

Transplant news

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Editorial

Dr Jerome Loveland
Editor

*M*ore than ever, I think that this issue highlights the patient at the core of any transplant programme, and further, that the operation itself forms only one very small component of an intricate multifaceted process, geared towards long term survival of the transplanted organ.

The success of transplantation is epitomised by Tanya-Lisa Elston who celebrated the 20 year birthday of her Related Living Donor Kidney transplant on the 12th October of last year. Her story is inspirational and typifies the trials and tribulations of what patients go through during their diagnosis, work up and listing for transplantation, as well as the procedure itself. Not to mention the ups and downs during the 20 years post transplant! Tanya-Lisa's article highlights the ultimate success however – a full vibrant life, complete with family, professional success and a commitment to giving back to the community that she is so much a part of!

Although perhaps a cliché, every year brings new challenges. Innovations in technology and advances in immunosuppression will continue. However, the foremost concern will remain as the massive disparity between patients listed for transplantation and the number of organs available to transplant.

Patients will die waiting for an organ. A universal focus must concentrate on this critical shortage, with educational drives to alert our population about both deceased as well as related living donor options for organ donation.

In addition to the obvious benefit of "life", the massive impact on "quality of Life" will be highlighted at the World Transplant games

where recipients' physical attributes will be compared to hundreds of other transplant recipients from around the world. The games will be hosted in Durban between the 28th of July and the 4th of August 2013, back-to-back with the South African Transplantation Society meeting, presenting a unique opportunity to bring the professional and patient communities together.

Further "hot topics" included in this issue include excellent insights into aspects of kidney-pancreas transplantation by Alan Cairns, after which other important issues that complement transplantation are discussed. Errol Gottlich on the importance and impact of allied professionals in the management of paediatric kidney recipients through the KidneyBeans Trust and Russell Britz expands on the importance of vascular access prior to renal transplantation.



Tanya-Lisa Elston celebrated 20 years of her Related Living Donor Kidney transplant recently. Read her inspiring story on page 7-8.

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Leading Light for Life

The current role of kidney-pancreas transplantation



Dr Alan Cairns
Chief Surgeon
Kidney Pancreas Programme
Wits Transplant Unit

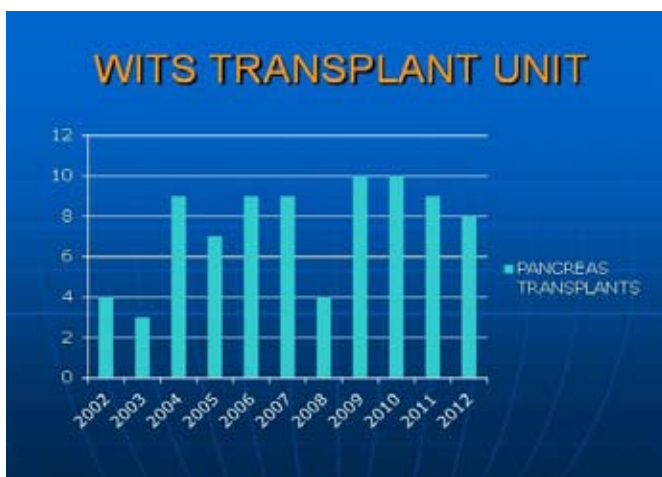
Transplantation of the pancreas into a human recipient was first attempted by Kelly and Lillehei in 1966, when they performed the first simultaneous kidney pancreas transplant at the University of Minnesota, an institution still at the forefront of pancreas transplant work.

By 1980, only 105 pancreas transplants had been documented worldwide, a procedure that continued to be considered experimental in nature until around 1990. By 1998 approximately 10 000 pancreas transplants had been performed, a figure that reached over 35000 by the end of 2010.

Pancreas transplantation is now widely accepted as a gold standard in endocrine replacement therapy, a mainstay in the treatment of insulin dependent diabetic patients with renal failure and other secondary complications. The International Pancreas & Islet Transplant Association (IPITA) now forms the largest sub-section of The Transplantation Society (TTS).

