Kidney Health
NEW ZEALAND
Prevention • Support • Research

SUMMER 2022 Newsletter

IN THIS ISSUE

Welcome to our Summer Newsletter

As this is my first newsletter as Acting General Manager, I'd like to introduce myself. Born in Australia, I have lived in Christchurch for the past 25 years. My journey with kidney health began 17 years ago with my son's diagnosis of Autosomal Recessive Polycystic Kidney Disease. Shocked by the wide variety of patient experiences, I began advocating within the health sector and have many years of consumer representation at local, regional and national level. After four years on the Kidney Health New Zealand Board, I have stepped into the Acting management role. My passion is improving access to, and the number of, organ donations.

Sadly, we acknowledge the recent passing of two key members of our community. A life member of Kidney Health New Zealand, Professor John Morton was a pioneer of kidney transplants in Christchurch. Throughout his medical career he treated hundreds of patients across the South Island. Also, Dr Terry Ryan, noted Ngai Tahu genealogist and our KHNZ Kaumatua, passed in October.

As always, our team are taking calls and emails, supporting our kidney community. They are conducting early detection testing and awareness at a number of venues around the motu.

We have commissioned some consumer research to determine what matters to kidney patients and their whanau regarding renal support and services – follow our Facebook page for more information. We have updated our Covid-19 prevention and treatment recommendations and we are hoping to shortly be able to announce Pharmac funding for some vital pharmaceuticals we have been advocating for.

Best wishes for the holiday season,

Regards
Traci Stanbury

PROFESSOR JOHN BOWER MORTON

John Bower Morton. Prof Morton, as he was known to many kidney patients and their families, has died after a short illness. John worked at Christchurch Hospital as a vascular and kidney transplant surgeon from 1973 to 1996.

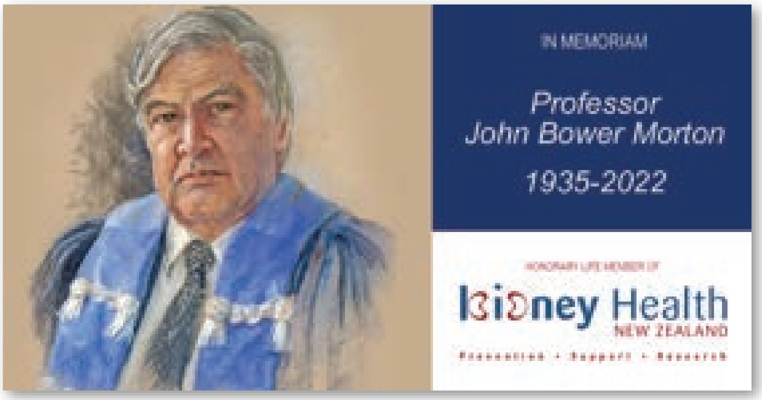
During that time, he provided skilled and compassionate care for hundreds of kidney patients in the South Island who remember him with affection and respect. Many dialysis patients will remember his expert surgery to create and maintain their fistula: for others his critical role as their kidney transplant surgeon. He worked tirelessly to improve the public's understanding of the benefits of organ donation and to improve the rate of donation.

In the early days of kidney transplantation in New Zealand, John was a leader in how best to obtain permission for organ donation, compassionately taking into account the needs of grieving families.
He pioneered the introduction of modern brain death protocols critical to ensuring community support for organ donation after death and the development of a national standard of practice for solid organ transplantation.

John's wisdom and encouragement were key factors in the start of living donor kidney transplantation in 1974 and in the Christchurch Transplant Group carrying out the first altruistic non-directed living kidney transplant in Australasia in 1998.

After retiring from surgical practice John was the Living Donor Counsellor for the South Island Renal Transplant service.

John was Chairman of the then New Zealand Kidney Foundation (now Kidney Health New Zealand) from 2003 to 2007 and was made an Honorary Life Member in 2007.



KAUMATUA DR TERRY RYAN, MBE

Kua hinga te tōtara i Te Waonui-a-Tāne

Kidney Health New Zealand is saddened to acknowledge the passing of our kaumatua, noted Ngāi Tahu genealogist, Dr Terry Ryan. Known for creating the genealogy bank for Ngāi Tahu, Ryan was recognised as an authority figure for the iwi's modern whakapapa record. During his life he played a part in drafting the legislation that helped te reo Māori become recognised as an official language, was the longest-serving staff member at Te Rūnanga o Ngāi Tahu and was made a Member of the British Empire.

