

Transplant News

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Editorial

Professor Russell Britz
Editor

Again an informative news letter providing insight into transplant processes. Stressed are the pre-transplant preparations and background infrastructure that are put in place to enable smooth and equitable allocation and outcomes for transplants.

Alison, the dietician working as an essential part of the transplant process, gives an indication of the vital role played by ancillary medical professionals in a successful outcome. Attention to detail and vital nutritional parameters must be achieved pre transplant in order to succeed in a paediatric (and adult) liver transplant.

Dr Markus Schamm gives an insight into the allocation of organs once they become available. He alludes to several factors that contribute to points gained while on the waiting list, the differences between kidney and liver allocation and describes the system based on equitable distribution of organs used in Gauteng. Each transplant unit in the country has their own set of rules that are differently applied. These set rules are freely available from the individual transplant centres. Sadly, Markus has left us; we wish him well in his new home in Auckland.

Dr Tina Sideris provides a range of psychological reactions to receiving an organ transplant that will no doubt reassure patients that their emotions and thoughts are not unusual. This reassurance will put many at minds at rest. The need for psychological support does not end at the time of the transplant.

"Organ donation: from Death to Life" should be included in the medical schools' curriculum. This is vital information and easily accessible via the internet. It is suitable for both public to enhance understanding of the donation process and medical staff in the management and referral of potential organ donors. Congratulations to Dr David Thomson for this innovative and important course.

Luke alludes to the strategies available to increase the living donor pool for kidney transplants. While highly successful in Europe, logistics and administrative processes are complicated. To my knowledge only one paired kidney exchange transplant between two recipients and living donors has been done in RSA. This is being explored in RSA to expand the donor pool.

The #TELL initiative in the last article is an example of the new age method of communicating and creating awareness. I would encourage everyone to join the conversation on this platform and make your views about organ donation known.

August is National Organ
Donor Month



Nutritional rehabilitation of babies that are waiting for liver transplant

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We know that infants and children with liver disease are at severe risk of malnutrition. It is well documented that if patients are severely malnourished at the time of liver transplantation their prognosis is far worse than more well-nourished babies. Studies have also shown that nutritional status is linked to length of hospital stay and serious complications post transplantation. It is essential that an infant or child is as well-nourished as possible at the time that they receive their new liver. For this reason nutritional support is a top priority for these children.

In some units the policy is only to transplant a paediatric patient when they meet certain nutritional parameters.

NUTRITIONAL ASSESSMENT

An infant or child with liver disease needs frequent visits to the dietitian for nutritional assessment and advice. The appointment needs to include the following:

- Measurement of anthropometrics
 - Weight
 - Height
 - Head circumference
 - Mid upper arm circumference
- Biochemical nutritional markers
 - Blood protein levels
 - Blood fat soluble vitamin levels
 - Iron levels
- Dietary review
 - Food diary or
 - Food recall

NUTRITIONAL REHABILITATION



Parenteral Nutrition



Enteral Nutrition

Initially the dietitian will offer advice on optimising a child's nutritional intake at home. If this is not possible or is unsuccessful then the child will need to be admitted to hospital for more aggressive nutritional therapy.

It is essential that an infant or child is as well-nourished as possible at the time that they receive their new liver. For this reason nutritional support is a top priority for these children.

Nutritional Intervention at home

The dietitian can advise on specialised formulas and feeds that can help the baby or child with liver disease grow. These formulas are usually higher in protein, energy and fat than regular formulas. The fat in these formulas have also been altered to aid absorption. These fats are called MCTs (medium chain triglycerides). MCT are not reliant on bile which the compromised liver battles to produce for its absorption.

One major problem that families face is that the formulas recommended for infants and children with liver disease are far more expensive than other formulas. These babies are also often demanding large amounts of these formulas making their nutrition even more costly.

Types of Nutritional Support

Enteral Nutrition generally refers to any method of feeding that uses the gastrointestinal (GI) tract to deliver part or all of a person's caloric requirements. This could be oral food or food delivered via a tube into the gastrointestinal tract

Parenteral Nutrition or intravenous feeding (IV), is a method of getting nutrition into the body intravenously, bypassing the usual process of eating and digestion. These are complex nutritional formulae that contain nutrients such as glucose, salts, amino acids, lipids and added vitamins and dietary minerals.