The Wits Transplant Unit experience

A programme offering simultaneous kidney pancreas transplantation was initiated in 2002 by the Wits Transplant Unit in Johannesburg and currently provides this service to the whole of South Africa, with recipients from all of the transplant centres being listed. To date, more than 80 of these transplants have been performed, with on average 8 to 10 patients a year



receiving a pancreas transplant in recent years. Since 2005, the majority of these transplants have been done at the Wits Donald Gordon Medical Centre.

Whole organ vs Islet Cell transplant

The goal of the procedure is to restore normal blood sugar levels by provision of sufficient functional islet cell tissue, which ensures sustained insulin production. This is achieved by a whole organ transplant, or in certain centres overseas, transplantation of islet cells in isolation. Islet cell transplantation is extremely technical in nature and relies on a large laboratory set-up, with the donor pancreas subjected to an intricate step-by-step process to produce viable islet cells.

Each recipient generally requires islet cells from 2 pancreases, which are then infused into the liver via a catheter inserted percutaneously. Following the transplant, the recipient is placed on immunosuppressive therapy as would be

the case if they received a solid organ transplant. This procedure, although very promising, is still in the development phase, with sustained insulin independence difficult to maintain. Substantial progress has been made, however, and it remains a valid option for diabetics with severe hypoglycaemia, hypoglycaemic unawareness, and glycaemic lability.

Types of procedure

In most cases of solid organ pancreas transplant, patients will also receive a kidney transplant at the same operation (simultaneous kidney pancreas transplant or SKP), which provides the most successful outcome in terms of graft and patient survival, with a pancreas transplanted at the same time a kidney less likely to fail than a pancreas transplanted alone.

Other options include pancreas after kidney (PAK) transplant, where a recipient has already received a kidney from a living donor, or had a cadaveric renal transplant and pancreas transplant alone (PTA). Worldwide, SKP makes up for 75% of pancreas transplants, PAK 18%, and the remaining 7% by PTA.

Recipient categories

- Simultaneous Kidney Pancreas Transplant SKP
- Pancreas after Kidney Transplant PAK
- Pancreas Transplant Alone PTA

Recipients

Ideal candidates for kidney pancreas transplant surgery are type I diabetics who have, or are at risk of developing, secondary complications of diabetes.

Patients with hyperlabile diabetes, as defined by

- Frequent hypoglycaemic episodes
 - Hypoglycaemic unawareness, and
 - Frequent episodes of ketoacidosis
- are targeted for listing, as these conditions may be lifethreatening.

Donors

As pancreas transplantation carries the highest complication rate of all solid organ transplants, donor selection is also of critical importance, with the following criteria being applied:

- Deceased Donor
- Heart beating (as opposed to “non heart beating” deceased donor)
- Minimum weight > 35kg
- Age < 55 years
- BMI < 33 kg/m²

