

Organ Donation New Zealand

ANNUAL

REPORT

2020



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ORGAN DONATION NEW ZEALAND

About Organ Donation New Zealand

Organ Donation New Zealand (ODNZ) is the national service for deceased organ and tissue donation. ODNZ is now managed by New Zealand Blood Service (NZBS) and the service is situated in the NZBS National Office in Auckland.

ODNZ coordinates all organ and some tissue donation from deceased donors in New Zealand and the donor coordinators provide information and ongoing support for families who have generously agreed to organ and tissue donation.

ODNZ works with health professionals in donor hospitals to ensure that processes for deceased donation are nationally consistent and of the highest medical, ethical and legal standards.

The Guiding Principles of ODNZ are:

1. Every opportunity for deceased organ donation should be recognised by Intensive Care Unit (ICU) staff and every family should have donation discussed with them by a health care professional with compassion, respect and appropriate knowledge and skill. Donation should be discussed with all families irrespective of whether the word 'donor' is on the driver licence.
2. The process of organ donation must accord with good medical practice, ethical standards and the law. The Human Tissue Act (2008) requires consent before organs or tissues may be removed from a deceased person for transplantation.
3. The family's decision about donation should always be respected. All donors come out of human tragedy and donation by the family is voluntary.

ODNZ provides education for health professionals, information to the media and responds to public enquiries.

This Report

This report outlines the activities of ODNZ and provides an authoritative account of organ donation and transplantation activity in New Zealand during 2020.

It is intended to be a valuable source of information for health professionals involved in organ and tissue donation and transplantation, as well as for the general community.

We gratefully acknowledge the following people for their assistance with information in this report: Jill Faulkner from the New Zealand Heart Valve Laboratory; Colleen Behr from the New Zealand Skin Bank; Helen Twohill from the New Zealand National Eye Bank; Dr Paul Manley, Claire Beckett and Susie Rich from the Renal Transplant Services; Helen Gibbs from the New Zealand Heart and Lung Transplant Service; Barry Harrison from the New Zealand Liver Transplant Unit.

FROM THE ODNZ CLINICAL LEAD

Organ Donation is only possible in certain situations where a person dies in an Intensive Care Unit (ICU). This situation can be unexpected, sudden and devastating for everyone. Despite their immense grief, the family/whānau is able to come together and consider the possibility of organ and tissue donation.

Organ Donation New Zealand (ODNZ) would like to sincerely thank all family and whānau who agree to consider the option of organ and tissue donation. Organ donation comes from human tragedy and would not be possible without the generosity of family/whānau at a very difficult time.

We would also like to thank the ICU teams for providing exceptional end of life care, for recognising and discussing the possibility of organ and tissue donation with family/whānau, and for providing information so that the family/whānau can make a decision that is right for them.

In 2020 there were 64 donors who donated organs following death, enabling 186 recipients to receive life-saving, kidney, liver, lung, heart or pancreas transplants. Many more people received tissue transplants (corneas, sclerae, heart valves and skin) from these donors.

Of the 64 deceased donors, 56 were donors after brain death (DBD, where the brain has died but the heart has not yet stopped) and 8 were donors after circulatory death (DCD, after the heart has stopped). There continues to be further potential for an increase in the number of DCD donations.

In addition to these 64 organ donors, ODNZ facilitated 58 tissue-only donations from people who died in a hospital, hospice or at home.

The number of deceased organ donors in New Zealand continues to rise with time, in association with a large increase in the recognition of opportunities for organ donation, an increase in discussions with family/whānau and an increase in consultations with ODNZ donor coordinators and medical specialists.

ODNZ continued to provide an organ and tissue donation service during all COVID-19 National Alert levels in 2020. However there were approximately 25% fewer deaths overall in New Zealand ICUs during National Alert Levels 3 and 4 than during the same period in 2019, with fewer deaths

in circumstances where donation might have been possible. This was accompanied by a reduction in actual organ donors, however there were no circumstances during these alert levels where donation was prevented due to COVID-19, or to the lockdown.

Education activities were affected by COVID-19 restrictions and a number of sessions were cancelled, including the ICU donation audit meetings, Donation Link nurse workshops and on site hospital education sessions. However some meetings were able to be held via video conferencing.

