

Transplant News

Vol 19 No 1 Issue 64 - June 2020

Official newsletter of the
South African Transplant Society

Editorial Board



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Editorial

Welcome to 2020 and what is going to be a very different kind of year for us all. Please focus on staying safe and let's all do our part to build a stronger South Africa by showing our compassion and togetherness in this time of crisis.

The need for organ and tissue donation and patients needing them is not going to disappear. In this edition of the Transplant News we have four articles for you to consider.

Sandra Venter gives us a closer look at the South African Tissue Bank Association (SAT-IBA) and the excellent work they are doing to bring together all the role players in the field. Their message that South Africa needs to create a culture of donation is exactly right. While organ donors can only come from patients who are supported in ICU on mechanical ventilation the opportunity to recover tissues is much larger. As a country we want it to be the norm rather than the exception to consent to donation and by linking tissue and organ donation messages together it means that all options of donation are offered to patients and their families at the end of life. We look forward to their hosting of the World Congress in Tissue Banking in Cape Town in September 2021 - a true honour.

Marchelle Lake gives an excellent review of the rehabilitative process in lung transplantation. In no other transplant is the evidence as strong to support pre and post conditioning around the time of your transplant. The link to outcomes is very real and hard work

really does take you places. Ultimately transplantation is about saving and improving the quality of people's lives and physiotherapy programmes contribute to that goal greatly not just for lung transplants.

Harriet Etheredge and June Fabian write eloquently about international perspectives on transplant centre accreditation. It is all about building trust and in South Africa we need to do that through transparency and accountability. In lieu of the government driving this process it is beholden on transplant centres to ensure the highest standards. Reporting anonymised aggregate data annually will allow centres to benchmark themselves against the national average and be upfront with donors and recipients about the organs they are entrusted to transplant.

We end off with Sam Nicholls giving an update on the activities of the Organ Donor Foundation (ODF), the growth they have achieved and their efforts to link with companies and organisations willing to link their databases with the ODF to spread the message of organ donation. While the ODFs focus is public awareness she makes the very important point that high performing systems place emphasis on the network of professionals dealing with families in their time of grief to ensure that no opportunity for donation goes unmissed. South Africa needs to expand this network to improve our consent rate. Consent is always required for donation to take place and being on the registry is a first step in this process.

Hope you enjoy the articles and please keep safe during these trying times.

Dr David Thomson
Editor

August is National
Organ Donor Month



The South African Tissue Bank Association (SATiBA)

Sandra Venter
Vice President, Public Relations Officer: Centre for Tissue Engineering
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The South African Tissue Bank Association (SATiBA) is a not-for-profit organization that aims to support all South African tissue banks in regulatory and legal matters, data collection, training, accreditation, quality assurance, communication and collaboration.

In broad terms, a tissue bank is a facility which recovers, processes, stores and distributes human tissue for transplantation and therapeutic purposes. While recognising that not all the elements of tissue banking are defined in the National Health Act, and considering the need expressed by industry partners, SATiBA includes the following disciplines in its operational definition of tissue banking: Cornea and eye, skin, bone and tendons, heart valves, stem cells, blood and blood-related products, amnion, gametes and bone marrow.

Since the inaugural meeting which was arranged in collaboration with the South African Transplant Society (SATS) in 2012, SATiBA has done the following:

- Registered as an NPC in 2015.
- Hosted 2 international congresses. Co-hosted the 2019 SATS SATiBA congress with the theme “Changing and Improving South Africa’s transplant future”.
- Hosted several locally relevant workshops around tissue banking issues.
- Formally endorsed the Declaration of Istanbul against organ trafficking
- Become a sister association of the European Association for Tissue and Cell banks (EATCB)
- Is actively involved as an observer member of the World Union of Tissue Bank associations (WUTBA).

Since transplantation is entirely dependent on people consenting to donate organs and tissue after death, it is necessary to develop specific strategies to create a South African culture of donation.

SATiBA will host the 9th World Congress in Tissue Banking in 2021 in Cape Town, South Africa.