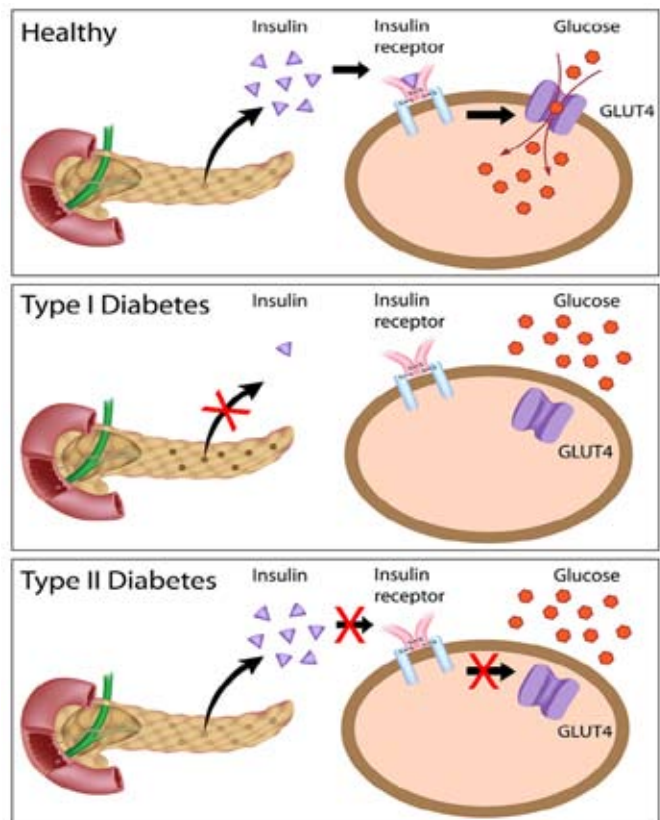
Diabetes

Patients who receive pancreas transplants trade their daily insulin therapy for daily immunosuppression therapy and improved quality of life. The potential of reversing already established secondary complications of diabetes by transplanting a functioning pancreas, is debatable, with at best, only partial reversibility achievable. Normoglycaemia does, however, result in stabilisation of the vascular and neurological complications associated with diabetes. Those with end-stage renal failure will be listed for an SKP, which corrects this aspect of their disease.

Insulin Therapy

Potential recipients undergo a thorough medical assessment to ensure the best possible outcome post transplant and to limit potentially avoidable complications. This procedure is essentially one of lifestyle modification and not a life-saving operation, as is the case with liver or heart transplants, as diabetic patients can still rely on insulin therapy.

Despite this, staying on lifelong insulin therapy also has obvious drawbacks - see limitations above.



Limitations of insulin therapy

- Unable to achieve sustained normalisation of blood sugar
- Risk of complications not eliminated
- Significant risk of hypoglycaemia - especially with intensive insulin therapy

Conclusion

Type I diabetics with end-stage renal failure, who do not have advanced coronary or peripheral vascular disease, may be candidates for an SKP transplant. Those with life-threatening hypoglycaemic unawareness or brittle diabetes resulting in poor quality of life, benefit most from this procedure.

We urge diabetic patients, especially those as described above, to consider the option of pancreas transplantation and to discuss it further with their treating physician, or a member of our transplant team. By expanding the list of potential recipients awaiting pancreas transplantation, we allow for better allocation and utilisation of grafts when they do become available.

The KidneyBeanz Trust



Dr Errol Gottlich
Founder and Trustee of KidneyBeanz Trust
Paediatric Nephrologist
Morningside Mediclinic Sandton

Children with severe kidney disease and their families experience a dramatic change of life circumstances which unfortunately is mostly for the worse.

The child is exposed to the following stresses:

- Often the need for dialysis – peritoneal dialysis is always favoured in order to treat the child at home but in certain circumstances haemodialysis becomes necessary
- Surgical procedures with the associated experiences of pain and discomfort
- Prolonged or repeated admissions to hospital and outpatient visits with regular blood-taking and/or drip insertions.
- Severe dietary and fluid restrictions
- An interruption in education and school attendance with separation from their normal social environment
- Mood changes and depression

Family members are also affected in the following ways:

- Intense parental and sibling concern and anxiety for the child with a life-threatening illness
- Depression and marital relationship complications
- Prolonged interruptions from work
- Income loss and an increase in expenses on medical services resulting in financial difficulties
- Need to be firm in enforcing dietary and fluid restrictions
- Overwhelming sense of not coping with the multiple and complicated demands of their child's illness

In the state sector it has been long recognised that these children and their families need support services which are mostly available. The opening of the Morningside Children's Kidney Treatment Centre as a private facility at Morningside Mediclinic in 2006 was allied with the registration of the KidneyBeanz Trust as a means of providing not only medical, dialysis and transplantation services to children but also to provide, through the Trust, a comprehensive programme of support services in order to ameliorate the significant deleterious effects that severe kidney disease causes.