Sadly, the 2020 Thanksgiving services in Auckland and Christchurch were also cancelled. These services are usually attended by over a thousand people including donor families, transplant recipients, their families, living donors and health professionals.

Following a review by the Ministry of Health, the ODNZ service was to be transferred in June 2020 from being a business unit of the Auckland District Health Board to being provided as part of New Zealand Blood Service (NZBS). However due to the COVID-19 pandemic and the redirection of essential health services, this transfer was delayed. Thanks to an immense amount of work by staff at ODNZ, NZBS and the Ministry of Health a successful transfer took place on the 30th November 2020.

I would like to thank my colleagues at ODNZ, the Donation Link teams, ICU nurses and doctors, operating theatre (OT) staff and other health professionals involved in organ and tissue donation, for their support and dedication to donation and enabling transplantation in New Zealand.



DR JOANNE RICHIE
MEDICAL SPECIALIST
ODNZ CLINICAL LEAD

STAFFING

Donor Coordinators

Janice Langlands (team leader), Mary O'Donnell, Lauren Sprenger, Sue Garland, Annette Flanagan and Lisa Craig are the ODNZ donor coordinators and provide a 24-hour consultation, advice and support service for health professionals involved in organ donation and tissue donation. They coordinate organ and tissue donations throughout New Zealand for transplant services in New Zealand and Australia and tissue banks in New Zealand.



Janice Langlands



Mary O'Donnell



Lauren Sprenger



Sue Garland



Annette Flanagan



Lisa Craig

Medical Specialists

Doctors Jo Ritchie (National Clinical Lead), Laura Bainbridge and Jonathan Casement are employed part-time as the ODNZ medical specialists. Dr Stephen Streat retired in November 2020. Doctors Kim Grayson, Tobias Mertz, David Closey and Myles Smith assisted with medical specialist on-call in 2020. The medical specialists provide 24 hour support and advice on all aspects of the donation process for the donor coordinators and health professionals.



Dr Joanne Ritchie



Dr Jonathan Casement



Dr Laura Bainbridge

Rebecca Oliver, communications advisor, is responsible for providing information to health professionals, media and the public. Leeny Gin is the team administrator for ODNZ.



Rebecca Oliver



Leeny Gin

Donation Link Teams

The Donation Link teams in donor hospitals consist of ICU Donation Link nurses and doctors and OT Donation Link nurses. They are the local experts and liaison for organ and tissue donation for their hospital.

The Ministry of Health funds part-time ICU medical and nursing staff in Donation Link roles and is responsible for these contracts.

ODNZ ACTIVITIES

Donor Family Support

The donor coordinators provide information and support for donor families both before and after organ and tissue donation. This includes the offer of hand prints and locks of hair, providing general information about the outcome of their donation and facilitating anonymous communication between transplant recipients and donor families and vice versa.

Thanksgiving Services are held annually and respectfully acknowledge the generosity of families who have donated organs and tissues following the death of a family member. Families of donors, recipients and their families and health professionals involved in both organ and tissue donation and transplantation are invited to these services. Unfortunately, both the Auckland and Christchurch services were cancelled in 2020 due to the COVID-19 pandemic.

Education

Core Family Donor Conversation Workshop (cFDC)

The Core Family Donor Conversation Workshop (cFDC) which was to be held in September had to be cancelled due to COVID-19. This popular workshop which aims to increase the knowledge and skills of health professionals having conversations with families of potential donors, will be rescheduled in 2021.

Link Nurse Education

The National Donation Link Nurse Workshop and Donation Link Nurse Induction Day were postponed until November 2021.

Advanced education has been developed for experienced ICU nurses to increase their awareness of patients who could potentially donate, to provide a better understanding of the donation process and the roles of the health professionals involved and to improve knowledge and skills in the conversations with families and colleagues. Advanced Study Days were facilitated in Hawke's Bay and Wellington hospitals.

ICU Donation Audit

Donation Audit Meetings that were to be held in May and November were cancelled due to COVID-19. A Donation Audit Meeting for ICU Donation Link teams will be held in March 2021 by teleconference.

An ODNZ medical specialist and a donor coordinator provided education and feedback on the ICU Donation Audit at Middlemore Hospital, Auckland City Hospital DCCM and by teleconference to Waikato Hospital.

Education continued...

