Transplant News continues to be a remarkable success on account of various factors, these being a superb production team, committed authors, financial support from Novartis, and, probably most importantly, you the reader! As many of you are no doubt aware, 2016 marks the 50th anniversary of renal transplantation in South Africa, and I have no compunction in saying that the quality of this publication equals the success that our transplant units have achieved in South Africa during the last half a century!

Always striving to improve, we have included a reader’s questionnaire at the end of this edition. We really do value your input into what you value most as the content of Transplant News. Please can I ask you to take the time to complete this survey card, detach it, and return it to our publishers.

That said, the team have once again put together a wonderful edition to see out a remarkable year. I think what embodies transplantation is the fact that it truly is a multidisciplinary field of medicine, requiring input from numerous professionals, all centred on optimising the outcomes for you, the patient. I think that this spirit is highlighted here, with wonderful articles from physicians, patients, allied professionals and, as ever, input from our all important colleagues at the Organ Donor Foundation.

Enjoy the read!!!
Immunisation and Travel in Transplant Recipients

Dr Cecil Levy MBCh (Rand), FCPaed (SA), Cert Nephrol (Paed) (SA)
Paediatric Nephrologist
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“Congratulations! Today is your day.
You're off to Great Places!
You're off and away!”

- Oh, The Places You’ll Go! Dr. Seuss

With their new found health, many solid organ transplant (SOT) recipients consider travelling to different and wonderful destinations. The problems are that their risk of infection remains high due to their level of immunosuppression, and the level of medical care available at their destination, should something go wrong, may not be of a high standard. These points should always be kept in mind when planning a trip away from home.

Pre-travel vaccines are very important for disease prevention and, ideally, SOT recipients should be vaccinated even before their transplant, including vaccines anticipated for travel.

In general, the intensity and timing of immune suppression in an individual traveller influences both the choice of vaccine and the body’s response to the vaccine. For this reason pre-travel assessment and vaccination should start at least 4–6 weeks before travelling. As the options for vaccination and the infection risk posed by each specific destination are changing all the time, it is recommended that you ask your transplant doctor to get input from a doctor who specialises in travel medicine about your specific itinerary and needs.

In SOT recipients the degree of immune suppression depends on the time after transplant, the immunosuppressant dosing and the presence of acute or chronic rejection episodes that might have needed higher doses of immunosuppressant medication. Although the risk for infection is usually greatest in the first 3 months following SOT, and then reduces over the next 12 months, recipients should remember that their level of immunosuppression always remains significant. In fact, even after vaccination, SOT patients should probably avoid travel to areas of high infection risk. These areas include countries in sub-Saharan Africa or tropical South America where yellow fever is prevalent, countries experiencing current measles outbreaks or measles endemic areas, and countries in Western Africa or south Asia where polio transmission still occurs.

All routine vaccines should be updated as needed before travel but, as a rule, live vaccines are avoided in all SOT recipients on immunosuppressant medication. In addition, it is important to remember that after SOT the body’s response to any vaccine (live or inactivated) may be inadequate which means that the SOT recipient may still not be adequately protected despite being vaccinated before travelling.

The live vaccines include yellow fever vaccine, measles, mumps and rubella vaccine (MMR), oral polio vaccine (OPV), oral typhoid vaccine (Ty21a), Bacillus Calmette-Guerin (BCG), live-attenuated influenza vaccine (LAIV) and live-attenuated varicella vaccine (chicken pox).

Where travel is unavoidable, passive immunisation can be provided for short term protection (e.g. pre-exposure prophylaxis with immunoglobulin), or the live vaccines can be replaced with inactivated (non-live) vaccines. (e.g. Salk or inactivated polio vaccine (IPV) and typhoid Vi polysaccharide vaccine).

With regards to the non live vaccines, although tetanus is rare among travellers all adults, including SOT recipients, should have a tetanus booster if they are not up to date before travelling. The incidence of pertussis has been increasing worldwide and SOT recipients need to be protected from this too, and diphtheria is common in resource-poor regions and vaccination against this also needs to be considered. SOT recipients who are crossing hemispheres should receive two vaccinations with hemisphere-specific trivalent influenza vaccine 4 weeks apart, and pneumococcal vaccine should also be given to SOT recipients if not administered within the past 5 years.

