Executive summary:

Our aim is to choose, develop and implement the best of breed, comprehensive system to provide healthy, safe cells, organs and tissues to all peoples of South Africa. The platform and / or architecture should provide for simplicity and easy accessibility.

At this moment, people are dying while waiting for lifesaving organs and tissue. The waitlist is growing daily, while the referral process for organ and tissue procurement is relatively unknown and therefore not used extensively or effectively. There is also a need for the sector to take responsibility for its future, due to the lack of government support and funding. This can only be achieved through agreement between the various stakeholders.

In the long term, we hope that the waiting list for organ and tissue transplants is reduced and lives are saved. One more little boy gets to live a normal childhood, playing with his friends, attending school, enjoying another birthday. Or another member of society gets the opportunity for independence, a chance to earn a living, support their family, make a meaningful contribution to society and the economy. No one dies while waiting for a lifesaving organ, or restorative tissue transplant.

Vision:

To coordinate and communicate the possible availability of cells, organ(s) and or tissue (cto ~ meaning all human derived products) for donation. While protecting and respecting patient privacy, dignity and preferences, improve the number of referrals for the availability of cto coming through. At the same time using fair and ethical cto procurement, banking and distribution.

Purpose: - Provide healthy, safe cells, organs and tissues to all peoples of South Africa.

To illustrate what we are talking about and the difference it makes in people’s lives, 5 stories:

Tina B, Africa’s longest surviving heart and bilateral lung transplant recipient shares her transplant journey.

After a two and a half year wait, Tina received a heart and bilateral lung transplant in 2011. At the time she also donated heart valves from my damaged heart (tissue donation).

Tina describes her life before transplant.

My heart stopped beating when I was 14 years old, and I had a pacemaker inserted to keep it pumping. The pacemaker was replaced just before I turned 22, but I never returned to my former strength as my heart was in failure. From then I was on a steady decline until eventually I was on oxygen 24/7. I slept 18 to 20 hrs a day and if I went anywhere, it was in a wheelchair with a portable oxygen tank. I had shaved off my hair because it was too exhausting to even brush it, let alone wash & dry it. I spent days at a time in bed, looking forward to an outing every 2 weeks or so.

Tina describes the emotions she experienced when she heard that she would be receiving her transplant.

Two weeks before I got ‘The Call’ that a suitable donor had been found, I had begun to lose hope and give up on the idea of a transplant. I was tired of fighting for energy to chew, fighting to breathe, fighting to stay alive. I was ready to die. So, when the call came, I was beyond excited. It was a lifeline for me, because I knew I was dying, and this was my very last chance to LIVE.

Describe life after transplant?

My life is completely different now! I have been able to take part in sporting events for the first time in my entire life! In 2014 my fiancé and I took part in the 30km Ama Shova cycle race, on a tandem bicycle. In 2015 we completed the Cape Town Cycle Tour, and in 2019 I took to the gym to build muscle and took part in the Arnold Classic Model Search, the 1st transplant recipient worldwide to do so!

Not only am I taking part in physically gruelling challenges, but I am finally independent, not relying on others to look after me and help me perform simple daily tasks. Over and above this I'm a business owner and an inspirational speaker!

Advice for awaiting transplant patients.

Be prepared! Get your mind right first, work through your fears, and maintain a positive attitude. Next, make sure you are as strong and as healthy as possible. Any operation is really taxing, and you’ll need to be able to survive and then have energy to recover fully.

Why do you think there is a shortage of donors in South Africa?

This is a worldwide problem. I feel there is a lack of knowledge about Organ and Tissue donation, as often people don't think about this topic until they themselves need an organ or tissue transplant. Adopting an opt-out program in South Africa would go a long to alleviating the shortage. Those who are opposed to donating would be able to opt-out, thereby keeping our Constitutional right to choose intact.

The biggest stigma or myth you have heard about organ donation?

I feel the biggest concerns around donation arise through movies and books that have portrayed donation in a negative light. Plots that show the illegal activities surrounding donation like selling or buying organs and such. Factually incorrect portrayals of the process, where the same doctor who is desperate for an organ to save a patient will pronounce another patient brainstem dead to procure their organs; simply doesn't happen in real life. Two independent doctors must declare the patient brainstem dead.