All around the world, the work of tissue banks is closely related to organ donation and for that reason SATiBA maintains good relationships with our colleagues in organ transplantation. Closely related to this is the need for effective organ and tissue donor public awareness initiatives. Over the last 3 years, a number of tissue banks have actively supported the work of the Organ Donor Foundation (ODF). This is an effort, not only to help build capacity, but also to significantly increase the dissemination of the message that organ and tissue donation saves lives.

As a result of the 2019 SATS SATiBA pre-congress workshop, SATiBA embarked on a sector analysis project late last year with the persistent shortage of deceased donors identified as the most pressing challenge. The meeting was attended by leaders in the tissue banking arena and representatives from SATS and the ODF. Several presentations highlighted the current barriers to donation and a long term plan of action to address these barriers was developed with several working groups formed to work on the following areas:

Governance structures

The main aim of this group is to look at current gaps in legislation and ways in which industry can assist and develop systems to provide an effective national framework for donation. Several opportunities were discussed, but the main priorities identified were:

- Drafting of a National Policy document on Organ and Tissue donation and transplantation.
- The establishment of a national procurement authority, drawn from effective models elsewhere in the world, which would include aspects such as effective governance structures, standardisation, and formal referral systems.
- Although formal accreditation is not an immediate priority, it is expected to flow from this initiative.

Data collection

To effectively address the current challenges, it is important to have access to the data – this group will aim to collect real-time data from all role players covering various components such as tissue demand and supply, referral data, waiting lists, quality control methods and patient outcomes. The database will be sustainable and publicly accessible with built in links to the Global Tissue Bank Registry. Furthermore, to aid standardisation, the project will include establishment of guidelines and appropriate nomenclature.

Creating a culture of donation in South Africa

Since transplantation is entirely dependent on people willing

to donate their organs and tissue after death, it is necessary to develop specific strategies to create a South African culture of donation.

The goal is to reach a place where public donation after death is the norm – something everyone does. Priorities for this group includes:

- Setting up of an auditable, well-equipped 24-hour call centre and promoting one single telephone number for all referrals and enquiries.
- Fostering of close collaboration between stakeholders such as the ODF, SANBS, WCBS, SATS and government.
- Development of a sector media strategy building on current ODF media reach.

To actively increase donation in hospitals, forensic services and funeral homes, we will:

- Collaborate with relevant institutions to effect routine death referral guidelines, including mandatory assessment for potential donation and promoting good end-of-life care practices.
- Maintain and develop further local SATiBA outreach projects.
- Appoint educational officers dedicated to medical training.

The need for awareness and continued education of medical personnel has been identified as a crucial step to enable donation in the hospital setting.

Education and information dissemination

The need for awareness and continued education of medical personnel has been identified as a crucial step to enable donation in the hospital setting. This group will work towards:

- Allocation of necessary funding
- One-on-one interactions with nursing staff as well as specialists
- Establishment of local hospital transplant committees

To ensure a positive transplantation future for South Africa all role-players are encouraged to assist and participate in this initiative.

In conclusion, in the five years since its initiation, SATiBA has established itself as a credible organization that represents and lobbies on behalf of its members, the central objective of which is to improve the quality of life of South African patients through increasing donation, procurement and supply of high quality products that are both safe and effective.

Biannual conference

SATiBA holds a conference and workshop on alternate years. In 2019, we hosted a very successful joint conference with the South African Transplant Society (SATS) in Gordon's Bay which included both plenary and parallel sessions.



In 2021, we will be hosting an international meeting on behalf of the World Union of Tissue Banking Associations (WUTBA) in the Western Cape. Also in 2021, it is envisaged that we will again hold a joint meeting with SATS, this time in Gauteng.