Remember that vaccination is just one aspect of travelling away from home. All SOT recipients should have a detailed medical letter containing information on medical history, a list of generic medications and doses, allergies and a list of reputable healthcare facilities at their destination (preferably transplant medicine specialist centres). Always make sure you have enough medication with you, and always have a plan as to what you will do should you fall ill while travelling. Full travel insurance is an important detail to consider and you may need a written waiver to enter a yellow fever area if you have not been vaccinated against the condition. Finally, remember to practice safe food and water consumption, mosquito and insect bite avoidance, safe sex practices and injury prevention at all times while on your travels.

“So...be your name Buxbaum or Bixby or Bray or Mordecai Ali Van Allen O’Shea,
you’re off to Great Places! Today is your day!
Your mountain is waiting. So...get on your way!”

- Oh, The Places You’ll Go! Dr. Seuss

References available on request.
The importance of exercise pre- and post-lung transplant

Byron Williams
Biokineticist
BA Sports Psychology
Johannesburg

Many people awaiting transplantation find it extremely difficult to perform any form of exercise and may even find completing general activities of daily living a challenge. As one’s disease progresses, it is commonly found that exercise levels decrease dramatically and one tends to resort to conserving energy and minimising excessive energy expenditure, thereby becoming sedentary. As a result of a sedentary lifestyle and a combination of different medications, there may be many other underlying concerns that manifest themselves, including a reduction in muscle mass, a low body mass index (BMI) as well as diabetes and hypertension.

Can exercise improve my condition?
Exercise is by no means a solution to recovering from lung diseases. However, when applied together with conventional medicine, it has been found to be extremely beneficial. Exercise has been proven to reduce high blood pressure, better regulate the uptake of insulin, as well as improve cardiac functioning, muscle strength and endurance. Research has also documented that another benefit of exercise is the improvement in mental health. High amounts of serotonin and dopamine are released after exercise. These are commonly referred to as “feel good” hormones that help alleviate stress and improve one’s mood and feelings of well-being.

How can exercise improve my breathing?
An exercise programme should be embarked on in conjunction with chest physiotherapy. When used together with different breathing techniques as well as rapid deep breathing resulting from exercise, it may assist in dislodging mucus build up allowing one to better expel secretions. It is essential to expel mucus that collects in the lungs, as built up secretions provide an ideal breeding ground for harmful bacteria, which result in a deterioration in health. By expelling this accumulated mucus one has a greater lung volume, thus feeling more able to breathe normally.

What type of exercise should I do before transplant?
Exercise should be focused mainly on improving both muscle strength and endurance while minimising the effort placed on the cardio-respiratory system. By limiting the effort placed on the cardio-respiratory system, one is able to exercise for longer periods of time without becoming overtired as a result of oxygen deficiency. Resistance exercise should be performed with some cardio-respiratory training, depending on the individual’s current circumstances.

Resistance exercise focuses on improving muscle strength as well as muscle endurance. This is achieved by completing exercise sets of fewer repetitions and a higher amount of resistance. Resistance training can be done by utilising exercise elastics as well as weights.

Is it necessary to build muscle before a transplant?
It is extremely important to build muscle before undergoing a transplant. Exercise improves BMI by building muscle mass, specifically around the upper torso and arms. It is important to undergo transplant with a healthy BMI (between 19-25). Research also indicates that individuals that been involved in preoperative conditioning “prehabilitation” have a faster recovery time.

Exercise post transplant
After one has received a transplant, it is very common to feel weak and have a low exercise tolerance, approximately 40%-60% that of normal values. These decreases are, however, usually not determined by the performance of the cardio-respiratory system, but the decreased performance of the muscles themselves and their poor response to exercise capacity. Careful considerations do, however, need to be taken when performing exercise in the initial stages post-transplant. Exercise should be graded and increased slowly, allowing the body to gradually build up a tolerance towards exercise.

Considerations when exercising
A biokineticist or medical professional should monitor exercise closely, making sure that oxygen saturation, blood pressure and heart rate do not exceed recommended levels. It is important to bear in mind the amount of rest time needed between exercise sets as well as between exercise days. Depending on the individual’s condition (illness severity) a longer recovery time may be needed.

