

Sunday Insight



DESPERATE:
Michelle Manu, 12,
needs a new kidney.
DOUG SHERRING

A waiting game

A falling road toll is good news — except for New Zealanders awaiting a life-saving organ transplant. **Abby Gillies** and **Joanne Carroll** investigate why New Zealand has one of the lowest organ donor rates in the world and report on new moves to encourage live donors to give the gift of life.

MICHELLE MANU desperately needs a new kidney. The 12-year-old from Otago has been on the emergency list for a donated organ for three years and is still waiting.

Three times a week she receives dialysis to clean her blood — a job her kidneys can no longer do.

New Zealand's rate of deceased organ donors remains low by international standards, meaning Michelle could face a long battle ahead.

"For Christmas I just asked to go home. It would be good because I could go to school all the time," she says.

Michelle is one of 656 New Zealanders waiting for a pancreas, liver, lung or kidney. A number of others are waiting for tissue transplants, including corneas, heart valves and skin.

While the country's waiting list for organs is higher than ever, our donor rate is decreasing, according to the Ministry of Health.

One reason attributed to the statistics is our decreasing road toll, which has meant a smaller pool of potential donors. The change in statistics are a difficult irony, says Organ Donation New Zealand donor co-ordinator Janice Langlands.

"It's good, except if you're a [organ] recipient. Twenty-five per cent of our donors now come from road trauma. Twenty years ago, 50 per cent or more of our donors were from young people dying from road accidents," she says.

However, work is underway to improve our number of live donors of kidneys and liver tissue, with some promising results.

Michelle's mum Sisifa Samuela, 35, says the last three years have been awful. "We're desperate, wanting help from someone," she says.

The mother of five says they continue to wait for the phone call that will change Michelle's life, but time is running out.

"She really needs it because some patients die if they don't get a kidney. Five years is the longest they want her to stay on dialysis."

At the beginning of 2008 Michelle complained that she was having trouble urinating and started losing weight rapidly. Doctors' tests confirmed her kidneys weren't functioning properly and after being assessed she was placed on the emergency waiting list for a donor.

Samuela has asked all her family members to be tested to see if they are a match. Her partner Bobby Manu, 30, is a match, but he has not been able to shed the 50kg from his 140kg frame required before doctors will go ahead with the transplant.

FOR MANY on the waiting list, the call will never come, says Langlands. Those needing a heart, lung, and liver will die without a transplant and for Michelle and others waiting for a kidney, without a

donor they will lead a life restricted by long-term dialysis treatment.

This year, up to 30 people are expected to die waiting for a kidney and up to three waiting for a liver. The figures for those waiting for other organs are uncertain, says Auckland director of abdominal transplantation, professor Stephen Munn.

A worldwide increase in diabetes and renal failure means kidneys are the most-needed organ. In New Zealand, 600 people require donor kidneys.

New Zealand's donor rate is the second lowest in the developed world, with about 40 deceased donors each year or nine in every million people. The only country that rates lower is Greece, where there are six donors for every million people. Compare that to Spain, which has the leading international donor rate, more than three times greater than ours.

The annual road toll decreased from 435 to 373 between 2004 and

2010. This, along with a lack of resources and misconceptions, contributed to our low number of donors, says Langlands.

"Spain does have a high donor rate. They have invested quite a large amount of money in hospitals identifying donors. We have a gentle approach to donation in New Zealand. We don't want families to feel coerced or pressured — it's different in other countries."

Some countries have considered payment for donated organs or contributions to funeral expenses to increase donor rates but Langlands does not support the idea.

"I think it should be an altruistic gift otherwise they could do it for the wrong reasons."

NELLIE COE'S son, 20-year-old Sean, died tragically after a car crash on New Year's Day.

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GRATEFUL: Kylie, Glen, Maddison and baby Sienna. LISA DAVIDSON

FROM p31

Four people have been given his liver, kidneys, pancreas and lungs. Coe says the decision to allow her son's organs to be donated was easy.

"For us it was very simple. We had talked about it as a family just a couple of months ago. My husband and I had told all our children we wanted to donate our organs and Sean agreed it was something he wanted to do, too.