“Every breath you take, every move you make” The rehabilitative process in lung transplantation

Marchelle Lake
Physiotherapist
Cape Town



The worldwide burden of chronic respiratory disease continues to rise, and lung disease now ranks amongst the leading causes of death.¹ Lung transplantation is an established therapy for end-stage lung disease that, in selected patients, can extend life and improve quality of life. However, it remains a complex therapy with a higher one-year mortality than for other solid organs. As there is a global shortage of donor lungs, the evaluation of a potential lung transplant recipient involves identifying factors that would adversely impact the success of a transplant. Physical frailty is a factor that has been shown to influence lung transplant outcome. Pre-transplant frailty is associated with delisting, waitlist mortality, decreased survival after transplant, and unplanned rehospitalisation after transplant.²



Zerina Antually (30) & Ilhaam Carr (22) -
Group Prehabilitation class

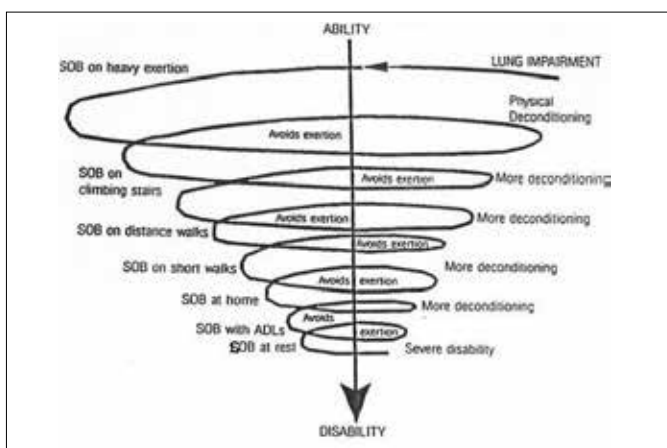


Figure 1. Downward “spiral of disability”
SOB - Shortness of breath

Frailty is defined as state of decreased reserve and resistance to stressors that results from cumulative declines across multiple systems, causing vulnerability to adverse outcomes.³ Common composite tools for quantifying physical frailty often include measures of leg muscle strength, gait speed, activity and energy levels, and weight loss. Physical frailty is common in advanced respiratory disease,⁴ and the progression of lung disease is associated with worsening exercise intolerance. This cycle of inactivity can perpetuate further disuse atrophy of the leg muscles, aggravating the tendency for exertion to cause breathlessness.⁵ It is this so-called “downward spiral” (Figure 1) that physiotherapy rehabilitation, through a structured programme of modified and appropriate exercise, hopes to interrupt. Physiotherapy rehabilitation is thus an important intervention that can modify frailty before a lung transplant, and can aid in facilitating the recovery of function post-transplant.⁶

Patiently awaiting the “call”

Prehabilitation

Successfully running a marathon requires training. Similarly, lung transplant recipients have better outcomes when they are not frail and are more robust before their transplant. Before transplant, waitlisted patients are introduced to the importance of exercise and activity, called “prehabilitation”. “Prehab” is a supervised programme of exercise training, health education, and breathing techniques, much like the validated pulmonary rehabilitation programmes that have been shown to improve quality of life in patients with advanced lung disease.⁷ Exercises are individualised to the patient, and modified according to the progression of the patient’s disease (with supplemental oxygen, if required) to maintain physical function and mobility.

Exercise training includes:

- Aerobic training: Such as walking on a treadmill/outdoors, cycling on a stationary bike
- Resistance training: Free weights, elastic bands, gym equipment, body weight exercises such as stairs, squats, wall push-ups.
- Flexibility exercises: Thoracic cage flexibility exercises to improve chest wall mobility.⁶
- Breathing exercises: Diaphragmatic breathing, inspiratory muscle training and pursed lip breathing to manage breathlessness.

Post-transplant Rehabilitation

Intensive Care Unit

To prevent muscles from weakening, rehabilitation within the ICU begins as early as possible, and the main priority is to get the patient out of bed, if their medical condition allows. Rehabilitation starts with sitting out in a chair, marching on the spot and progresses to walking within the ICU. During this time, the patient may still require supplemental oxygen, and the aim is to wean this off as soon as possible. Chest physiotherapy plays an integral part after the transplant, assisting with coughing, clearing mucus from the lungs and teaching diaphragmatic breathing exercises to prevent atelectasis.⁶



Lisa Beyers (18) 7 days post-transplant - performing chest physiotherapy

In the hospital ward

Once transferred from the ICU, inpatient rehabilitation continues. The main goal is to mobilise independently in the ward and perform activities of daily living. At this stage, rehabilitation is focused on strengthening to facilitate discharge from the hospital. Exercises can include stationary cycling, treadmill walking, stair climbing and strength training.⁶



Anchen Van Dyk (23) training on the treadmill

Discharge from hospital

A structured outpatient rehabilitation programme is followed for the first three months following your lung transplant. As part of your transplant clinic visits, you will attend rehabilitation. The aim is to achieve functional goals and return to pre-transplant strength. Goal-setting in this phase is very important. Exercise training is individualised to assist with reaching these short and long-term goals.