Describe transplant in one word.

Life

Hénu Pienaar – Awaiting heart transplant

Little Hénu is one of many children waiting for a miracle. He urgently needs an organ transplant. Here is his story of survival and hope.

During a routine paediatrician visit, Hénu was diagnosed with HLHS (Hypoplastic Left Heart Syndrome); a condition that would require at least 3 major heart surgeries. Diagnosed with heart failure during February 2020, the little boy has been on the waiting list for a new heart, for some 9 months now.

Hénu’s condition has taken a heavy toll which has affected his gross motor skills development. He is far less active than his peers, tires easily, is on heavy doses of medication and is unable to attend school.

His parents long for the day he can experience ‘normal’ toddler life and activity levels.

There are a multitude of reasons behind the shortage of donors in South Africa.

Hénu’s Mum Melanie explains “People find the concept of donating their child’s organs appalling, almost as though they are then responsible for the death of their child. I have experienced some religious objections against it, too. Mostly people are just afraid that they will not be given a chance at surviving because the medical team want their organs more than they want their patient’s survival. Lack of awareness, selfishness and a sense of pride (even in death) are other arguments I’ve encountered”.

The biggest myth about organ donation she has experienced is “Doctors will declare you brain dead just to get your organs.”

Philadelphia Chauke – Cornea recipient

Meet the capable, independent Philadelphia Chauke, from Pretoria, South Africa.

After completing matric, Philadelphia noticed that her eyesight was deteriorating. After having her application to the South African Police Services set aside following failed eye tests, she missed her opportunity to become a police officer. Philadelphia obtained a receptionist job in government and even after being prescribed thick lensed spectacles, was unable to see properly. Her vision was deficient to the extent that it negatively impacted her work, almost costing her job.

Phila received the gift of sight in 2000; a human cornea transplant. She was fortunate to have been on the waiting list only a year. There is a critical shortage of corneal tissue in South Africa, and whilst it is possible to source from United States and Europe, this merely inflates the costs to patient and public or private medical aid. Globally, the number of corneal transplants is around 100,000 and in South Africa the number is around 1,000 per annum. (Stats referenced in 2015). At that time, a corneal graft procedure cost ballpark R50,000.

When she received ‘the call’ Philadelphia had mixed feelings, both elated and concerned at the same time. On the one hand her life would be changed for the better, but on the other, she feared that her body might somehow ‘reject’ the new corneal tissue. Something more prevalent in organ recipients. It is interesting to note that, more success is achieved in corneal transplants than in any other transplant surgery, and in South Africa most surgeries have a successful outcome.

Philadelphia describes her corneal transplant as ‘lifechanging’; her eyesight improved to such an extent that she was able to further her studies and acquire two qualifications. Firstly, a Diploma in 2008, followed by her Undergraduate Degree in Security Risk Management in 2014.

The advice Philadelphia gives to patients awaiting their transplant, “Keep the faith, and don’t lose hope”.

She believes that the reason there is a shortage of donors in South Africa is due to a lack of awareness around tissue and organ donation in South Africa. Added to this, the communities’ general perception that ancestors will reject the person if buried without all their organs intact. There is also a myth that organ donor patients who are terminally ill, will be killed or left to die, for their organs.

To address this issue, we, as ordinary South Africans, need to have the conversation around donation whilst still alive. “My death should give someone else life, or at least improve the quality of life for someone”.

Philadelphia sums up her gift of sight as “A second chance”.

Nombuyisela Skafu – Kidney recipient

Nombu shares a message of hope and awareness, from Joe Slovo, iBhayi (Port Elizabeth), South Africa.

The 38-year-old has escaped death several times during the past few years.

During her first pregnancy in 2010, she suffered kidney failure, “My baby was born at seven months, weighing only 1.4kg”.

“Because I am HIV-positive I developed infections,” she said. She was placed on dialysis in 2012 and continued with treatment for 32 months. This ruled out any chance for a ‘normal’ life for the previously avid runner.