References available on request.
Kidney transplants and cardiovascular disease - Nutritional guide

Now that you have healed from your kidney transplant, you may feel very liberated with regards to your food choices. Whilst limiting potassium, phosphorus and sodium may become a thing of the past you must now take care of yourself to prevent chronic lifestyle diseases. Cardiovascular disease (CVD) is one of the leading causes of illness in kidney transplant recipients. Prevention, detection and early treatment are vital to ensure good health and great quality of life. In this article we will discuss how best to look after yourself to prevent this so that you can live your healthiest life!

There are three factors that are common between kidney transplant recipients and cardiovascular disease risk. These include (but are not limited to):

### 1. Maintain a healthy weight

Significant weight gain (approximately 10% increase) after receiving a kidney transplant is common. Not only may this put your graft at risk but also increases your risk of chronic disease. Maintaining a healthy weight (BMI 18.5 – 25.0kg/m²) can be achieved by ensuring your intake of energy (calories) is balanced with your requirements. In order to lose weight, you must eat fewer calories than you use to create energy deficient. This can be achieved by eating the right kinds of food in controlled portions.

- Choose nutrient-rich foods which have an abundance of vitamins, minerals, proteins, fibre and other nutrients but are lower in kilojoules such as a variety of fruits and vegetables, whole grains, low fat dairy products, lean proteins, legumes and nuts and certain vegetable oils.
- Being physically active can help you manage your weight, as well as reduce your stress levels.
- Ensuring that you get sufficient sleep can also help you to achieve and maintain a healthy weight.

### 2. Control abnormal cholesterol (Dyslipidemia)

Nutrition can have a great impact on correcting abnormal cholesterol levels. Here are some practical general guidelines to consider:

- Replace saturated fats (like chicken skin, animal fat, full cream dairy) with poly and mono-unsaturated fats (like olives/oil, avocado, nuts and seeds):
  - Remove the chicken skin and serve with avo.
  - Remove the fat from your meat and rather cook with olive oil.
  - Choose low fat dairy and flavor with seeds or nut butter.
- If you have high triglycerides, ask your doctor about medium chain triglyceride and fish oil supplementation.
- Choose foods (not supplements) rich in vitamin E such as sunflower seeds, hazelnuts, almonds and almond butter, wheatgerm, spinach and avo.
- Avoid trans fats which are usually found in takeaways and convenience foods like crackers and biscuits:
  - Limit/avoid takeaway foods, rather choose fresh homemade foods.
  - Check the label of your pre-packed food (it should say trans-fat free).
- Mainly choose wholegrain, high fibre starches instead of refined foods high in sugar and flour:
  - Choose starchy that look the same on your plate as they do on the plant!
  - In other words, limit white/brown breads, pasta, roti's/ wraps, papp etc and rather choose their whole counterparts such as corns, beans, lentils, barley, pearled wheat, quinoa etc.
  - Oats contains a substance called beta-glucan which can help naturally lower your cholesterol. Try eat rolled oats instead of the instant/quick cooking variety.
- If you drink alcohol, drink sensibly or abstain if possible. An excessive intake of alcohol contributes to high triglyceride levels and blood pressure and in addition to that, alcohol is energy dense and can easily contribute to weight gain. The maximum intake of alcohol is of 1 to 2 drinks per day for men and 1 drink per day for women. A standard drink

<table>
<thead>
<tr>
<th>Major Risk Factors</th>
<th>Modifiable Clinical Risk Factors</th>
<th>Modifiable Lifestyle Risk Factors**</th>
</tr>
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<tbody>
<tr>
<td>Impaired kidney function</td>
<td>Raised Low-density Lipoprotein (LDL) cholesterol</td>
<td>Obesity (BMI &gt; 30 kg/m²)</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>Raised triglycerides</td>
<td>Poor diet</td>
</tr>
<tr>
<td>Age (&gt;45 yrs. for men, &gt;55 yrs. for women)</td>
<td>Low High-Density Lipoprotein (HDL) cholesterol</td>
<td>Physical inactivity</td>
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<tr>
<td>Diabetes mellitus</td>
<td>Raised inflammatory markers</td>
<td>Stress</td>
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<tr>
<td>Family history of premature CVD (men &lt;55 yrs., women &lt;65 yrs.)</td>
<td>Raised blood clotting factor</td>
<td>Insufficient sleep</td>
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<tr>
<td></td>
<td></td>
<td>Tobacco use – particularly cigarettes</td>
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<tr>
<td></td>
<td></td>
<td>Excessive alcohol consumption</td>
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is equivalent to 1 beer dumpy (340ml), 150ml medium dry white/red wine or a 30ml tot of tequila/brandy/gin/vodka or whiskey.