"We wanted to help other people. There are a lot of people that need organs to save their lives or to give them a better quality of life," she says.

Coe is surprised New Zealand has such a low rate of organ donation.

"I can't understand why more people do not donate. I would have thought it was more common. It's something you can do to help others," she says.

"Sean was a young fit guy. The surgeon said he had great healthy organs and whoever gets them would be very lucky."

Despite a great need for organs, several factors must align for a successful transplant. Doctors could not find a match for Sean's heart in New Zealand and there was no time to get it to a patient in Australia so the heart was returned to the family.

"I find it very comforting that Sean has saved four people," says Coe. "It is like Sean lives on in those people. That's why I would like to meet them one day."

Organ recipients are not told the identities of the donors, however recipients' and donors' families are able to send anonymous letters to each other via Organ Donation New Zealand. At the time of the transplant, the donor's family is told the patient's age, gender, which organ they are receiving and the reason for the operation.

Kylie Wedgwood would like to write to the family of the donor who gave her husband Glen, 29, the chance to live a healthy life.

"I want to say thank you and let them know how he is now. He has a normal life and feels good. I'd like to put a smile on their face after all the grief," says Wedgwood.

Glen, a builder from Whangarei who now lives in Alexandra, had suffered from renal nephropathy, or

kidney damage, since he was 2 years old. He spent more than a year on dialysis before his kidney transplant three years ago.

"Before I went on dialysis I went in for blood tests and the doctors said they were surprised I was able to walk into the hospital," he says. "One of my kidneys wasn't working and then the other failed."

Test results showed his father, Ray, was a match, but his father was diagnosed with cancer just before the operation. It was a heartbreaking time.

"We tried other cousins but none were matches or had something wrong with them, so I went on the cadaver list for about a year before I got my kidney in October 2007," says Glen, who was living in Queenstown when he got the call at 9am one morning that a medical flight was waiting to take him to Christchurch for the transplant. "By 2pm, I had a new kidney."

Kylie Wedgwood was pregnant with the couple's first daughter, Maddison, at the time. The couple now have another daughter, Sienna, aged 3 months.

"We have a lot to thank the donor and their family for," she says. "We are a young family just starting out. If Glen couldn't work it would have been so hard. His transplant put us on the right path."

GLEN WEDGWOOD is one of the lucky ones. Those on the list face an "emotional roller coaster", waiting an average of three years for an organ, says Munn.

"They hope someone will die to give them an organ but they don't want anyone to die. It's a very difficult time."

However, Munn says there is also good news for those waiting — the number of live kidney and liver donors are increasing.

The process of assessment for both donors and recipients is extensive, says Munn. It is based on their need for a transplant, physical strength to get through the operation and psychiatric and social evaluations.

Most deceased organ donors have died of a stroke or physical injury to the brain. Organ donation can only happen when a person is in an intensive care unit and has fatal brain damage.

In a carefully-timed exercise, often outside usual business hours, surgeons travel anywhere in the country to collect the organs within a tight time frame.

Hearts and lungs are only able to survive for up to six hours, livers up to 12 hours and kidneys and pancreases up to 24 hours.

Those receiving kidney transplants can have the operation in Christchurch, Wellington or Auckland, but transplants for all other organs can only be done in Auckland.

For recipients, often from isolated parts of the South Island, making the last-minute dash to the operating table can also lead to heartbreak.

"There has been an occasion where a transplant hasn't been able to take place because of weather. In the winter we do get fog and airports close. It's tragic. It's uncommon, but it does happen," says Munn.

"I've had a time when a patient was waiting in Blenheim and couldn't get on the last flight of the day and we've had to say, 'We're giving it to someone else on the list.'"