Donation after Circulatory Death (DCD) Implementation

Introduction to DCD presentations were facilitated at Tauranga, Rotorua and Whangarei Hospitals. DCD implementation commenced at North Shore Hospital with education sessions for ICU medical and nursing staff as well as for OT nursing and anaesthetic technicians. This training will be completed early in 2021.

Māori Health Education

A Hui was held in Whangarei Hospital to provide education and awareness about organ and tissue donation. ODNZ Medical Specialist Jo Ritchie and ODNZ Donor Coordinator Sue Garland attended this hui together with donor family member Wikitoria Smith and organ recipient Ronald Iraia who shared their personal experiences with organ donation and transplantation.

Medical Grand Rounds

ODNZ Medical Specialist, Stephen Streat presented at the medical grand round in Whakatane Hospital. This presentation included an update on organ and tissue donation in New Zealand and addressed some of the common myths about donation.

Education Day for Medical Specialists

An education day was organised for the medical specialists who provide on-call for ODNZ. This day covered all aspects of the donation process and also gave the medical specialists an opportunity to meet the transplant professionals and to receive updates from the transplant services.

Study Days and Health Professional Education

In 2020 full day workshops, half day workshops and educational sessions were held in the following hospitals:

- Whangarei
- Taranaki
- Hawke's Bay
- Hutt
- Wellington
- Christchurch
- Dunedin

This education provided nursing staff from ICUs and OTs, and other health professionals involved in donation and transplantation, with information about the organ and tissue donation process.

The donor coordinators also provided short educational sessions for health professionals in hospital wards and departments, hospices and for nursing students, postgraduate nurses and medical students at educational institutes and universities.

COMMUNICATION

New ODNZ Contact Details

In November 2020 the ODNZ service transferred from the ADHB to become part of NZBS. ODNZ is now physically located at the NZBS National Office at 71 Great South Road in Epsom, Auckland.

The ODNZ general email address has changed to contactus@donor.co.nz and ODNZ staff emails to firstname.lastname@nzblood.co.nz. The 0800 number for general public enquiries 0800 4 DONOR (0800 436 667) and the 24 hour number for organ and tissue donation referrals (09) 630 0935 remain the same.

Newsletters

A hard copy newsletter providing news and information for health professionals in donor hospitals was produced by ODNZ in August and November 2020. These newsletters featured information about organ and tissue donation and transplantation, along with stories from donor families and transplant recipients.

ODNZ NEWS
AUGUST 2020

Organ donation and COVID-19
It goes without saying that the first half of 2020 has been one of unprecedented change and challenges across the health sector.

Transition of ODNZ Deceased Donation Service to New Zealand Blood Service
Prior to COVID-19, ODNZ was due to transition to the New Zealand Blood Service (NZBS) by 1 July 2020. However the service transfer was delayed due to the COVID-19 outbreak and the redirection of resources involved in managing the health sector response. A new date has not been finalised, however, the Ministry of Health is working closely with NZBS and other groups involved to set a new date, which is anticipated to be within the next six to nine months.

Summary of organ donation in 2019
Thanks to the generosity of 74 donors and their families, 227 recipients were able to receive heart, lung, kidney, and liver and pancreas transplants last year. Many more people received tissue transplants (corneas, sclera, heart valves and skin) from these donors.

Rise in kidney transplants
Last year there were 221 kidney transplants in New Zealand, the highest number ever recorded. This included 130 deceased donor transplants (3 double kidney) plus an increasing number of living kidney donations (91).

Organs retrieved from deceased donors and transplanted in 2019

Heart	17	Lungs	26	Liver	52	Pancreas	4	Kidneys	133
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Upcoming Events

STUDY DAYS / EDUCATION SESSIONS	DATE	WORKSHOPS	DATE
HAWKE'S BAY OT	12 SEPT	NEW LINK NURSE INDUCTION DAY	4 NOV
NORTH SHORE ICU	16 SEPT	OT LINK NURSE WORKSHOP	5-6 NOV
ROTORUA ICU	16 SEPT	ICU DONATION AUDIT MEETING	5 NOV
HUTT VALLEY OT	25 SEPT	ICU LINK NURSE WORKSHOP	6 NOV
CHRISTCHURCH	9-10 OCT	THANK YOU DAY	15 NOV
MIDDLEMORE ADVANCED	12 OCT		
HAWKE'S BAY ADVANCED	11 SEPT		
TAURANGA	20 OCT		

WWW.DONOR.CO.NZ 08 630 0935 (24 HOURS)

ODNZ NEWS
NOVEMBER 2020

Date confirmed for ODNZ transition to the NZ Blood Service
In November 2019 the Organ Donation and Related Matters Act was passed and it was decided that the NZ Blood Service (NZBS) would take over the clinical governance and oversight of Organ Donation New Zealand (ODNZ) from the Auckland District Health Board.