Dr Elmi Muller\*, then heading up a programme at Groote Schuur Hospital, Cape Town for HIV-positive patients to receive kidneys from HIV-positive donors, contacted her and facilitated her kidney transplant in July 2015, following a 2 and a half year wait.

When she received ‘the call’ Nombu was ‘over the moon’ to have her prayers finally answered.

“My only thought was that God was with me.”

“After the transplant God gave me another gift. I now have another baby.” Adding to her post-transplant accomplishments, Nombu also qualified and competed in the 2018 South African Transplant Games, proudly representing her region in various road race categories.

She has also become involved in promoting transplantation through the Organ Donor Foundation’s Uluntu programme, and believes that the population are not well informed about organ and tissue donation. She sums up transplantation as a ‘process’.

She encourages other HIV positive people, “everything happens for a reason. If you need a kidney, take an HIV-positive kidney. That kidney already knows all the medicine you will have to take. It won’t get a shock like that of an HIV-negative person. Your life will be wonderful after a transplant.”

Her message to those on the transplant list is to stay strong, do not lose hope and stay infection free. To my fellow South Africans, don’t take your organs to heaven, we need them here! Especially us Blacks Bantu abahle masinciedaneni.

\* Muller is recognised as a global authority on kidney and liver transplantation in HIV-positive patients and was responsible for changing national and international policy through her work on both HIV positive patients and organ trafficking.

Mike Cohen – Heart Recipient

Meet Mike, heart transplant recipient, family man, dynamic MD of a mineral commodities company and ex Rugby 7-aside player, from Johannesburg, South Africa.

Before his transplant, Mike could barely walk 10 meters at a time. He was too weak to play with his two-year-old daughter. Life was anything but normal. He tried his utmost to continue working, but most of his time was spent in and out of hospitals, and he spent most of his days feeling as though he was being ‘strangled’ from the inside out; barely surviving.

After a four month wait, Mike received his life-saving donor heart during January 2020.

When ‘the’ call came, it was 20:30 in the evening, and he was sitting on the couch surrounded by his family. Describing his emotions, “I felt peace of mind as I knew I had no other option, and anything was better than how I was feeling. This was my only chance to have a good life again. Of course, my wife and mom burst into tears of joy. The hardest part was saying goodbye to my daughter, not knowing if I would see her again”.

Mike describes life post-transplant as AMAZING. He has regained the 25kg of muscle mass lost through his ordeal and is back to low intensity exercising for an hour a day, taking one day off a week. He gyms every morning and follows a strict rehabilitation program set by his sports physician and cardiac team.

“I can easily walk 8km, and I am so full of energy. I am passionate about my work. I am so grateful for my health and every extra day that I get to spend with my beautiful wife, daughter, family, and friends. I can honestly say my health has improved 100-fold on every level since my transplant. The best part is being able to pick up my daughter and being able to play with her, something I will never take for granted. Best of all we are expecting a little ‘miracle’ boy in September, and this would never have been possible if it were not for the heart transplant and my donor family”.

The 42-year-old advises patients on the waiting list for a transplant, to have faith, listen to their doctors and not be afraid. “Do what you physically can to stay strong, try keep your head in the now, and don’t watch the movies that will probably never be acted out”.

Mike believes that one of the reasons there is a shortage of donors in South Africa, is that people fear that they will be targeted for their organs once they are on the list. He attributes this to cultural beliefs and a general lack of awareness around the subject.

Summing up his transplant in a single word, Mike chooses “Miraculous”.

Values:

* Our foundations are firmly built on fair, objective and ethical practices that protect the privacy, dignity and best interests of our patients, partners and colleagues alike.
* We value integrity and rely on the trust and support of the community and its members it serves through transparency and professional conduct
* We value compassion and honour its donors and their families. We are respectful of the gift of life and give tribute to its power through community education.
* We value quality and strive to uphold stringent standards to ensure high quality in products that will be to the benefit of recipient patients.
* We value responsiveness and operates in a detailed oriented manner to ensure we meet the needs of our members, partners and the community we serve.
* We value education and recognises that education is needed to uphold public trust and ensure the effectiveness of tissue banking.
* We value innovation and support development towards improved programs, service expansion and research and technology
* We value respect for both death and life and the legacy and hope left behind by donors.

