medical narrative of how I was ill, what I had suffered from, how I had got my new kidney and how well I was afterwards. And whilst telling it I felt muzzled. There were many things I could not identify, that lurked just beyond my frame of perception.”¹

Writing about her experience, Dr Richards realised that she struggled to find what her illness and treatment meant to her.^{1,2}

As a psychologist meeting people who present with organ failure, I am struck that many are at a loss for words. ‘Shock’ is frequently used to describe the reaction to needing organ replacement. Initially it seems words cannot adequately express what it’s like learning one has an organ that is not functioning, and what it’s like to face the threat of death. Fortunately, medical explanations of how the body works, and how it can be treated, provide immense relief and hope.

Nevertheless, most patients know that generally the medical conversation does not cover the disruption of life, and the suffering that is a consequence of organ failure. By enabling reflection on what it’s like living with organ failure, and on the accompanying emotional and cognitive challenges, psychological consultation provides an opportunity for making sense of the shocking experience.

The psychological changes accompanying organ transplant are associated with three factors:

1. Organ dysfunction
2. The threat of death
3. Receiving the organ of another

Each of these is more or less prominent, with subtle differences in meaning during different phases of illness and treatment – pre transplant, actual transplant and post transplant.

Pre Transplant

Organ dysfunction

Loss is a dominant theme in this phase of the illness.

- Loss of physical wellbeing with fatigue, weakness and pain, and therefore loss of the capacity to act and relate
- Loss of capacity due to ‘brain fog’ and mental confusion
- Loss of work and income
- Loss of independence

The emotional symptoms that accompany organ failure and the losses involved are consistent with the diagnosis of **DEPRESSION**

- Low mood
- Feelings of guilt and worthlessness
- Hopelessness
- Feeling everything is an effort
- Withdrawal
- Irritability
- Poor sleep, loss of appetite and loss of libido

The emotional symptoms that accompany physical vulnerability and becoming dependent on others are consistent with the diagnosis of **ANXIETY**.

- A sense of impending doom
- Repetitive thoughts of the worst outcomes
- Fear of losing control
- Somatic symptoms – racing heart, sweating, light headedness, shaking, and panic.

When one organ doesn’t function the physiological fallout may affect other organs, including the brain resulting in **COGNITIVE DECLINE**.

- Lowered ability to concentrate and pay attention
- Short term memory deficits
- General feelings of fogginess and lowered ability for planning and organising
- Difficulty in solving visual and spatial problems.

The threat of death

Death is at the core of organ failure, and its prevention at the centre of organ transplantation. While in health we are generally detached from our mortality, illness “reattunes” us to the existential certainty of death³ and the fear of non-existence and leaving loved ones.

Receiving the organ of another

Generally there is tremendous relief about the fact that receiving the organ of another person may alleviate suffering and prevent death. Yet, it is not unusual for relief to co-occur with:

- Guilt about the death of the donor
- Worry about the dangers of surgery for living donors
- Fear that the organ won’t work
- Waiting with a sense of being in limbo not knowing if an organ will become available

In conclusion it must be emphasised that these psychological and existential challenges should not be considered secondary effects. Instead they are best seen as part of the illness, and requiring serious attention and care.⁴

References available on request.

The hope and healing of a second chance: A father's story

Mr Jooste Vermeulen
Father of a transplant recipient
Organ Donor Foundation



It is hard to describe the feeling of immeasurable gratitude, and especially because there are so many people to say thank you to. Rijk Vermeulen, my 14 year old son, was gifted an opportunity to quality of life and ultimately for us, his family, a chance to have him alive with us for much, much longer. The loved ones of a passed away child made this offering by giving consent towards the donation of their precious one's liver and kidney to our Rijk in January 2017. There is no financial or any other measure that can compare to the selfless gift from Rijk's donor family. Thank you to our donor family.



Rijk spent most of his first two years in hospital

In 2006 Rijk was diagnosed with congenital haemolytic uremic syndrome, which is an aggressive ultra rare condition that affects the complimentary immune system that damages the organs, and in most cases leads to end stage renal failure. Rijk was one year's old when he was put onto peritoneal dialysis for 5 years. After complications he was moved on to haemodialysis until he was 12 years old when he received his liver/kidney transplant.



Rijk adored the staff during dialysis at Red Cross Children's Hospital

Talking about hardship for Rijk while waiting for an opportunity to improve his quality of life is worthy of a mention, but at the same time, not forgetting how lucky Rijk was to have received his transplant. For many of the 12 years, countless days were spent admitted in hospital. Many days spent in ICU and many more in hi-care. Rijk went under the knife 31 times. His first and second birthday was celebrated in the ward where Rijk's mummies (the ward nurses) got to know Rijk and me very well. Without realising it time started to morph into one continuous battle and months turned to years and unforgettable friendships were forged with other parents, nurses and doctors. Many nights I slept on hospital floors too scared to go home. It was during these days that I realised just how lucky we were despite our struggles. I for one, at least had an old jalopy to bring Rijk for dialysis. No need to brave the relentless winter rain of Cape Town on a Minibus Taxi even if we did smell of petrol when we arrived for dialysis at 6 in the morning.