ODNZ Staff Update

Farewell to Stephen Streat
ODNZ Clinical Director Stephen Streat will be retiring at the end of November 2020. For many years, Stephen has been a leader in organ donation in New Zealand and Australia. He has always been a strong advocate for the respectful care and support of donors and families.

New Medical Specialists
We have recently welcomed three new locum medical specialists to the ODNZ team: Kim Grayson from Wellington ICU, Tobias Metz from Auckland CVICU and Myles Smith from Dunedin ICU. They will provide on-call support alongside the current ODNZ medical specialists Jo Ritchie, Laura Blandridge, Jonathan Casement and Dave Cloney.

Upcoming Events

STUDY DAYS / EDUCATION SESSIONS	DATE	WORKSHOPS & EVENTS	DATE
WELLINGTON ADVANCED	18 NOV	THANK YOU DAY	15 NOV
DUNEDIN OT	20 NOV	NEW LINK NURSE INDUCTION DAY	25 MAR
DUNEDIN ADVANCED	28 FEB	OT LINK NURSE WORKSHOP	26 MAR
DUNEDIN HOSPITAL	27 FEB	ICU DONATION AUDIT MEETING	28 MAR
		ICU & OT LINK NURSE WORKSHOP	27 MAR

WWW.DONOR.CO.NZ 08 630 0935 (24 HOURS)

ODNZ Link Nurse Communication

The Donation Link nurses also received regular e-newsletters keeping them up to date with ODNZ news, education dates, organ donation and transplantation news and links to new extranet content.

Public Awareness

In 2020 ODNZ facilitated a wide variety of media coverage aimed at educating people about the life changing nature of organ and tissue transplants and to encourage more people to talk about donation with their families.

The ODNZ team also responded to over 200 public enquiries via the 0800 telephone number (0800 4 DONOR), by email and via the ODNZ website www.donor.co.nz.

Pamphlets and posters were also distributed by transplant recipients to their family and friends, neighbours, community groups, libraries, schools and doctor's surgeries.

Thank You Day 2020

Each year the lives of many New Zealanders are transformed by the kindness of strangers who at a time of immense personal tragedy, agree to organ and tissue donation.

Thank You Day 2020, held on Sunday 15th November, was an opportunity to acknowledge all deceased donors, donor families/whānau who have generously donated organs and tissues, saving the lives of others.

Previously ODNZ has filmed messages of gratitude from transplant recipients and launched these on Thank You Day. However, in 2020, due to the COVID-19 pandemic and to protect the health and safety of transplant recipients, ODNZ invited organ and tissue transplant recipients to create and submit their own thank you messages. These messages were edited into a final video which was released on the ODNZ website and social media on the 15th November.

Elliott, an eight-year-old liver transplant recipient and Anna, a kidney transplant recipient and teacher, shared their messages of gratitude, alongside recipients from around New Zealand.

Wiremu, a recipient who received a heart transplant 17 years ago, summed up what receiving a transplant meant for him: "I'm so blessed to be surrounded by the love and presence of my mokopuna. Without my heart transplant, these moments of connection would never have transpired. I'm so lucky".



Elliott Gulliver shares her gratitude for her liver transplant

The lives of Elliott, Anna, Wiremu and their families have been transformed by organ and tissue donation and they are all incredibly grateful to their donors and their donor's family. All three recipients endeavour to live life to the full and make the most of the second chance they have been given.

With the support of the ODNZ Donation Link teams and DHB communication teams throughout New Zealand, the Thank You Day video was also shared on hospital television screens, as well as on staff intranets, at shift changeovers, staff meetings and on social media.



Anna Maharaj recently celebrated 19 years post kidney transplant. She shared her heart felt message of gratitude for her donor and the donor family in the ODNZ Thank You Day video 2020.