A home-based exercise programme is designed to continue exercise training at home. Once individualised goals are attained, patients are discharged from the formal service but encouraged to maintain rehabilitation as part of their daily life.



Tanya Bothma (40) and Anchen Van Dyk (23) hiking up Lion's Head post double lung transplant

In summary, rehabilitation provides an essential role in optimising functional capacity and fitness pre-transplant, and it improves the outcomes and quality of life post-transplant.

Acknowledgement

The author wishes to acknowledge with thanks the assistance and collaboration of Prof Greg Calligaro in writing this article.

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Promoting transparency, accountability and trust through Transplant Centre Accreditation - international perspectives

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What makes a transplant centre? Is it the fact that organ transplantation is performed at that location? Is it the skill of the healthcare team? Is it the needs of patients?

The answers to these questions vary depending on country and context. Certainly, organ transplantation requires a diversity of highly specialised health professionals, and transplant patients have unique healthcare needs. However, the making of a 'transplant centre' often extends much further – into a framework of extensive legislation and accreditation – depending on the country. The activities of transplant centres need to be guided by high-level national policies such as the system for organ donation (donation after circulatory death, living donation etc), stipulations about who may procure donor organs and how these will be allocated across the pool of potential recipients in need.

In many countries, hospitals may not offer organ transplantation unless they are accredited to do so by a national oversight body. This requirement is endorsed by the World Health Organisation – who mandate that member states adopt appropriate frameworks for transplant oversight and regulation.¹

In the United States of America (USA), transplant programmes are accredited by the Organ Procurement and Transplant Network (OPTN).² The OPTN is well-funded, and accreditation is dependent on factors such as the number of transplants performed at the centre, the rate of complications, the techniques used and transplant outcomes (how many recipients are still alive, and how many still have their transplanted organ). Notably, all OPTN-accredited transplant centres are obliged to report this data twice a year, and it is then made publicly available.³ Similarly, in the United Kingdom, all transplant centres must be accredited by the Human Tissue Authority (HTA), under conditions similar to those in the USA.⁴ Rigorous accreditation also takes place in several other countries.¹

We need to remember that none of these accreditation standards are intended to be punitive or prevent hospitals from offering transplantation. Rather, they are geared towards promoting patient safety and enhancing outcomes, hence they are a mechanism to assist facilities in providing high quality transplant services.

Transparency, accountability and trust

A main pillar of transplant centre accreditation is making information about transplant numbers and outcomes available in the public domain. This is essential because it promotes transparency and accountability – both of which are vital to maintaining public trust in the healthcare system.

Transparency empowers patients with information upon which they can base their decisions. For some, this may entail seeking treatment at one facility over another. For other patients, it is simply about “knowing what to expect” from the institution at which they seek care. Transparent practices and policies avoid the opacity which is often construed as governments, facilities or practitioners “hiding something”.

Accountability involves taking responsibility for the services one provides and seeking to address deficiencies within a transplant programme should these be found. Accountability to a regulatory body like the OPTN² or HTA further enhances public trust, because continued accreditation through these mechanisms is a “stamp of approval” for transplant centres.

Such accreditation frameworks are essential to protect the welfare of patients. For instance, research has consistently demonstrated that transplant centres performing a “high volume” of procedures report better outcomes than those who undertake less than 20 organ-specific transplant operations per annum.⁵⁻⁷ Transplant volume is important, because it serves as a proxy for the skill and expertise that each transplant programme has to offer. Those reporting higher volumes likely have more experienced staff, who have cared for more transplant patients, than programmes in the same country reporting lower volumes. Systematic findings like this have resulted in widespread consolidation of numerous transplant programmes into much larger, high-volume centres internationally – and this has improved patient outcomes.