3. Correct high blood pressure (Hypertension)
You should routinely measure your blood pressure and manage it through appropriate medication and lifestyle changes.

- Excess salt intake can raise blood pressure thus you should limit your salt intake to less than 1tsp/day (2300mg sodium).
- Avoid adding salt to your food before eating and cook with the minimum added salt by using a variety of herbs and spices to flavour your food.

In addition to this, limit your intake of salty snacks such as salted peanut nuts and biltong.

Conclusion
By following these recommendations you can lower your risk of cardiovascular disease to ensure that you lead a healthy fulfilled life with your new kidney! Please remember that this article does not replace individual nutrition advice and you should always discuss any dietary changes and supplementation with your doctor and dietitian.

References available on request.

Organ Donor Tribute Day (10 August 2016)

It was the strangest feeling. There was sadness, oh so much sadness but there was also a happiness I cannot explain. It was the combination of these two emotions so tightly interwoven that will forever stick this day in my mind.

Organ Donor Tribute Day is an annual event that celebrates and pays tribute to organ donors. The event also aims to thank the families of organ donors for their bravery and exceptional gift. The day is filled with testimonies of both donor families and organ recipients followed by a candle lighting ceremony for the deceased. This year the event was held at St. Columbus Church in Parkview.

The stories that were told were stories so impassioned and so emotive; the stories of loss and tragedy but also the stories of immeasurable gain. Those lost were mothers and fathers, children and friends, brothers and sisters and somebody’s love. But the lives that were saved were all of the above as well.

Any recovery takes effort and immense quantities of time. Recovery from the loss of a loved one is no different except that perhaps full recovery is not always possible and here lies the extraordinary beauty of transplant surgery, here there is a chance for recovery for both the recipient and the donor family.

After the candles of remembrance had been lit, white roses were handed out to the donor families and recipients. I was offered a rose and tried to deny it claiming that “I wasn’t really a part of this, I wasn’t a family member, I hadn’t lost or gained anyone, I was here as a student for our Chanceplant initiative”, I was cut off straight after I said ‘part of this’ to which I was told, “we are all a part of this”.

This phrase will forever be engraved in my mind because no matter what nor whom, we are all a part of this. And the notion of “I” falls away entirely as it has become and always will be a “we”.

My final gift

It is now time for me to move on
Into the dusk, but also the dawn.
I will remain as the morning comes
As I’ve left behind a gift for someone
So another may walk, may talk may see
Where their life was locked, I offered a key
I am a donor to someone in need
My final gift my final deed.
(author unknown)
Obliviousness, not diseases, is what kills the nation

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

Since establishment 5 years ago, Open-Eye Foundation has operated by the motto: “An Informed Nation is a Healthy Nation” and it is this very motto that continues to drive our mission today. We have endeavoured to take health education and information to those that need it the most, the underserved and illiterate (or as we like to call them - The people on the ground). These are the people that account for almost 80% of the country’s population, they are the ones plagued by chronic illnesses such as diabetes and hypertension and make up 80% of the patients on the transplant waiting list. Frankly, they are the ones that can turn the tide on organ shortage in South Africa but sadly, they are the ones that are most reluctant to become organ donors.

The Problem
It is generally well-known that Africans donate the least organs. This is not only true in South Africa but globally as well. In actual fact, most Africans couldn’t be bothered with organ donation, not until their loved ones or they themselves are faced with a dreaded disease causing organ failure to come knocking at their door. And even with this misfortune, many Africans are so unfamiliar with the practice of organ donation and transplants that they simply rule it off as being “un-African” or “a white man’s thing” and sometimes even “un-Christian”. Some folks quickly dismiss information on organ donation as being “scientific/medical propaganda” and refuse to hear any further as soon we mention the removal of one’s organs to save other people’s lives. They become very skeptical and a bit paranoid to say the least! Sadly, these are some of the ignorant and misinformation views that we are met with whenever we do our outreach campaigns at majority African spaces such as malls, churches, taxi ranks and even clinics in the townships.