ORGAN AND TISSUE DONATION

Table 1: Number of Deceased Organ Donors in New Zealand

In 2020, 64 deceased organ donors from ICUs in 15 donor hospitals donated organs (and tissues) for transplantation. Of these, 56 donated following brain death (DBD) and eight donated following circulatory death (DCD).

This does not include tissue-only donors (eyes, heart valves and skin).

Hospital	2016	2017	2018	2019	2020
Auckland City CVICU	0	0	0	0	0
Auckland City DCCM	7[2]	21[5]	11[1]	11[1]	11
Christchurch	11[1]	11[1]	12[1]	17[5]	9[1]
Dunedin	11[1]	7[1]	4	10[3]	5[1]
Gisborne	0	0	0	0	0
Grey Base	0	0	1	0	0
Hawke's Bay	3	2	2	3	1
Hutt	0	0	0	0	2
Middlemore	2[1]	4[3]	6[3]	3[1]	4[2]
Nelson	3	1	3	3[1]	1
North Shore	0	3	2	2	1
Palmerston North	0	0	2	0	0
Rotorua	0	1	1	1	2
Southland	1	3	1	0	2
Starship Children's	0	0	0	1	1[1]
Taranaki Base	0	1	0	2	1
Tauranga	3	0	0	4	1
Timaru	0	0	2	0	0
Waikato	6[1]	9[2]	5[2]	5[1]	11[2]
Wairau	0	0	0	0	0
Whanganui	2	1	0	0	0
Wellington	11	6	9[1]	11[1]	12[1]
Whakatane	0	1	0	1	0
Whangarei	1	2	1	0	0
Total number of donors	61[6]	73[12]	62[8]	74[13]	64[8]

Note: [] DCD donors

Table 2: Cause of Donor Death by Year

	2016	2017	2018	2019	2020
Intercranial haemorrhage	30	38	24	24	23
Cerebral infarct	6	6	3	2	6
Trauma (road)	6	6	11	10	10
Trauma (other)	2	4	11	11	5
Hypoxia-anoxia	15	16	9	18	18
Other	2	3	4	9	2
Total	61	73	62	74	64

Table 3: Age of Deceased Donors by Year

	2016	2017	2018	2019	2020
Mean	48.1	48.8	46.9	47.4	46.7
Median	52.7	51.6	49.0	50.1	52.5
Minimum	17.7	14.3	14.5	13.8	10.2
Maximum	80.0	82.6	81.2	82.9	81.0

Table 4: Ethnicity of Deceased Donors by Year

	2016	2017	2018	2019	2020
European	47	58	46	62	51
Maori	5	7	7	6	5
Pacific People	1	4	4	3	6
Other	8	4	5	3	2
Total	61	73	62	74	64

Table 5: Organs and Tissues Retrieved from Deceased Donors and Transplanted

	2016	2017	2018	2019	2020
Kidneys	95	121	94	133	103
Hearts	11	23	19	17	13
Lungs	20	23	28	26	24
Livers	51	48	44	52	42
Pancreas	4	4	6	4	3
Eye tissue	28	37	26	29	39
Heart valve tissue	20	20	7	15	13
Skin	2	2	0	1	8

Table 6: Organs from New Zealand Deceased Donors Transplanted in Australia

In 2020 some organs from New Zealand donors were transplanted to Australian recipients and vice versa in accordance with the Transplantation Society of Australia and New Zealand (TSANZ) Clinical Guidelines for Organ Transplantation from Deceased Donors, Version 1.4 – July 2020, which is available via their website: www.tsanz.com.au

	2016	2017	2018	2019	2020
Liver	7[1]	1	6[1]	6	5[1]
Heart	0	0	0	0	0
Lungs	3	3	0	0	2
Kidney	0	0	0	0	0

[] Split livers

Table 7: Organs from Australian Deceased Donors Transplanted in New Zealand

	2016	2017	2018	2019	2020
Liver	8	2[1]	3	4	7
Heart	0	1	1	0	0
Lungs	0	0	0	0	0
Kidney	0	0	0	0	0