The dietitian will also advise on high protein energy foods from an appropriate age. It is important to feed these children well from the start and to avoid salty processed foods and sugary drinks that may compromise their nutrition.

Nutritional Intervention in hospital

If a child is not managing to grow at home it may become necessary for the child to be admitted to hospital for more aggressive nutritional therapy. This usually involves feeding the child with a small feeding tube that is inserted through the nose and on into the stomach (nasogastric feeding). Children with liver disease usually grow better on small continuous feeds delivered through the day and night via a pump. The children can continue eat and drink normally when this happens.



Occasionally if the liver is really damaged making it unable to absorb fats and synthesis protein adequately then intravenous nutrition may be required.

The dietitian will also advise on high protein energy foods from an appropriate age. It is important to feed these children well from the start and to avoid salty processed foods and sugary drinks that may compromise their nutrition.

To deliver intravenous nutrition we need a catheter (tube) called a broviac line to be inserted through the chest into a large vein. Intravenous nutrition is not as safe as enteral nutrition as these lines have to be treated in a strictly sterile manner in order for the child not to develop line infections.



Nutrition Post Discharge

Once the nutritional goals for a child are met and sustained in hospital the aim is to get the child home as quickly as possible. In some cases if the family can manage a child is sent home with a nasogastric tube if they are still not managing their full nutrition orally. It is not often possible to send a child home on intravenous nutrition. Out patient monitoring by the doctors and dietitian remain essential to ensure a child's nutrition does not rapidly deteriorate.

Transplant waiting list - where are we now

Dr Markus Schamm

Head of Transplant Unit

Charlotte Maxeke Johannesburg Academic Hospital

Kidney and Pancreas Transplant Surgeon

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Having been newly diagnosed with organ failure, and being told you need a transplant, presents an unfamiliar field, with many fears and stressors.

The patient finds himself in a very vulnerable position, needing to come to grips with the reality, that he or she is dependent on a dialysis machine, and/or the selfless gift of a donated organ. The patient has to place his/her trust in the hands of doctors to look after their needs and wellbeing.

Patients who are suffering from end-stage organ failure, require a meticulous care and an assessment of their suitability for transplantation. Unfortunately not all patients with organ failure are candidates for transplantation. Factors which may preclude the patient from receiving an organ are: E.g. severe health related issues other than kidney or liver failure (severe heart or lung disease), recent or current cancer, unresolved psychological/psychiatric issues, as well as drug dependency.

In order to maintain an equitable and moral listing process, patients are presented at a multi-disciplinary panel meeting. The panel of experts will then decide if the patient meets the requirements to be listed for transplantation. The panel may also advise further investigations, or decline the patient from being listed.

Patients who have kidney failure (end-stage renal disease), may be listed on the 'kidney transplant waiting list' once they have established renal failure (requiring dialysis), or are very close to requiring dialysis (GFR <15). While waiting on the kidney transplant waiting list, the patient will be looked after and maintained on dialysis by their nephrologist.

Since there is no 'dialysis' machine for patients with liver failure, waiting with established liver failure is impractical, as such patients would die within days. Liver failure patients are thus listed for transplantation once they meet certain clinical and biochemical criteria (MELD or PELD score). This ensures that patients are transplanted once the benefit of transplantation, outweighs the potential risks, of the liver transplant procedure.

Both liver and kidney transplant patients are listed according to their blood group compatibility, whereas kidney transplant patients additionally require tissue typing (HLA typing).

Kidney transplant waiting list

Each region in South Africa manages their own waiting list. Patients are only permitted to be listed on one waiting list. If you stay in KZN, you may therefore choose to be listed in Johannesburg, and not in KZN.

The kidney transplant list is divided into Groups O, A, B, AB, and each of these groups is further divided into 'young' (< 55 years) and 'old' (> 55 years).

State and private patients are listed on the same list, as are adults and children, and need to fulfil the same listing requirements. With each 'deceased donor' organ procurement, two kidneys become available for allocation. Whenever possible, one kidney is allocated to a state patient, whilst the other goes to a private/medical aid patient.

