

Giving kids with kidney disease a chance

Kidney Beanz has been overcoming the challenges of paediatric kidney transplantation

Dr Errol Gottlich

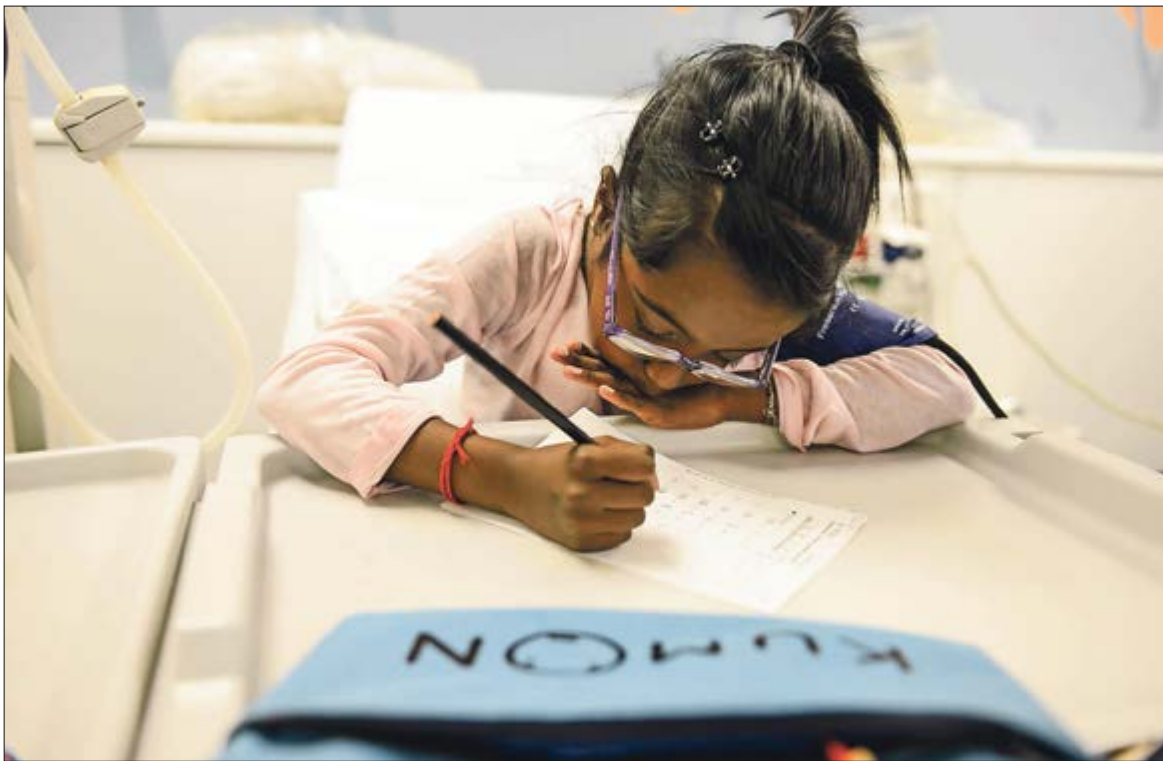
Reminiscent of the arc of a full rainbow, a little girl lies stretched over a bright red exercise ball. The physiotherapist gently encourages her to relax and breathe slowly in order to loosen up her stiff back muscles — the result of sitting for 12 long hours a week in a dialysis chair. An occupational therapist demonstrates a fine motor activity to a young boy. Downstairs in the paediatric ward, a dietician hands over a diet sheet to an anxious mum, whose daughter has just been diagnosed with kidney failure. A restrictive diet short on dairy products, low on salt and restricted to 500ml of fluid a day is going to be a momentous challenge for the mother to apply. In ICU, the managers of the Kidney Beanz Trust visit each child. With empathy, they introduce themselves and the trust to the distraught parents of critically ill children, offering whatever support is required.

Dr Errol Gottlich founded the Kidney Beanz Trust in 2007 as a non-profit organisation - at the same time that the Morningside Children's Kidney Treatment Centre at Morningside Mediclinic opened. The trust's mandate is to support children with life-threatening kidney disease. It's warm, brightly coloured offices and well-equipped therapy rooms look out over the busy central hub of Sandton. The noise of the traffic and building construction is drowned out by the laughter of the children and the constant chatter between therapists and their patients.

Children develop severe kidney disease for a number of reasons. These may be congenital abnormalities of the kidneys and bladder, inflammatory conditions or chronic urinary tract infections. Whatever the cause, chronic kidney failure in a child is a permanent condition. The consequences impact on the child's life, the family's circumstances and on society in general. Chronic kidney failure affects every organ in a child, and it's not only a physical condition. Children on treatment miss a significant amount of schooling and quickly fall behind. Lack of contact with friends and a distorted body image based on chronic swelling or short stature makes them feel different and often leads to a sense of isolation and depression. Parents are placed under enormous financial and marital stress by caring for a child with a life-threatening disease.

The main treatment options for chronic kidney failure are dialysis and kidney transplantation. The months spent on dialysis and the journey towards a transplant can be difficult and complicated. These children often experience multiple admissions to hospital, frequent blood tests and minor surgical procedures as part of their therapy.