[] Split livers

Table 8: Summary Data from ICU Donation Audit Database

	2017	2018	2019	2020
All deaths in ICU	1308	1329	1362	1189
Deaths ventilated in ICU with severe brain damage	494	480	471	417
Possibly brain dead ¹	195	201	182	185
Possibly brain dead ¹ and organ donation formally discussed with family by health professionals	131	132	115	121
Possibly brain dead ¹ and organ donation formally discussed with family by health professionals and family agreed to donation	67	63	68	63
Possibly brain dead ¹ and tested	113	100	101	97
Possibly brain dead ¹ and tested and determined to be brain dead	109	99	100	95
Potential donation after withdrawal of therapy (WOT) ²	230	228	216	194
WOT ² in a DCD accredited hospital ³	173	169	153	154
WOT ² in a DCD accredited hospital ³ formally discussed with family by health professionals	36	37	49	47
WOT ² in a DCD accredited hospital ³ formally discussed with family by health professionals and family agreed to donation	15	14	16	9

1. Possibly brain dead: Fixed dilated pupils and no apparent brain reflexes just prior to death.

2. Possible donation after Withdrawal of Therapy (WOT): Aged 70 or less and had treatment withdrawn and died in ICU 90 minutes later or less.

3. DCD accredited hospitals: Auckland City (DDCM), Starship Children's, Middlemore, Waikato, Hawke's Bay, Wellington, Nelson, Christchurch and Dunedin

Table 9: Summary Data from ODNZ Referral Database

	2016	2017	2018	2019	2020
Telephone discussions about potential organ donation	168	271	230	246	226
Brain dead donors	55	61	54	61	58
DCD donors	6	12	8	13	8
Total donors	61	73	62	74	64

The number of referrals to ODNZ includes some who do not appear in the ICU Donation Audit because, for example, they might have died without ever having been admitted to ICU, or might not have died in ICU.

Our beautiful son Caleb was warm and funny with an enormous heart. From the age of two he was quick on his feet, keeping us on our toes and there was never a dull moment.

Caleb truly believed life was for living, relaxing was not in his vocabulary and his life was full of adventures, like climbing mountains. He climbed Mount Cook five times, went climbing in Patagonia and scaled El Capitan, one of the most prized big wall climbs in Yosemite National Park in the USA.

Caleb was also approached to participate in The NZ Hunter program on Duke TV, where he excelled in the environment he loved.

The NZ Hunter team described Caleb as someone with legendary climbing and hunting skills and that “beyond his almost super human abilities, Caleb was one of the humblest, personable, kind hearted outdoor people you could meet, and he mentored many young hunters and climbers over his extraordinary lifetime.”

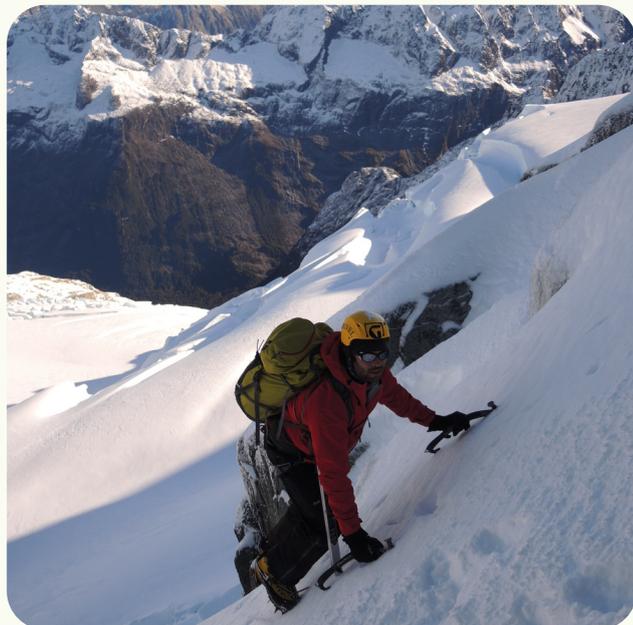
Caleb always found time for people less fortunate than himself and he decided to make an impact on people's lives by mentoring fatherless children. He encouraged them to pursue their dreams and taught them that all things are possible.

At the time of his death, Caleb was pursuing one of his dreams to be an alpine guide and he was an avid climber and member of the NZ mountain club.

Caleb was a donor on his driver licence and so this was not a difficult decision for us to make. He had also expressed his wishes in discussions with his work colleagues.