Transplant Centres in South Africa

Although there is no accreditation authority for transplant centres in South Africa, it should not negate the requirements for transparency and accountability. Whilst this may not be a priority at national government or legislative level, it can still be endorsed by transplant centres themselves - and transplant societies - in the spirit of empowering patients and furthering public trust in the organ donation system.

As a starting point, centres offering transplantation services should willingly make aggregated, anonymised data about their performance publicly available. Such a strategy could

also assist individual transplant programmes in coordinating their activities, such as sharing resources to upskill staff across transplant specialities where needed.

Essentially, as transplant centres we need to remember the patients who we seek to serve. These patients are often very vulnerable, and they rely on highly specialised medical expertise to provide lifesaving management. In this high-stakes context, patients and the SA public deserve to know how donated organs are used and their outcomes.

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Why is it hard for South Africans to say YES to organ and tissue donation?

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The answer is complex and the challenges of addressing it are extremely difficult. There are, however, two ways to address this problem that would have an immediate impact.

1. Expand our network of procurement officials.
2. Increase public awareness and education.

Lets explore option 1, which is to establish an extensive network of procurement officials in hospital, who are medical professionals immediately available to assist doctors and families when a potential donor is identified.

This is the most effective way to improve consent for donation. It is, however, a resource-heavy process requiring substantial sustainable financial investment in personnel and training that neither the private or public sector is driving in a co-ordinated fashion at present.

A good example to illustrate option 1 would be Spain who enjoys the highest consent rate in the world. The model in Spain is ideal due to there being 480 procurement officers, of which half are medical doctors. In contrast, South Africa has under 30 procurement officers often tasked with fulfilling other roles beyond deceased donation.

The expense to set up an efficient network to bring about change is a challenge but must remain a long-term goal.

The other area to improve is option 2, which involves intensified public awareness and education. This is where the ODF fits in.

Since 2011

- The ODF has grown by 684%
- We have increased our staff by 600%
- We now have 1200 volunteers working throughout South Africa.

There are 2 branches to our activities:

- Public education
- Public awareness

The first branch, public education, is achieved through the ULUNTU Project and is directed where it is most needed. It involves face-to-face educational programmes at schools, clinics and state hospitals in under-resourced areas.

The second branch is public awareness and involves driving organ and tissue donor registrations of those who already know about transplantation. During the past 3 years the ODF has run a staggering 432 events to aid registrations.

In addition to the high number of awareness events and educational programmes, we also reach South Africans through the media.

During the past 5 years the ODF used 115 million Rand worth of media coverage. We have potentially reached South Africans - 872 026 323 times.

Other initiatives we've used to increase registrations

- We have successfully increased our media coverage
- On average we have 3 awareness events per week nationally.
- The Uluntu project has educated thousands upon thousands of clinic and hospital visitors and school learners.
- We have shortened the registration process to reduce drop-offs
- We have a successful social media presence with over 100 thousand followers.

WHY then do we only have 300,000 registered organ and tissue donors on our registry?

In spite of this success, we are aware that we did not reach every single South African. We are still faced with limitations. We do not have the resources or the technical platforms to reach as far

as we need to and while we reached some South Africans many times, others may not have heard our message.

We could have many more registered donors

As a new approach, on Valentine's Day, 14th February, Premier of the Western Cape, Alan Winde and his wife Tracy Winde held an event at their home, Leeuwenhof to address this issue and increase the number of registered donors. Heads of companies, cabinet ministers, government and industry leaders were invited to attend a cocktail sunset event where a video presentation was shown to all guests to encourage them to support the ODF via their companies electronic platforms or other avenues. On the evening almost 40 companies and individuals pledged their support to assist the ODF, through their electronic platforms where clients or staff or the public interact, to increase organ and tissue registration.

We hope to scale up the sign-up of many more donors onto the registry through events like this in the future.



Our guests



Our wonderful MC Pippa Hudson of Cape Talk



Fantastic staff of the Premier's office and Leeuwenhof



MD of Capital Legacy - our fantastic sponsor and partner



Leeuwenhof



Tsogo Sun - one of our pledge companies



Our hosts for the evening - Premier Alan Winde and Tracy Winde



Cycle Tour Trust pledging their commitment