Unlike the kidney transplant programme in Cape Town, who are performing HIV (+) to HIV(+) transplants, and therefore have a separate list for HIV(+) patients, HIV(+) patients in Johannesburg are listed on the same list as HIV(-) patients. HIV(+) patients are therefore as eligible for an organ that becomes available, as patients who are HIV(-).

Patients are allocated points on the list based on the following parameters:

- Time spent on the waiting list
- Age of the patient
- PRA (panel reactive antibody)
- Having had a transplant before

Within each group there is a 'Top 50' group. These are the 50 patients at the top of the waiting list and are next in line to receive a kidney transplant. The Top 50 list allows the doctors to prepare the patient more intensely for the upcoming transplant and allows for a smaller group of patients to regularly submit blood samples to the laboratories for crossmatching. It allows the doctor to identify and address issues which might have arisen over the years of waiting on the list.

Each patient on the list also receives a calculated PRA (Panel Reactive Antibody) value. This value is calculated from 0 – 100, and represents the reactivity of the patients' blood to a panel of antibodies common in a representative population. The higher your PRA, the lower your chance of 'crossmatching' negative to a donor. Only 12 patients with a PRA greater than 30 are allowed in the Top 50, so as not fill all Top 50 slots with patients who are less likely to crossmatch negative, and thereby risk not being able to allocate donated kidneys.

Organs that come from deceased donors above the age of 55 years, who also have co-morbidities like hypertension (high blood pressure), diabetes mellitus (high blood sugar), and/or have died from a stroke, are considered potentially less ideal kidneys and are therefore only offered to patients above the age of 30 years. The aim of this is to try not to allocate organs to younger patients, where it would be ideal to achieve the longest possible graft survival.

Future prospects

Currently blood samples are being sent to the SANBS for tissue typing, and on the day of transplant for a CDC (complement dependent cytotoxicity). Another specimen is sent to the NHLS for a Luminex test. This dual system was established to limit the event of acute rejection, which occurs when the recipient and donor are not compatible.

With the acquisition of a new tissue typing machine (high resolution sequencer) by the NHLS, the need for the 'double checking' process may soon be at an end. The new sequencer will allow for a very accurate analysis of the donor and recipients tissue type, and will together with the CDC, allow for very accurate and safe organ allocation. This system will possibly also do away with the 'Top 50' idea, and will do away with the need to regularly submit so many blood samples.

Living donor kidney transplantation

Depending on which blood-group the patient belongs to, you

may wait up to 10 years (sometimes more) before an organ is allocated to you. During this period the patient has to continue with dialysis. This is a very time consuming treatment, and carries a significant risk of deteriorating health, and even death.

A kidney transplant from a living donor (related or unrelated), is a far better option than waiting for deceased donor kidney transplant. Identifying a potential donor (family member or friend), is therefore strongly encouraged and usually results in much better patient and graft survival.

Making sense of organ transplantation

Every morning I awoke for the first eight years post-transplant I was filled with awe and gratitude for my new and bounteous health that I feared might disappear without warning.

Somewhere in the decade that followed I became used to my bounty. And so I continue, a patient and yet not a patient, well and yet not, able-bodied and yet disabled, treated and not cured, healthier than I have ever been, thanks to a part of a stranger's body that somehow has managed to live in mine for over 20 years."

Pre-transplant loss and anxiety dominate the psychological challenges associated with organ dysfunction, the threat of death and receiving the organ of another. Post-transplant these factors take on a different tone. Organ preservation, survival, and incorporation of the other's organ, become prominent, but are never finally resolved.

Amongst the biggest psychological challenges after organ transplantation is how to remain steady in the face of the in-betweenness that becomes a feature of life. Starting with the call to say there is a matching organ, people undergoing transplantation inhabit ambiguity – excitement and anxiety, hope and fear, joy and worry, accomplishment and uncertainty.

Actual Transplant

- **The Call:** Even though most have been waiting in sickness for months if not years, the call to come in for surgery generally catches organ transplant candidates by surprise. With hundreds of scenarios going through the mind, it is not unusual for "the call" to generate conflicting emotions, at once excited anticipation and anxious trepidation.
- **Intensive Care Unit:** In the immediate aftermath patients are relieved to find themselves in ICU because this signals survival. The ICU plays a fundamentally important role in stabilising patients after complex surgery.² At the same time patients in ICU may be beset by confusion, disorientation, rapidly changing intense emotions and visual and auditory disturbances. These experiences are frightening but with psychiatric and psychological support they subside within a relatively short time. Peri-operatively survival, graft rejection, and medical complications are the main source of psychological stress and anxiety.³ For some the fears generated by mental disturbance in ICU linger. Once again psychological treatment can bring relief.