It's comforting to us that Caleb lives on in some form, the organ donation process has been a positive experience for us all. As with Caleb's extraordinary life, it's nice to know that the organs he donated helps the recipients to live a better quality of life.

Belinda & Stephen



ORGAN TRANSPLANTATION IN NEW ZEALAND

Organ transplantation in New Zealand includes:

- Kidney transplantation (deceased-donor and live-donor)
Auckland City, Starship Children's, Wellington and Christchurch Hospitals
- Liver transplantation (deceased-donor and live-donor)
Auckland City and Starship Children's Hospitals
- Heart transplantation
Auckland City and Starship Children's Hospitals
- Lung transplantation
Auckland City and Starship Children's Hospitals
- Pancreas transplantation
Auckland City Hospital

Data in Tables 10-14 includes all transplants performed in New Zealand (including organs from Australian deceased donors). See Tables 6 and 7 for details of Trans-Tasman organ sharing.

Table 10: Kidney Transplantation by Year and Donor Type

	2016	2017	2018	2019	2020
Recipients, deceased-donor, single kidney	85	115	97	127	97
Recipients, deceased-donor, double kidney	5	3	1	3	3
Live-donor	82	69	84	91	87
Total number of recipients	172	187	182	221	187

Table 11: Heart and Lung Transplantation by Year

	2016	2017	2018	2019	2020
Heart	11	24	20	17	13
Lung	17	20	28	26[1]	22[4]

[1] Single lung transplant

Table 12: Liver Transplantation by Year and Donor Type

	2016	2017	2018	2019	2020
Adult, deceased donor	46	45	41	48	41
Adult, live adult donor	2[1]	1	0	1	0
Child, deceased donor	10	7	6	6	10
Child, live adult donor	1	2	2	3	3
Total	59	55	49	58	54

Note: [] Domino transplant

Table 13: Pancreas Transplantation by Year

	2016	2017	2018	2019	2020
Pancreas	4	4	6	4	3

Table 14: Multiple Organ Transplants by Year

This table does not include the number of recipients of two kidneys or two lungs.

	2016	2017	2018	2019	2020
Kidney and pancreas	4	4	6	4	2
Liver and kidney	1	1	2	0	0
Liver and pancreas	0	0	0	0	1
Heart and liver	1	0	1	0	0
Heart and kidney	1	0	0	0	0
Lung and liver	1	0	0	0	0
Total number of multiple transplants	8	5	9	4	3

I was 17 when I was given a second chance at life. I remember waking up one morning, a couple of days after the transplant, finally feeling like myself again. I hadn't felt this way since I was a child. It was as if the cloud of Wilson's disease had stopped fogging up my mind and I was, once again, able to be me. I am grateful for this gift every single day. It hasn't always been easy, but I now have a family of my own and a supportive husband, the love of my life, who has walked this journey with me the entire way.

My journey to receiving a donated liver was fast and sudden. There was no real warning prior to it happening. Although in hindsight I had been experiencing the symptoms of Wilson's disease for the majority of my childhood; little things like repeated strep throat and nose bleeds that would last for hours, as well as stomach bugs and pain. These were always explained away by thoughts of potential viruses or maybe allergies and sometimes even "attention seeking". It wasn't until the age of seventeen that things really started to escalate. Among other tell tale signs of my body's inability to excrete copper, my personality suddenly changed, I lost my ability to concentrate, I had long drawn out speech and my mind was no longer my own.

After many visits to the GP, I happened to see a doctor who thought my abdominal pain was worth investigating laparoscopically, thinking that I may have endometriosis. This thought would ultimately save my life. The surgeon did not find any endometriosis, he did however, think it would be wise to look at my liver considering my blood work was showing less than desirable Liver Function Tests (LFT). His words after the surgery were "your liver looks like a forty-year-old alcoholic" needless to say he strongly advised the referral to a gastroenterologist.

It took only one meeting with Dr Michael Burt to be confident that Wilson's disease was to blame for the deterioration of my liver and my ever increasing physical and mental illness. A few more tests would confirm the diagnosis, the last being a liver biopsy, the thought of which paralysed me with fear.

It's funny looking back now and remembering how scary the words like 'biopsy' and 'blood transfusion' sounded. There's no way I could even fathom an organ transplant!