In 2012 the Trust moved into bright and fully equipped rooms adjacent to the Morningside Children's Kidney Treatment Centre in which offices and a therapy and play area are housed.

Currently the Trust provides a significant array of services:

- Educational support
- Paediatric neurodevelopmental occupational therapist
- Paediatric psychological support and play therapy
- Parental psychological support
- Paediatric dietary advice
- Physiotherapy
- Massage therapist
- Transport subsidies for those children on dialysis who need to travel far distances to access therapy three times a week
- Clothes and nappies for in-hospital patients who are often from very disadvantaged families.
- Dialysis and transplantation educational support programmes
- Fun outings and a yearly Christmas party
- Public education programmes

So far the Trust has assisted 105 children of which 46 have been transplanted since 2006. Of these 39 were kidney transplants, 6 were combined kidney and liver transplant and 1 was a combined kidney and pancreas transplant. The KidneyBeanz Trust, with the assistance of sponsors, has assisted a number of these transplanted children to participate in National and International Transplant Games. The International Transplant Games will soon be hosted in Durban and a number of KidneyBeanz children will be representing their country as they so successfully did 3 years ago in Sweden.

The major driving force of the growth in the Trust over the last few years has been Mrs Annemarie Wagner, who provides the neurodevelopmental occupational service as well as the general management of the Trust's activities. Annemarie herself has been a kidney donor to her daughter. The Trust is a not for profit organisation and therefore relies on fund raising in order to provide services. Since 2011 the Trust has been promoted in a touching advert in cinemas nationally and on DSTV. A number of spinathons and an increasing number of riders in the 94.7 cycle race wearing KidneyBeanz cycling gear has taken the Trust's objectives into the community. Both corporate and individual sponsors support the Trust which, through the energy and guidance of its Trustees and Trust champions, keeps adding new initiatives and services for our child and family recipients.



Teaching session in KidneyBeanz therapy centre



Physiotherapy in KidneyBeanz therapy centre



Various therapy sessions in KidneyBeanz therapy centre



Our KidneyBeanz Transplant Olympian contenders

It is often however the very families who have received support services that give back to the Trust in so many ways. The result is that the Trust is an extremely close group of people, professionals, families and supporters, who all recognise that in order to deliver the best of care and to achieve the best outcome, one not only has to provide medical services but also ensure that as many other needs are provided for as well. The KidneyBeanz Trust has succeeded in providing these services and will continue to ensure that these services are expanded in order to grow the aims and objectives for which the Trust was established.

Further information on www.kidneybeanz.co.za



supporting children with life threatening kidney disease www.kidneybeanz.co.za

Dialysis access for the uninitiated



Professor Russell Britz
General Vascular
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Renal replacement therapy is required once kidneys fail. There are three methods of renal replacement. Haemodialysis requiring blood to flow through a machine in order to remove most but not all of the things a healthy kidney would remove, peritoneal dialysis that involves instillation of fluid into the abdominal peritoneal cavity for diffusion of substances into the fluid and then drainage out of the peritoneal abdominal cavity and kidney transplantation.

The most desirable of these is kidney transplantation and preferably this should be performed just before dialysis is required. This is otherwise known as pre-emptive kidney transplantation. Living donor kidney transplants do better than deceased donor kidney transplants and are encouraged. If a pre-emptive kidney transplant is not possible, try again. It's that important. But if all options for living kidney transplant have been exhausted, dialysis will be required. This is seen as a holding procedure until a deceased donor kidney transplant can be accomplished.

The average waiting time on a kidney transplant list in South Africa is currently 5 to 6 years. Dialysis is required during this time. The choice is then between peritoneal dialysis and haemodialysis. Peritoneal dialysis may be more convenient and undertaken at home minimising effect on lifestyle. Haemodialysis is, as a rule, more effective and controlled but requires 4-5 hours in a dialysis unit 2-3 times a week affecting lifestyle significantly. Which option is most appropriate for an individual can be decided by and in consultation with the managing nephrologist.