Post Transplant

With reliable evidence of organ function, and recovery of physical strength and capacity, organ recipients are declared well enough to be discharged. This opens the way for adjustment to a reconstructed body, and to the challenges of re-engaging in living.

- **Euphoria:** The elation and exhilaration felt at survival and renewed well-being, are not sustainable, and may be followed by drops in mood before settling into a more balanced appreciation of life.
- **Ambiguous health:** Successful organ transplantation requires lifelong adherence to immune-suppressant medication without which, organ rejection is certain. Settling the immunological barriers via sensitive dosages of medicine constitutes a constant reminder to recipients that one is between health and sickness, "treated but not cured".
- **Incorporating the organ of another:** Receiving an organ, a gift that can never be reciprocated, can be overwhelming. Realising that there has been 'life giving' reconstruction of the body with the organ of another generates a medley of feelings - immeasurable gratitude, survivor guilt, and an immense sense of responsibility to preserve the organ. As a way of dealing with these feelings some recipients establish a relationship with their organ, even going so far as to assign it a name, like an imaginary friend, thereby gradually facilitating adaptation.
- **Re-engaging in living:** Survival generates a sense of mastery and accomplishment. At the same time disability and illness pre-transplant significantly impact confidence. Returning to work and activities of living can be intimidating, so recipients may need supported re-integration. In as much as recipients can be supersensitive, significant others and families are equally fearful of organ damage. For example, there are reports of partners of organ recipients avoiding sex for fear of damaging the organ. Parents of transplanted children delighted to have children in health, may become over-protective isolating their children for fear of viral or bacterial contamination or other risks to the grafted organ.⁴

In these and other ways individuals who have undergone transplantation must accept ambiguities, a multiplicity of transitions, and uncertainties.⁵ Acceptance makes space for awe and gratitude.¹

References available on request.

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Online Organ Donation Course

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 Consultant in Critical Care and
 Transplant Unit, Transplant Surgeon
 Groote Schuur Hospital and University of Cape Town
 Lead Academic, "Organ Donation: From Death to Life" online course
 Cape Town



Considering someone for organ and tissue donation at the end of life is complicated. The boundary between life and death is more complex than ever before and it falls to medical professionals to help clarify the situation at an often confusing and emotionally stressful time. How that situation is handled has an effect on whether a family will consent to organ and tissue donation.

The online course **"Organ Donation: From Death to Life"** aims to educate medical professionals and the public about the science behind death determination, when deceased organ donation is possible and what it takes to make it happen.



Screenshot of a lecture video

Created by the Centre for Innovation in Learning and Teaching at the University of Cape Town the course runs monthly on Coursera.org as a massive open online course (MOOC) and is free for anyone to review. You just need an internet connection and an email address to create an account on Coursera. All the content is contained in a series of short (3 - 8 minute) videos divided over 4 weeks, with each week taking around an hour to complete.

Week 1	<ul style="list-style-type: none"> Brain death Informed consent
Week 2	<ul style="list-style-type: none"> End of life care Donation after circulatory death Tissue donation What happens to the body
Week 3	<ul style="list-style-type: none"> Organ Donor Management Organ Allocation How it all happens
Week 4	<ul style="list-style-type: none"> Religion and Culture Money, Travel and Organ Trafficking Organ Donation Systems

Course curriculum

Watch intro video on Youtube. Search for **"Organ Donation: From Death to Life"** or scan here:



This course is of particular importance in South Africa where we have one of the lowest donation rates in the world and most of our medical schools do not have active transplant programmes.¹ It is a challenge to expose health care workers in training to teaching on best practices for organ and tissue donation.

By law the transplant team is always completely separate from the treating clinical team so we rely on non transplant doctors to certify death and make the referral to the transplant team.² Every hospital with a mechanical ventilator can potentially support a brain dead patient and allow an approach for consent to be made to the family. It is important that opportunities for donation are not missed from a lack of knowledge about the process. As doctors it should be a standard of care to ensure the option of organ donation is compassionately explored in all appropriate situations at the end of life in the best way possible.