The day came to have the dreaded liver biopsy. A kind nurse held my hand as a sedative was given to induce me with a deep sense of relaxation. Then just like that, the biopsy was done. The kind nurse once again held my hand as she explained that I would need a blood transfusion as my blood wasn't clotting, but there was nothing to worry about as this was normal. My worst fear was over and I was discharged the next morning, eagerly awaiting the result and a plan on how to combat this disease.

At first the tiredness was easily explained. I often felt tired, plus I was still recovering from the biopsy. I just chose not to question the yellow skin and distended stomach. I continued life as normal for the next 48 hours, brushing off my friend's concerns.

Mum didn't call an ambulance when she found me in the shower without the energy to move. She helped me gather my strength (and clothes) and drove me to the hospital. It's thought that maybe the biopsy created a "gateway" for the copper stored to escape into my body. But maybe it was just a coincidence, maybe my body had just had enough.

I was positive and felt in control right from being admitted. I didn't share the same concerned look that the doctors and my family shared when talking with me. I was convinced I only had a stomach bug and that I would be home in time for Christmas.

The next morning, the 22nd December, I flew up to Auckland for observation and to be assessed for possible liver transplantation. I was admitted to a ward for only a matter of hours before transferring to the Critical Care Unit. My body was deteriorating fast. It became apparent that the Wilson's disease could not be treated and my only chance of survival would be through receiving a liver transplant. My name was added to the top of the transplant list for NZ and Australia. It was Christmas Eve and with this update, my family and my love, were told I would only live another 72 hours.

As devastating as this news was for my family to hear, they pushed on, full of hope, determined to find a donor. Thanks to their endless love and support, together with that of my friends and the outstanding nurses and doctors, I lived past the predicted 72 hours.

My mother was found to be a perfect match as a live donor however this wouldn't be without risks. My health had deteriorated to the point of needing a whole liver and the chances I'd survive on three quarters were slim. However, my transplant team and my family were willing to try and it was decided that the surgery would go ahead the following morning.

Full of nerves for the following day's event, my mother needed a sleeping tablet. I'm told it was at the exact moment she went to take the tablet that the head of the Liver Transplant Unit came through the door exclaiming "don't take that! We've found a liver!"

It's an odd feeling. One that I can't find the words to express. It's only because another person, another loved one, passed away that I was able to survive...

I am eternally grateful.
Emma



TISSUE-ONLY DONATION

Table 15: Deceased Tissue-Only Donation Facilitated by ODNZ

In 2020 there were 58 deceased tissue-only donors facilitated by ODNZ. Four of the tissue-only donors were Intended Organ Donors where organ donation did not proceed and tissue-only donation was facilitated. Tissue donation can include skin, eye and heart valve tissue.

Referred from:	Ward/Unit	Tissue (only) Donor
Auckland City Hospital	CVICU	2
	DCCM	8
	NICU	1
	Wards 64,72	3
Christchurch Hospital	ICU	9
Dunedin Hospital	ICU	4
	Ward 8A	1
Hawke's Bay	ICU	1
Hutt Hospital	ICU	1
	Medical Ward	1
Middlemore Hospital	ICU	1
North Shore Hospital	Waitakere Medical Ward	1
Southland Hospital	ICU	1
Tauranga Hospital	ICU	2
Waikato Hospital	ICU	2
	Ward M5	1
Wairau Hospital	ICU	1
Wellington Hospital	ICU	4
Whangarei Hospital	Ward 16	1
Coronial Service	-	3
Hospices	Harbour Hospice Hibiscus Coast	1
	Mercy Hospice	1
	Nelson Hospice	1
Family	-	7

The corneal coordinators from the New Zealand National Eye Bank facilitate eye-only donation referred directly to their service, as well as from the Bereavement Team at Middlemore Hospital.

The heart transplant team also co-ordinate heart valve donation from some explanted hearts of heart transplant recipients.

Table 16: Tissue Donation in New Zealand

Number of Donors	2016	2017	2018	2019	2020
Skin	10	5[1]	3*	8	12**
Heart Valves	32	34	24	32	28
Eyes	144	188	145	131	119

[1] Living donor

* Skin retrieval not possible from January to July 2018 ** Skin retrieval not possible from August to December 2020

www.donor.co.nz