While it is still not clear why these misconceptions still exist we believe that a majority of them might be due to a strong reluctance for humans to contemplate their own mortality, maybe preferring to avoid the stress or maybe they just haven’t been exposed to enough information on organ donation and the success stories the result from it.

One thing is clear though, in order for the number of organ donors to increase and/or the supply of organs to meet the demand, BIG changes need to be made. More efforts need to be put in place to ensure that this particular audience truly understands organ donation.

Change the message
It is without a doubt that the message is ineffectively reaching the people on the ground. The main message is framed to show organ donation as being “cool” and “not that big of a deal”. While this might shine organ donation in a positive light and appeal to the modern youth in black communities, it doesn’t quite resonate with the elders as they are still very much riddled with misconceptions and myths surrounding organ donation. When a serious matter such as the removal of a vital organ is at hand, the least of their worries is whether or not they are perceived as cool. We should custom make messages for the elders in black communities so that they feel confident enough to donate, as they are the ones that give consent.

Consent vs Deceased’s last wish
I believe that a deceased’s last wish ranks above any decision that a next-of-kin can ever make on their behalf and that that decision should be honored no matter what…especially when it comes to a matter as personal as organ donation. The fact that family consent is legally required even when a deceased’s wishes on organ donation are clear shows a huge flaw in the system and, if the stats are anything to go by, signals that any efforts made towards ending organ shortage will surely continue to fail.

Collaboration to advocate for change
Any way we may look at it, whether you are a patient on the transplant waiting list, a recipient of an organ or even a medical practitioner of any sort…we are all part of one team! We need to all collaborate and appeal to the masses to become organ donors, especially, organ recipients. Our unique stories and experiences are a very powerful tool that should be used to pay it forward and bring about the change that’s needed to ensure that more lives are saved. Because when you really look at it OBLIVIOUSNESS, NOT DISEASES, IS WHAT KILLS THE NATION.
What a journey my life has been. I was diagnosed with type 1 diabetes in 1986 just before I turned 11 years old, and despite my best efforts at control of my blood sugars, I was best described as “brittle”. But I lived life to the fullest, achieving virtually every goal I could – especially when I was told I couldn’t! I went to university, I learnt to fly a paraglider and I met and married the love of my life. We had grand plans to start a family but after several years of marriage and lots of practice, we were told it could not happen because I was in end stage kidney failure. I went through the long and arduous process of pre-transplant work ups to get onto the transplant list. During this time, despite the odds, I fell pregnant. Unfortunately my poor kidney function couldn’t support a little growing life and we lost our child. But my husband and I faced forward in hope that a transplant would save my life. I eventually had to go onto dialysis and my health continued to deteriorate. I wasn’t doing well. I was giving up hope. Then the call came…. May 2016 Today is my “angel”versary. Today I celebrate my 2nd chance anniversary. This is the day my donor (my angel) and I joined into a unique and treasured relationship; the day my angel and their family gave a gift of life to me, and created hope for a future filled with possibilities. My angel and I share a special symbiotic relationship. I get to live on because of the pancreas and kidney I received. My angel gets to live on in me. I promised my angel we would have the best adventures together. We will fulfil all our dreams and aspirations as far as possible. My angel and I continue to reach amazing little milestones all the time. Our daily walks get further and faster. Sunsets and sunrises are appreciated more fully. Goals can be set and we can look forward to future events with more certainty. Two years ago today my journey and purpose in life began to take shape. That purpose now is to create a support network for kidney patients and their families, for awaiting transplant patients and transplant recipients and to use every opportunity to promote organ donation in South Africa and especially in KZN. Beyond the support network, my purpose is also to put sustained effort into organ donor awareness. I am living proof organ donation saves lives – and this fact has to be a powerful motivator in getting others to register as organ donors. I am but one of a handful in 2014 that was so lucky to have a simultaneous pancreas and kidney transplant that saved my life. The sad truth is that the numbers of transplants of all types of organs are dwindling year on year – especially in KZN where I live. This is why I became an organ donor volunteer and advocate of a healthy lifestyle and continue to support organ donor awareness initiatives in my spare time. I finished my MBA during the first 7 months after transplant (proving that I am slightly mad) and proving also that with determination and courage, no matter what the circumstances and challenges we are faced with in life, virtually anything is possible. I have continued to work full time and be active and overall very healthy. These goals would never have been achieved if it were not for my angel-donor, my transplants and the exceptional medical care I received in the months afterwards. (Prof Britz and team, Prof Paget and all the Wits DGMC staff, you guys are THE BEST!) The sad truth is that the numbers of transplants of all types of organs are dwindling year on year – especially in KZN where I live. This is why I became an organ donor volunteer and advocate of a healthy lifestyle and continue to support organ donor awareness initiatives in my spare time. What lies ahead? So I will continue to tell my story and continue to create hope, to motivate and inspire. My husband and I are registered organ and tissue donors. Everyone should be. Whilst I am here, I will pay it forward with my awareness efforts and support network. And should it end up that one day my life cannot continue, I will pay it forward by donating whatever can be used to give someone else hope and a future so that they can fulfil their dreams and have adventures and make meaningful differences to the lives of others. What will May next year or the year after next hold for me and my angel-donor?.....just watch this space! You never know.... the possibilities are infinite!
More than 26 million times South Africans were exposed to organ and tissue donation in August 2016