Donor guide

Tissue	Organs
Eyes Corneal transplantation can prevent blindness and restore sight to people with disease, trauma or infection to their cornea. Can be stored for three weeks.	Lungs Transplants required by people with severe lung damage by disease such as emphysema and cystic fibrosis. Recipients per year: 9.
Heart valves Transplants are required by people who have had valves damaged by disease or a congenital condition. Babies born with abnormal or missing heart valves can be saved with transplants. Can be stored for a few months.	Heart People with severely damaged heart muscles will die without a transplant. Recipients per year: 11.
Skin A natural dressing for severe burns, skin tissue promotes healing, reduces infection and fluid loss. Can be stored for one year.	Liver Liver failure, such as caused by hepatitis B or C, can be treated with a successful transplant. Recipients per year: 35.
	Kidney People on dialysis due to kidney failure lead normal lives following a transplant. Recipients per year: 50.
	Pancreas A transplant can help people who have insulin-dependent diabetes and kidney failure when combined with a kidney transplant. Recipients per year: 3.

Numbers are approximate
Source: Organ Donation NZ

In a kidney transplant, a fist-sized incision is made through the skin and muscle in the patient's lower abdomen. In the three-hour procedure, the inner lining is pushed aside and the kidney placed inside the pocket. The artery and veins of the kidney are then connected to those in the leg.

Success rates are good by international standards, says Munn, with 90 per cent of donated kidneys expected to function a year later.

However, stating donor on your driver's licence does not guarantee your organs will be used, should the unthinkable happen. The family of the deceased will be asked for consent.

It is a persistent myth that the families of people who donate their organs often override that decision, says Langlands. About half of New Zealanders tick "yes" to organ donation on their driver's licence, but only about one in 20 families then say no.

Families tend to respect their loved one's wishes, in the hope something positive could come out of their death, says Langlands. A bigger issue was families not knowing their loved one's wishes about donation and many were faced with guessing what they would have wanted.

Surgery to replace a diseased organ with a healthy one and for patient care for three months costs \$50,000 to \$200,000.

ETHNIC BACKGROUND was no barrier to donation but it is important to acknowledge cultural rituals in the process, says Auckland DHB general manager Maori health Naida Glavish.

For Maori, that involves saying a karakia (prayer) to get closure from the old organ and to give thanks for the gift of the new one.

"It is as important to ensure the psychological wellness as well as surgical precision and effectiveness," says Glavish.

The number of deceased Maori donors has increased in the past 20 years because of education and an awareness of the higher need for donors, and there has never been a problem with Maori becoming live donors, she says.

LIVE ORGAN donation is an area of growth and needs to be a focus if we are to make up for the shortfall left by deceased donors, say transplant services.

This is when a family member or someone else compatible donates one of their kidneys or part of their liver to a recipient.

Work by the Ministry of Health is underway to increase live donor rates. This includes making the process of donation and transplantation easier, improving support for live donors and extending the forms of live donation available.

Dunedin List MP Michael Woodhouse is advocating for a law change to encourage more live donation. The former CEO of Mercy Hospital has drafted a bill that proposes paying live donors 80 per cent of lost earnings for up to 12 weeks.

He likened it to compensating employees who could not work because of an accident.

It was intended to ease the financial burden for the "heroic act", not to motivate people to donate for the wrong reasons, says Woodhouse.

"If we are to improve our rates of organ donation, I think it has to come from live donors."

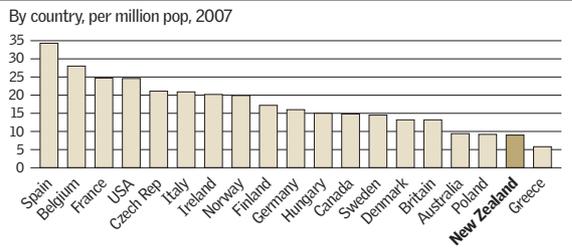
Most of all, families need to talk about organ donation, says Woodhouse.

"People need to have that conversation with loved ones at a time when it's not emotional. That is the most important thing that any New Zealander can do."

Until a donor is found, the Manu family continues to wait and hope.

"I hope for her to get better, just for her to get better," says Samuela.

International donor rates



Who can donate?

- There is no age limit for becoming a donor.
- You can still donate even if you're a smoker or you drink alcohol. There are very few illnesses that would prevent you from donating.
- One donor can save the lives of up to 10 people.
- For more information see www.donor.co.nz