> "To me whakapapa means to create the "papa" within oneself. The "papa" is your rock, your anchor, your foundation. Whakapapa lives within, it can assist one's own self and personal development. Turn the gaze inwards, correct oneself and your world will change – this is whakapapa."
>
> – Dr Terry Ryan

Dr Terry Ryan MBE

TE HERENGA WAKA VICTORIA UNIVERSITY OF WELLINGTON

Seeking participants for research

Te Herenga Waka Victoria University of Wellington are looking for any people and their whānau, particularly if you have Māori and/or Pasifika heritage, to participate in PhD research.

This research is for the development of a medical alert to protect the veins of patients with chronic kidney disease, to minimise harm, and maintain or preserve vascular access for haemodialysis treatment. If you have a fistula, or have in the past, or may have a fistula in the future, could you please share your experience with us.

This includes a 1-hour kōrero/interview, to share your experiences, so that together we can build an inclusive alert. Participation will be on a volunteer basis and $50 koha vouchers will be offered to participants.

This project has been approved by the Te Herenga Waka-Victoria University of Wellington Human Ethics Committee 0000030257.

Please contact Lina Goldstein - PhD Student at lina.goldstein@vuw.ac.nz

CONSUMER AND COMMUNITY ADVISORY COMMITTEE

Expression of Interest for Membership

Calciphylaxis is a rare disease, involving painful skin wounds, that occurs in some people with end-stage kidney disease. Better Evidence And Translation for Calciphylaxis (BEAT-Calci) is the name of a clinical trial that aims to find the best treatments. The BEAT-Calci team understands that research needs to be performed in collaboration with consumers. They are looking for consumers to join their Consumer and Community Advisory Committee (CCAC) who have direct experience and an active interest in kidney disease and an interest in being involved in planning research and communicating evidence.

Participation will involve a one-hour teleconference meeting every 4-6 months and contributing to tasks in between meetings, such as reviewing participant and community facing documentation. There is a minimum contribution of 12 months.

To express interest, please contact: BEAT-Calci.study@sydney.edu.au, telling them a little bit about your experience, and interests relevant to the research.

COVID-19 UPDATE

There are many COVID-19 medicines for people with kidney disease. The 2 major groups are:

- Prevention (used when you're well and before you have COVID-19), and
- Treatment (generally used within 5 days of developing COVID-19 symptoms).

Both of these groups of medications are used to reduce the risk of getting "severe" COVID-19 i.e. to reduce the risk of needing to be admitted to hospital / developing life-threatening disease.

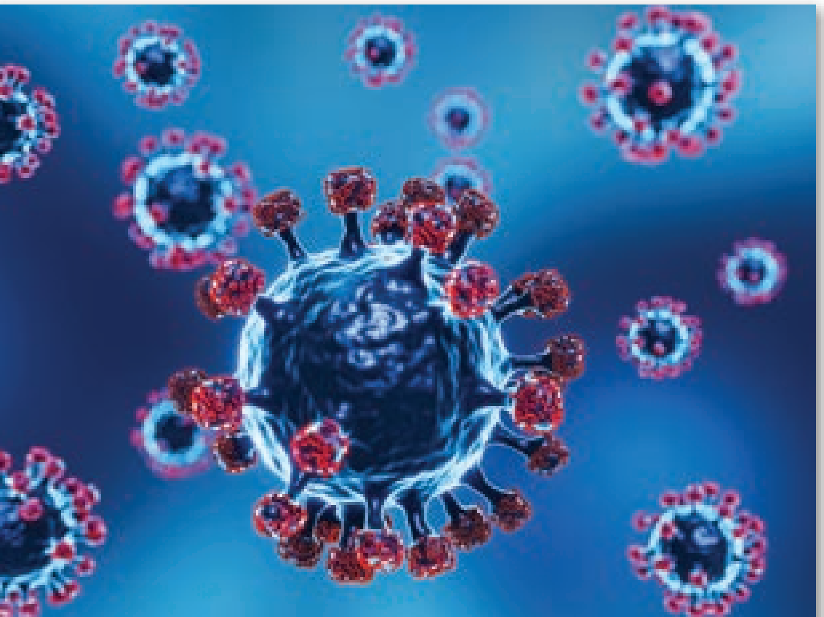
These treatments have changed since the COVID-19 pandemic started, as new medicines have been developed and as we learn more about what works. Which treatment to use depends on the exact details of your kidney disease and overall health, as well as the treatment plans that your local healthcare teams have put in place for people living in your area.

The major Prevention medications are:

• VACCINES

Vaccines show the body's immune system a tiny piece of the COVID-19 virus, and so gets the body's own immune defences ready in case that person catches the COVID-19 virus. These immune defences mean that the body can deal with the virus, and reduce the risk of severe COVID-19 even if you catch COVID-19.