"Access" is the mechanism whereby the dialysis will be undertaken.

- Peritoneal dialysis requires a Tenckhoff Catheter insertion into the abdomen. Infection of this catheter is a major problem and meticulous cleaning/hygiene is a requirement.
- Haemodialysis may be undertaken by one of two methods:
 - **Temporary Catheter Placement.** This may be a short term solution that requires replacement within a week at most ("Quinton" catheter) or a more permanent solution that can last weeks to months if well looked after ("Perm" catheter). "Permcaths" are tunnelled beneath the skin and have a cuff that lies between the skin and the blood vessel that helps combat infection.

They may last up to a year in exceptional cases before requiring replacement. Infection of these is again a major problem.

- **Permanent "Fistula" Formation.** A fistula is a communication between an artery and a vein that lies just under the skin, is easily needled and has high blood flow from one to the other. It is preferably constructed using one's own vein (Arterio-Venous Fistula) but may be constructed using an artificial material, usually PTFE (Arteriovenous Graft) as the conduit. Each of these has a finite lifespan and many will need revision or replacement. As many sites as possible must be used to construct these in order to plan for longest duration of dialysis possible.

Rules in dialysis access

There are several RULES in dialysis access that are all important:

- All require meticulous hygiene and cleaning especially in the dialysis units when being accessed
- Fistulae are preferable to temporary catheters for haemodialysis
- Quinton and Perm catheters should avoid the femoral vein in the groin and must not be placed in the Subclavian veins, but should rather be placed in the Internal Jugular veins in the lower neck. Placement in the Subclavian veins is often associated with significant damage to the venous drainage, preventing subsequent creation of Arteriovenous Fistulae.
- Fistula success rates are significantly improved by preoperative evaluation of the vascular structures with Duplex Doppler (Ultrasound) studies.
- The order of choice for fistula creation is: at the wrist with own vein (even if at slightly higher risk of nonmaturation); at the elbow with own vein; superficialising a deep vein of the upper arm, using a PTFE graft; placement of any fistula type in the legs.
- The earlier the referral for access creation, the more successful it is. Recommended is a pre-emptive fistula once creatinine clearance rates have fallen to 25ml/min. Dialysis will be required at a creatinine clearance rate of around 15ml/min.
- Ensure that the surgeon is familiar with the operation, that the dialysis unit "needling technician" is competent and does not continuously needle the fistula in the same spot. Look after the fistula, it is a lifeline and may be very difficult to replace if lost.

What can you say about celebrating 20 years with a new kidney?



*Tanya-Lisa Elston (Coucourakis)
kidney transplant recipient
Former Deputy Chair of the Kidney Association of SA
Founding member of the SA Transplant Association
World Transplant games double-medallist*

quite a lot, actually!

On 12 October 2012, I celebrated my 20th “Kidney Birthday”, a special day of great celebration and reflection, celebrating the joy of being a wife, daughter, big sister, godmother, aunt and friend – the joy of being able to realise my potential, develop my passions and follow my dreams - all because of the unwinding support and belief of doctors, my cherished family and lifelong friends - and the courageous, loving and heroic gift from my father, that made it possible.

There have been good and great days along the way – and many stresses and disappointments too – but really, looking back – what I had before my transplant was life interrupted and I’m sure my parents remember all too well, carrying me out of the school boarding house in the middle of the night on countless occasions, infections, doctors, appointments, tests, x-rays and more tests.

I made it through almost weekly visits to doctors and hospitals, and, as a ‘semi-compliant’ patient, I am ever thankful for Dr. Peter Thomson, who was a guiding light and a patient listener for me and my family – one who allowed me to stay with him in paediatrics until I turned 21... (let’s call it a streak of stubborn refusal to leave on my part) – or a streak of immense compassion on his...

I filled more vials of blood than you can imagine, endured countless hours waiting at clinics, for results, for meds, for news, another prognosis... I was shunted from pillar to post, and subjected to endless prodding by the residents at the Jhb Gen – granted... some were quite good looking, if I remember correctly...