I learned that the battle was not always won and children I got close to - me often entertaining them with stories - beds were vacated for good during the midnight hours when the wailing of a mom woke me up. The unspeakable darkness that filled the pit of my stomach and overwhelmed my mind was hard to ignore, thinking: When will a white sheet cover my Rijk's precious face?

Then the days got even darker and the uncertainty turned into resentment and anger and you secretly wish for an outcome even if the outcome is a final chapter. This is the time you start to envy the parents whose children left the hospital for good - dead or alive.

Despite years slipping by one never became used to the intensity needed to keep focused on monitoring Rijk's fluid intake and diet. All drinks had to be controlled to prevent the build-up of sodium causing severe thirst. Only 300ml, just more than a cup of fluid was allowed in 24 hours. To motivate a child to do this for two or three years is an immense challenge. To do this for 12 years left deep-rooted emotional scars both for Rijk and his loved ones.

Children on dialysis are known to go to any length for that extra drop of water even if it means having a drink from the toilet if a parent is not watchful. At home taps were locked or removed and only left in places that could easily be observed by me. Socialising and school is an impossible option as water, drinks and the wrong foods were easily accessible everywhere.



Few days after successful transplant



Rijk's first ever swim

There is no comparison of Rijk's life before the transplant to afterwards. Rijk couldn't attend school due to being at dialysis 3 times a week and no schools had the resources to ensure that he didn't steal water while there. The closest to

normal schooling was the time spent at Kidney Beanz Trust. He couldn't play at friends' homes and he had to be watched constantly during outings ...and essentially the days of his life revolved around a desperate need for all the wonderful drinks, ice creams and food that others enjoy. Post transplant and Rijk's quality of life is a miracle. He still has diet and sodium restrictions but can now enjoy a varied diet and no longer suffers from constant thirst. He is enrolled in school and loves it. He has friends and best friends and can visit and play freely. For the first time, after 12 years he was finally able to live a normal life.

The turnaround in Rijk and our lives is because a donor family during their worst moment and at a time of terrible grief said yes to consent. His life is a miracle due to the tireless efforts of the transplant coordinators, nurses, doctors and medical experts who have cared for and treated Rijk to ensure he would not only live but to live with joy and not pain.

50th anniversary of paediatric transplantation - 50 years giving children a second chance of life

For more than half a century, pioneering paediatric doctors have walked the extra mile to give our children a fair chance to receive a life saving organ transplant when needed.

As South Africans we are resourceful and talented and every one of our transplant teams are determined to ensure that no stone is left unturned to give our little loved ones, our precious children, a fighting chance to get a much needed heart, liver, kidney, bone marrow or skin, when they desperately need it.

Many significant milestones have been achieved which need to be celebrated: The 50th year since our first Paediatric Renal Transplant at Red Cross Children's Hospital/Groote Schuur Hospital; and in the years of success that followed: The 40th year since the first Paediatric Bone Marrow Transplant and Paediatric Heart Transplant and the 30th year since the first Paediatric Liver Transplant.

These "firsts" were merely starting points and since then we have achieved:

- 249 Paediatric Kidneys
- 135 Paediatric Livers
- 120 Paediatric Bone Marrow Transplants
- 22 Paediatric Hearts

We celebrated these achievements on the 5 March 2019 at Red Cross Children's Hospital with specialists of yesterday

and today reminiscing good and sad memories of success and some...

Those that attended the special occasion enjoyed a plethora of golden memories and were given a glimpse into what lies ahead for paediatric transplantation in South Africa.

Synopsis of the day

The day's programme included a series of short talks and vignettes by doctors, nurses, parents and patients concentrating on the past, present and future as a collaboration between Groote Schuur Hospital, Red Cross War Memorial Children's Hospital and University of Cape Town.

"Having a second chance at life especially our little paediatric patients, gives joy to not only the family of these vulnerable little ones, but it gives us within the health system great joy to be able to add value to the lives of children in this country. I would like to commend all our specialist doctors, and nurses for the wonderful work they have done over the years at Red Cross War Memorial Hospital and Groote Schuur Hospital. It is an honour to celebrate this milestone"

Dr Nomafrench Mbombo
Western Cape Minister of Health

Organ Donor Foundation: Looking back over the past year

Samantha Nicholls
Executive Director
Organ Donor Foundation
Cape Town



Uluntu Educational Project

The most exciting and promising development of 2018 – 2019 is the Uluntu project, which has shown tremendous growth and from which we have learned a tremendous amount.

The most important and telling fact was from surveys conducted, which showed almost 80% of South Africans know about transplantation. We should stop a minute and think about the following fact.

The people we surveyed told us that 80% of them will accept an organ and tissue if they need it but this is the telling reality – over 70% are not comfortable to be an organ & tissue donor.

The conclusion we make is that, although South Africans know about or have heard about transplantation, they do not have enough information to make an informed decision towards consent.

What must we do about that? It is clear that people need intensified education to make an easy decision for organ donation consent.