Samantha Nicholls
Executive Director
The Organ Donor Foundation, Cape Town

The good name of the Organ Donor Foundation (ODF) combined with a great relationship with the media ensured coverage to a total value of R5,536,453.00 (That is over R177,000.00 media coverage per day). This resulted in the staggering number of people reached on radio, TV and print. Organ and tissue donation was covered 97 times on radio during August.

ODF Director of Communications, Jooste Vermeulen confirmed: “Continuous hard work over the past four years combined with building relationships with media partners and tested branding and messaging, contributed to our awareness strategy that is starting to bear fruit.”

Management at the Centre for Tissue Engineering acknowledged the success and growth of the ODF and as a result thereof successfully facilitated a collaborative partnership between stakeholders in tissue and the ODF. The tissue partners contributed over R1 million towards tissue donor awareness, which the ODF will administer and use for organ and tissue donor awareness until July 2017.

Samantha Nicholls, Executive Director of the Organ Donor Foundation said that she is confident that this partnership will result in more organ and tissue referrals in 2016/2017. She is also excited about a new era of partnerships being formed in the transplant community where stakeholders can work together to the benefit of everyone and increase organ and tissue referrals in South Africa. Mrs. Nicholls said: “I am sincerely grateful to partners in tissue for taking the leap of faith by investing funding to increase organ and tissue awareness. The ODF is the perfect choice to make this project a huge success as we solely specialise in organ and tissue awareness.”

Transplant News Reader Feedback 2016

Please help us improve this newsletter for you. Please complete this form and email to: lakeann@mweb.co.za or fax to: 086 648 4586 before or by 30 January 2017.

1. In what town/city and province do you live? 
   Town: __________________    Province:________________

2. How do you receive Transplant Newsletter? 
   □ My Doctor
   □ Transplant Society (SATS)
   □ Organ Donor Foundation
   □ Support Group
   □ I don’t normally get a copy
   □ Other (please specify) __________________________

3. Gender: 
   □ Male □ Female

4. Age group: 
   □ Adult (18+)
   □ Teen (13-18)
   □ Child (Under 13)

5. What is your interest in Transplant News? 
   □ Organ Donor
   □ Transplant Recipient
   □ Family of transplant patient
   □ Doctor
   □ Dialysis patient
   □ Transplant waiting list
   □ Other (Please specify) __________________________

6. If you are an organ recipient, are you a recipient of: 
   □ Lung transplant
   □ Heart transplant
   □ Kidney transplant
   □ Liver transplant
   □ Other (please specify) __________________________

7. In which of the following types of articles you are most interested? 
   □ Organ donation
   □ Patient stories
   □ Motivational
   □ Exercise and nutrition
   □ Lifestyle tips
   □ Questions and answers
   □ Psychology
   □ Transplantation News
   □ Support group info
   □ For family/relatives
   □ Other (Please specify) __________________________

8. What other articles would you like to see featured? 
   ____________________________________________________________
   ____________________________________________________________