Currently, the Morningside Children's Kidney Treatment Centre manages 2 954 patients, all of whom are eligible for services provided by the trust. The trust's supportive ser-



A young patient at the Morningside Children's Kidney Treatment Centre at Morningside Mediclinic does her schoolwork from her bed. Children here undergo much of their schooling while attached to a dialysis machine. Photo: Sandy Maytham-Bailey

vices run in parallel, and in support of the medical management in order to ensure a holistic and optimal treatment program. Since 2007 the Kidney Beanz Trust has supported the transplant journey of 68 children treated at the Morningside Children's Kidney Treatment Centre. 60 children have had a kidney transplant, seven children a combined kidney and liver transplant and one child underwent a combined kidney and pancreas transplant.

The trust is currently establishing a bladder function assessment unit and making an ultrasound machine available to assist in the medical assessment and management of patients at the Morningside Children's Kidney

Treatment Centre.

The Kidney Beanz Trust extended its supportive services to the Charlotte Maxeke Johannesburg Academic Hospital paediatric renal unit in 2015. This large public sector service currently manages 4 375 patients. A needs analysis identified that extra staff were required. The trust employs two auxiliary nurses and a unit coordinator to ensure optimal operational efficiency.

Managing a child with kidney failure and preparing that child for a kidney transplant is a long, arduous and complicated process. About half of the recipient children at the Morningside Children's Kidney Treatment Centre have received a kidney from a par-

ent or a living donor while the other 50% received a deceased donor kidney. Due to the severe shortage of deceased donors, children often need to wait between three to six years, often on chronic dialysis, until that life-changing telephone call comes through from the transplant unit.

The joy and relief that parents express when their child is found to be compatible with a donor is totally overwhelming for both family and caregivers. To the child, the parents and their extended family, the kidney transplant symbolises a second life. The relief they feel is not only because their child now has a real chance of survival, but also because they are released them from the incredible

hardship of living with kidney failure and the anxiety and uncertainty that comes with waiting for a transplant.

The Kidney Beanz Trust eases those burdens by providing on-site supportive services — generally not adequately funded by medical aids — to these children and their families. The trust's staff and array of services ensures that these children and their families face the headwinds of treatment with support and empathy.

Children can be transplanted from 10kg in weight or three years of age. A best-case scenario is that the transplanted kidney functions for between 20 to 30 years post-transplant. Though this represents a significant lease on life, most childhood kidney transplant recipients will need one or even two more transplants in their lifetime. This places significant importance of getting the first transplant done as best as possible to ensure that the lifespan of the transplanted kidney is as long as possible.

As much as the transplant process is miraculous, so too have been the benefits of the Kidney Beanz Trust for so many of the young children who have benefitted from the trust's services. Recent outcome data from the University of Witwatersrand Donald Gordon Medical Centre Transplant Unit shows outstanding graft survival outcomes for the 68 children transplanted so far. After having received transplants, children regularly visit the trust to keep in contact with everyone who helped them along their recovery journey. In many ways, I am sure that these visits serve as personal reminders of how fortunate they have been to experience the dedication of the team of trust managers and therapists.

Dr Errol Gottlich is a specialist paediatric nephrologist. For more information visit www.kidneybeans.co.za or write to info@kidneybeans.co.za

Bringing kidney awareness and screening to schools

Initial results reveal 14% of South African youth have hypertension

Professor Anthony Meyers

The NKFSA Kidney Awareness and Screening Programme aims to provide basic education for grade 11 and 12 school learners regarding the incidence, dangers and causes of high blood pressure (genetic and lifestyle associated) with special discussions, for instance, on the role of salt in modern diets. We intend over time to bring attention to these facts to school learners across South Africa.

By doing so, we will have made significant inroads into the ability to diagnose high blood pressure at an early stage so that, with adequate treatment, we can prevent thousands of citizens from suffering many of the cardiovascular and kidney disease consequences of hypertension. Globally these consequences contribute to about 13.5% of the annual deaths in any given population, though potentially most of them can be avoided.

The programme entails a series of basic lectures delivered by local experts discussing the incidence, age

of onset, risk factors and effects on the heart, brain, blood vessels and kidneys of poorly controlled hypertension, diabetes and other causes of kidney disease. This is then followed by a talk on healthy living in terms of diet and exercise. Emphasis is placed on the "hidden salt" foods also common to modern diets: processed foods, pre-cooked meals, dining out, take-away foods and snacks (junk food).

After the introductory lectures each learner is interviewed and simple measurements are performed. These consist of recording their age and sex; family history of blood high pressure, diabetes or both; height and weight (to calculate body mass index); mid-waist circumference; obtaining a urine sample for dipstick tests examining red and white blood cells and/or protein levels, and obtaining a blood pressure reading. Total confidentiality is maintained and nobody has access to the learners' names other than the relevant guardians or parents. All the screening tests are conducted on a volun-



Children undergoing dialysis for kidney disease. Photo: Sandy Maytham-Bailey

tary and full consent basis.

The NKFSA intends to analyse the test results with a view to publishing in a leading South African medical journal. Results from the initial phases have revealed some astonishing facts about South African youth, with interesting variances in different settings. The main concern is that on average at least 14% of youths have hypertension, which, if not identified and treated early, will

result in major future health problems that will likely cost the country dearly.

We believe that participation in our Kidney Awareness and Screening Programme is of great importance to the future health of the South African population.

Professor Anthony Meyers is the chairman of the National Kidney Foundation