A difficult case

Then, there was Prof. Van Blerk, who, after enduring conversations, spirited debates and numerous presentations about my case both in SA and abroad, told our family – **“I know you’re a difficult case and they say you aren’t transplantable, but I believe you are!”**



Tanya-Lisa with her family

There have been good and great days along the way - and many stresses and disappointments too – but really, looking back, what I had before my transplant was life interrupted

At 19, it came. My first day of dialysis, fistulas and subclavians (thanks Roger P. for putting in that first one – it formed the basis of our friendship today..!) The three-times-a-week routine of early morning breakfasts, where I savoured the forbidden avocado, chocolate, bananas and crisps and looked forward excitedly to wearing my “thin jeans” after the fluid that made it hard to breathe was removed, once again. In those long four hours, I tried to read, play games, chat or do some work – more often, I battled nausea and extreme tiredness and the afternoons went by in slow motion - but I got up and went to University most days after I was done.

University life

University was a challenge and I spent an extra year finishing my degrees, but I didn’t really care - I wanted to do so many things, and I did – I indulged my passion for tennis as a member of the university team, co-founded an NGO that is thriving today and actively participated and led a variety of cultural and other organisations, even becoming President of one, 30 years after my dad held the same position! Most importantly, I graduated and I cemented very special, lifelong friendships (and snagged a husband) all because of that extra time – none was wasted.

After 2.5 years on dialysis and comprehensive family testing to find the most suitable kidney for me – my mum, dad and

sister were all a match! How lucky! The day finally arrived; 12 October, 1992, my appointment with a magician fondly known as “Dokkie Botha” - the day of my related living donor transplant – or as it is more commonly known in our house – the day “Dad’s Rolls Royce spare” was given with unconditional love – and because he really thought it would get him out of mowing the lawn...!

I spent 11 days in hospital, my dad spent 6 – my mother spent all her waking hours with us, so did my dear sister, Sonia. Mum never wavered throughout the years of my illness. She never stopped looking for answers and better solutions, never tired of taking me to my next appointment. My parents and sister were always there, supporting, encouraging, and holding me up. My friends Giorgio, Danai, Christine and Nicola were invaluable.

I tried all the tricks in the book after my transplant, to be discharged by October 22nd for my sister’s birthday...but Sunday the 23rd it was...and life began again. Six weeks later, I drove to University, calling mum on the way, just to let her know that it was too late to stop me.

Six weeks later, I drove to University, calling mum on the way, just to let her know that it was too late to stop me.



Tanya-Lisa with her dad (above) and with her parents and husband Garreth (below)



I married Garreth in 1999, and we are happy after 14 years, with many adventures behind us and many more to look forward to. I have travelled with my family, my husband and with my friends and we have many happy memories and wonderful stories to share. I have achieved some milestones in my career too – being included as one of SA’s Top Women in Business and Government on two occasions and now directing the communications and public affairs for the agency that manages organ and tissue donation and transplantation in Toronto, Canada. Funny how life works.

Most importantly, over all the years, I remember clearly all the people who brought me to this 20th birthday – and I value each person’s time, patience, knowledge, perseverance, compassion, understanding and love. I also value the debates – I was and am not an easy, take-it-at-face-value kind of patient (stop smiling, Roger), but together, after 20+ years, I believe we are all stronger for the parts we have played and the ways we have challenged each other.

Kidney failure is not easy, it makes life uncertain. I never let it define me. I was born with it, lived with it, suffered through it, adapted to it. It

is a part of who I have become. One day, that uncertain life changed through a selfless, loving gift. That day, just living became having a life - one to cherish, enjoy, take hold of, share, create things with and be thankful for.

For me, the best way to show my gratitude and thanks, is to stay healthy, keep aspiring, thank those around me for shielding me and for encouraging me, appreciate them, understand that they have travelled this road with me and then, to keep moving forward, so that I take and run with the opportunities life puts in front of me.