For example it is critical that a discussion about prognosis is completely separate from any request for organ donation. There is evidence that having the organ donation request made by a transplant coordinator specifically trained in making requests and able to devote as much time as required by the family is more likely to obtain consent.

In South Africa simply being on an organ or tissue register to donate is not valid consent. The family will always be approached for consent. By improving knowledge of best consent practices, cultural and religious considerations and the logistics of the organ donation process this course aims to help make referral for organ and tissue donation comfortable and hopefully routine for all clinicians. Death is something we will all encounter. Everyone can make a difference.

The course "Organ Donation: From Death to Life" is certified for 30 CPD points (5 ethics) by the Health Professions Council of South Africa and is endorsed locally by the South African Transplant Society and internationally by the Transplantation Society.

To earn the optional completion certificate you need to pass the multiple choice assessments at the end of each week and either apply for financial aid (granted to all people accessing the course from the developing world) or pay the course fee of \$49.

References available on request.

Sign up at Coursera.org for free. Go to:
www.coursera.org/learn/organ-donation
 or scan here:



Broadening our horizons to improve access to kidney transplantation

Mr Luke Steenkamp
Transplant Coordinator
Cape Town



Kidney transplantation is associated with an improvement in quality of life and offers a survival benefit in most patients with chronic kidney disease, compared to dialysis. In an ideal world, patients with chronic kidney disease should be transplanted before the need for dialysis arises. In reality, very few are afforded the opportunity of undergoing preemptive living donor kidney transplantation. Approximately 2 000 patients on dialysis are currently awaiting kidney transplantation from a deceased donor. With one of the lowest deceased organ donor rates in the world (1.4 donors per million population), waiting times are long and waiting lists continue to grow. As a result, new strategies to improve access to transplantation in South Africa, are constantly being considered.

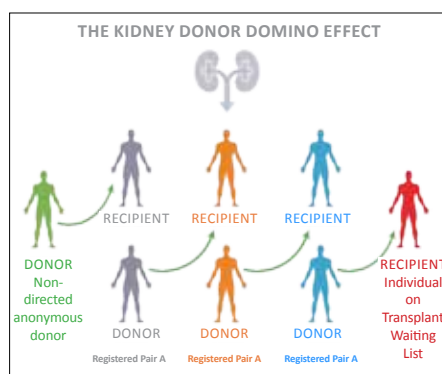
Once the need for transplantation has been established, patients have to either wait for a family member/friend who is willing to donate to come forward or wait for a suitable deceased donor kidney. However, even if a willing and healthy living donor comes forward, approximately half are incompatible with their intended recipients on the basis of bloodgroup or HLA typing. In the past, these donor/recipient pairs would have been told that a transplant between them would not be successful and that the recipient would have to wait for another willing and healthy living donor to come forward. However, some patients might only have one living donor option.

Recently, certain strategies have been implemented to facilitate donation and transplantation, despite an initial bloodgroup or HLA incompatibility. These strategies can broadly be categorised into those aiming to facilitate compatible transplants from incompatible donor/recipient pairs and those aiming to ameliorate the recipient's immune response during and after (traditionally) incompatible transplants.

Kidney-paired donation

A compatible transplant is always preferred above an incompatible transplant. Should an incompatible donor/recipient pair be willing to donate/receive a kidney to/from another incompatible donor/recipient pair, two compatible living donor transplants might be possible. All willing participants' details are entered into a database that utilises advanced software to identify as many compatible transplants as is possible. For example, donor 1 (husband) is unsuitable to donate to his wife (recipient 1) because of blood group incompatibility. Donor 2 (sister) is unable to donate to her brother (recipient 2) for the same reason. Donor 1 is blood group compatible to recipient 2 and donor 2 is blood group compatible to recipient 1. Should no HLA incompatibility be demonstrated between the above

donor/recipient pairs, the strategy will result in two compatible transplants instead of none.



Domino transplants

Non-directed altruistic donors can be used to initiate a chain of living donor transplants between willing incompatible pairs. The process unfolds where the non-directed donor donates to recipient

1, enabling his/her original donor to donate to recipient 2 and so forth (**Figure 1**). The longest single centre chain to date, has resulted in 80 compatible living donor kidney transplants and utilised a non-directed donor to initiate the chain.