The ODF has realigned its focus significantly and will be focusing the majority of its energy towards educational projects in vulnerable communities. This forms the basis and the primary focus of the Uluntu Project.



Uluntu Project

Awareness Events

During the past 12 months, the ODF shifted its focus and increased its face to face and educational drives and with that a lot more activities on the ground. Awareness events are a fantastic opportunity to intergrate organ donor awareness into our community. In the last period, the ODF participated in **111 awareness events** – this is an average of **almost 3 per week**.

The ODF would not have been able to achieve such a strong presence and to carry out so many activities without help from our extremely passionate and dedicated volunteers located throughout the country.

All new volunteers are fully trained at the volunteer training courses. We have 1165 registered volunteers on our books in South Africa and we often approach them to do awareness at main city centres and even to the remote corners of our country.



In July, due to the support of the tissue partners, the ODF was finally able to send out brand new volunteer kits to the most active volunteers. The volunteer kits include a branded trolley bag, tablecloth, table x-frames, pull up banner, branded golf shirt, perspex brochure holders and promotional materials, amongst other items.



Awareness event stand

Sporting Events

The past year was a busy one and we were fortunate to be present at many sporting events – far too many to report on individually. To mention but a few: It was an honour to have a presence at the National Transplant Games held in Port Elizabeth and to support and encourage all the participants. We again are extremely grateful and appreciative to the riders who represented the ODF at the Telkom 947 Cycle Challenge and

to Captain Paula Terblanche and her fellow police officers who represented the ODF at the SAPS National Cycle Championships held in Mpumalanga, which led to the entire SA Police Gauteng Team registering as organ & tissue donors. We had a fantastic presence at Walk the Talk in Johannesburg on 22 July and of course one of the most memorable was Spinnekop, Eric Nefdt whose story was covered in the previous Transplant News.



Walk the Talk

Our annual 5km Zoo walk took place on the 6th October at the Jhb Zoo and was a wonderful success. We would like to thank our sponsor Tiber who made this fantastic day possible, which is so important to our patrons in transplantation.



Johannesburg Walk

We ended off the year with the Ride for Hope when we welcomed Braam Blom and his family on 10 December at the Netcare Christiaan Barnard Memorial Hospital where he was welcomed back by the ODF, hospital management and staff after a grueling 1850km journey to raise awareness.



Ride for Hope

Media Exposure

During this past year, the Organ Donor Foundation received over R14,5 million Rand worth of free media coverage with a reach of 141 million times – this means that South Africans were reached almost 3 times each. 114 times organ donor awareness was published in magazines and newspapers, 110 times on the internet and 96 times on radio and television.

The value of partnerships and collective efforts

August 2016 marked the beginning of the highly successful partnership between the ODF, Bone SA and the Tissue Banks: The Eye Bank Foundation of SA, Gauteng Cornea and Eye Bank, KwaZulu Natal Cornea and Eye Association, Tshwane University of Technology's Centre for Tissue Engineering and the University of Free State Tissue Lab. **The partnership has provided the means to achieve so much more than we could have on our own and we are extremely proud and excited to announce that the partnership has continued for a third year.**

Partnerships are key to achieving more and it was as a result of fantastic partnerships with Capital Legacy, Dischem and Pick n Pay pharmacies and new partnerships with Leap Frog Property Group, Creative Coffee (NetCafé & Coffee Couture) and Spinnekop that made it possible for us to be everywhere at the same time this year.

World Transplant Games 2019

Hermann Steyn
Executive Secretary
South African Transplant Sports Association



South African Transplant Sports Association (SATSA) are delighted to announce that a team of 62 athletes will represent South Africa at the World Transplant Games in Newcastle, UK from 15 August 2019 until 24 August 2019.

The World Transplant Games, take place every 2 years, and are supported by the International Olympic Committee. It represents the largest organ donor awareness event in the world, featuring a week of 16 sporting events. Team South Africa will join over 2 000 other transplant athletes from 70 countries across the globe.

Hermann Steyn, Executive Secretary of SATSA said: "We are thrilled to welcome 15 new faces to our squad. Our athletes certainly deserve the same recognition as the Olympic and Para Olympic Games. These athletes have all survived a heart, lung, kidney, liver or bone marrow transplant.

"It is always a little daunting competing at the World Transplant Games for the first time, but with the help of those who have



been before the experience will ultimately be a rewarding one for the athletes!

"Selection on our team is just the beginning! It is an enormous commitment of both time and money. The last 6 months have been busy for the athletes, keeping fit, regularly training in their sport, attending two training camps, doing publicity and trying to raise the R 32 000 per person to get there! However, the opportunity to represent their country, celebrate life and in doing so, paying tribute to their donors, is the goal"

Hermann added: "Not only are these athletes' ambassadors for our country, but they also hope to raise more awareness here in South Africa and globally, of the need for more people to sign on to the Organ Donor Register and discuss their wishes with family and friends.

To register on the Organ Donor Foundation, please go to www.odf.org.za to register online. Most importantly, please discuss your wishes with your family and friends – thank you