Proposed solution:

Organ donation, recovery and matching is quite an intricate and complex process involving various role players, processes, and regulations. Today, it is largely being done manually, which leaves plenty of room for improvement. In this regard, one of the suggestions being considered is to build an automated solution that is technology led and enables different role players in the ecosystem to undertake their functions in a far more coordinated manner. While there are various entities involved the ask is to facilitate their interactions in a seamless way and that is where technology will be a great enabler.

One of the proposed solutions is to start with a call centre to coordinate and facilitate the existing process of contacting a coordinator who then takes over and manages the process from then on.

It is foreseen that a future possible solution may integrate with the existing database which stores details of registered donors. This will allow for various facilities including hospitals, forensics, funeral parlours who will have access to this web-based application to send a trigger to the nearest available set of medical coordinators with specific donor details. Leading technologies like geographic information system (GIS) mapping can be used to establish proximity of resources and facilities.

Upon receiving this trigger from the web based system, the medical coordinators can express their interest and proceed with the screening process against a pre-populated checklist that is hosted on the application. Information related to the organ donor will be captured, stored, and updated on the system right throughout the organ donation process. It will act as the single source of information for medical coordinators to plan and execute their activities at every stage. The application will also host the latest details of the transplant centres, eye banks, tissue banks and others who play a vital role in organ donation. Easy access to this information will allow the medical coordinators to be far more efficient. Also, the specific entities involved in the value chain can be notified at appropriate stages via the system to allow them to do relevant planning.

This application will act as the single repository for all the business rules that will enable seamless decision making and help in exception handling in a far more informed way. In addition to this it will make use of functions like alerts, notifications, reminders, and automated workflow which will enable the medical coordinators to function efficiently and effectively. Overall, the intent is to ensure that we can minimise potential cases where organs available for recovery are going unattended.

Marketing & promotion:

One of the biggest challenges in implementing this project will be buy in from all stakeholders (medical fraternity, donors, hospitals / institutes, government). The best way to handle this, will be by defining and using a structured change management effort.

Change management is defined as the methods and manners in which a company describes and implements change within both its internal and external processes. This includes preparing and supporting employees, establishing the necessary steps for change, and monitoring pre- and post-change activities to ensure successful implementation.

Significant organisational change can be challenging. It often requires many levels of cooperation and may involve different independent entities within an organisation. Developing a structured approach to change is critical to help ensure a beneficial transition while mitigating disruption.

Changes usually fail for human reasons: the promoters of the change did not attend to the healthy, real and predictable reactions of normal people to disturbance of their routines. Effective communication is one of the most important success factors for effective change management. All involved individuals must understand the progress through the various stages and see results as the change cascades.

Training will be handled as part of and as ongoing effort of change management. Coaching is seen as an ongoing effort, if the system is not used at a specific site, it is probably because of not enough or ineffective training. There will always be new personnel in the various institutes, which means training can never stop.

Awareness of what organ and tissue transplantation means and the various issues around it, as explained in the 4 featured stories, are mainly addressed by the Organ Donation Foundation (ODF). As part of the change management effort of this project, we will address school children in the area that we are working in and hand out t-shirts with something like SAVE 7 LIVES printed on it to start conversations around this topic.

Management:

Establishment of a focused team is paramount. Our project is handled at the moment by a team of 3 persons (on a voluntary basis and will stay voluntary). This team will be expanded as time goes by and funding is realised.

Funding structure:

Our effort to fundraise is based on the following:

1. International crowdfunding via GlobalGiving site.
2. Donations via the ODF (Organ Donation Foundation) website.

Governance structure:

This project is run under the auspices of SATiBA (The South African Tissue Bank Association) with full cooperation and collaboration of SATS (Southern African Transplantation Society).

The following stakeholders / affiliates / collaborators will be approached to be involved.

Organ Donation Foundation (ODF)

All transplant centres and tissue banks

National department of Health (NDOH)

All interested hospitals / institutes, for example:

 Netcare

 Mediclinic

 All state hospitals