ABO and HLA incompatible transplants

Without the implementation of strategies to ameliorate the recipient's immune response, the organs will undergo hyperacute rejection resulting in graft loss. In certain circumstances, your transplant team might offer you the opportunity of undergoing an ABO or HLA incompatible kidney transplant, provided that you understand and accept the risks of a more aggressive immunosuppressive regimen. Generally speaking, ABO incompatible transplants have a higher chance of short- and long-term success compared to HLA incompatible transplants. When the normal ABO-compatibility rules are followed during organ allocation, any recipient can be transplanted with a type-O organ, resulting in a long waiting time for type-O recipients. Therefore, type-O recipients are one of the biggest beneficiaries of ABO incompatible transplants. In HLA-incompatible transplants, desensitisation protocols are used to sufficiently decrease the antibody levels in the recipient's blood to achieve a negative crossmatch test. The recipient's blood is then closely monitored after transplant to identify the need for further plasma exchange.

As a transplant community, we are adopting new strategies to maximise the utilisation of willing and healthy living donors to improve access to transplantation for all. However, we will continue to engage with the public in order to educate and promote deceased donation.

Transplant Education for Living Legacies (TELL)

Adv. Bonnie Venter LLB, LLM
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Most organ and tissue donation activists reach a fundamental moment in life where they make the decision to become a life-saving organ and tissue donor. But, little do they know that even though becoming a donor is a wonderful, selfless gesture, it does not necessarily guarantee that their wishes will be honoured when the time comes.

In South Africa, like many other countries, regardless of following an opt-in or opt-out procurement system, the potential donor's next of kin always have to confirm the wishes of their loved ones to donate. Due to a keen, combined desire of three activists to empower the public to make informed decisions regarding donation, the TELL (Transplant Education for Living Legacies) non-profit organisation saw the light.



In South Africa, like many other countries, regardless of following an opt-in or opt-out procurement system, the potential donor's next of kin always has the final say in whether the donor's organs and tissue should be donated or not.

In October 2018, I, Alice Vogt and Fawn Rogers co-founded TELL with a mission to change and lead the conversation around organ and tissue donation awareness in South Africa. Alice and Fawn both received lung transplants which place them in the unique position to understand the experience of patients in either pre- or post-transplant stage. I, on the other hand, have entrenched myself, for the last decade into developing a better understanding of the legal, clinical and public aspects of organ donation and transplantation. Together, we strive to not

only assist the community in understanding organ and tissue donation but to eventually support and embrace donation in a similar way that we, as a nation always accept a braai as valid substitution for any meal, support our cricket, rugby and soccer teams no matter their ranking and embrace our diversities as a rainbow nation.

We knew without a doubt what TELL's goal would be, but the question soon arose of how we would realise this goal. We decided to tackle the acute organ shortage by applying a two-fold approach.

#TellYourTribe

Firstly, by actively encouraging all potential donors to start the conversation with their loved ones through our public awareness initiative known as #TellYourTribe. This initiative is one of our main driving factors at TELL, as we have the desire to resonate with the public in a fun, inclusive and relatable manner, while increasing donation awareness and get the conversations going.

#TellYourTeam

Secondly, since South Africa's low organ donation rate could be contributed to the timely identification and referral of possible donors, we decided to implement a hospital education initiative known as #TellYourTeam. With this initiative, we collaborate with hospital groups and transplant coordinators to drive routine referrals to become a common practice in South Africa.

After implementing the two-fold approach, we found ourselves in a position where we were focusing on the potential donors and the dedicated health professionals who make transplantation a reality but what about the organ recipients? They are after all the main reason why we want to instil a culture of organ donation amongst the community. To overcome this missed opportunity for positive change we decided to assist pre and post-transplant recipients as well as donor families with two separate online support systems which provide them with a safe environment where they can interact with like-minded people who understand what they are going through.

Almost ten months down the line, we still believe that the most important part of organ and tissue donation is the conversation. If you want to join us in this conversation and assist us in a push for a holistic approach to save the lives of those waiting for a second chance at life, you can find us on Facebook, Instagram and Twitter @tellorgza.