People who are at high risk of severe illness from COVID-19 can now get a 3-dose "initial" course and 2 "booster" doses of the vaccine.



The criteria for "people who are at high risk of developing severe disease" includes people living with a kidney transplant, people taking mycophenolate mofetil, and people receiving haemodialysis and peritoneal dialysis .

• EVUSHELD

Evusheld is not a vaccine, but is another medicine that protects from COVID-19, and reduces the chance of becoming very sick if you catch COVID-19.

Evusheld is given by two injections before a person gets COVID-19, or at least two weeks after their recovery from COVID-19. Evusheld is mostly used before you get COVID-19 rather than after but, in some circumstances, it may be used as a treatment.

Evusheld is for people who are at high risk of developing severe disease" aged 12 and over, who don't have COVID-19, but have medical conditions that mean that their immune system may not build strong defences after getting the vaccine. This group of people includes some people living with a kidney transplant, some people who have received some immune-system suppressing drugs (e.g. rituximab)

The major Treatment medications are:

• ANTIVIRAL TREATMENTS

COVID-19 antiviral medicines are given to people who are most at risk of becoming very unwell from COVID-19 infection. They may help you get better faster and stay out of hospital. These medicines are free for eligible people with COVID-19 within five days of their symptoms starting.

People who are at high risk of severe illness from COVID-19 (and therefore eligible for these treatments) are:

- aged 65-plus
- aged 50-plus AND Māori or Pacific ethnicity AND OR have not had a full initial course of COVID-19 vaccinations

- people with any combination of three or more high risk medical conditions (for people with kidney disease, these include chronic kidney disease, hypertension, diabetes, obesity (BMI >35kg/m2), heart conditions and chronic lung/airways disease)
- people who have a severely weakened immune system
- people who have been admitted to intensive care because of COVID-19 and have tested positive again

These antiviral treatments are usually considered in the following order:

1) PAXLOVID

Paxlovid contains two antiviral medicines that you take together (nirmatrelvir and ritonavir). These two antivirals work together to reduce the amount of virus in your body. A course of Paxlovid tablets is taken for five days.

It is important to tell your usual healthcare provider or pharmacist of any illnesses, medicines, herbal remedies or supplements you are taking. Paxlovid may affect some of the other medicines or herbal remedies you are taking and cause serious side effects.

- Some medicines that kidney patients take mean that Paxlovid can't be used (e.g. tacrolimus)
- Some medicines that kidney patients take need to be planned carefully by your doctor/pharmacist when using Paxlovid
- Some people with more advanced kidney disease (people with a lower eGFR) may need a lower dose of Paxlovid or may not be able to use Paxlovid – this will also need to be planned carefully by your doctor/pharmacist.

When people can't use Paxlovid, other antiviral treatments are available (see below).

2) REMDESIVIR

Remdesivir injection is also available. It's given by a slow injection (usually over 30-120 minutes) into your vein (called an intravenous infusion) once a day, usually for 3 days. It is only useful if started within 7 days of the start of your COVID-19 symptoms. You'll usually get the infusion at your local hospital or in a local health centre. Because treatment with Remdesivir usually involves a visit to the hospital to receive the infusion, demand may exceed infusion centre capacity or drug supply, so some referred patients may not receive Remdesivir. In some regions, some people living with a kidney transplant may be eligible to receive Remdesivir.

3) MOLNUPIRAVIR

For people who are at high risk of severe illness from COVID-19 and who are not eligible to receive either Paxlovid or Remdesivir, then the final option that's often available is Molnupiravir. In New Zealand Molnupiravir is available as capsules, and the standard dose is 4 capsules twice a day for 5 days.

Other ways of staying safe

There is also advice about other ways of staying safe, such as using good hygiene practices, meeting outside where possible, not visiting people at risk of severe disease if you are unwell, etc.

More information on all of the above medication can be found here: https://www.healthnavigator.org.nz/medicines/

RESEARCH - REMOTE PATIENTS IN NEW ZEALAND

Exploring rural and remote patients' experiences of health services for kidney disease in Aotearoa New Zealand: An in-depth interview study.

The research, funded by Kidney Health New Zealand, was conducted by EIT researchers Dr Rachael Walker and Professor David Tipene-Leach, in conjunction with Sandra Hay from the Department of Nephrology at the Canterbury District Health Board; Curtis Walker of the Department of Medicine, Midcentral District Health Board; and Professor Suetonia Palmer from the Department of Medicine at the University of Otago in Christchurch. The team would like to sincerely thank all participants, Kidney Health New Zealand and the Auckland District Kidney Society for their assistance with this research.

The rationale for the research is that people with chronic kidney disease (CKD) living in rural communities have increased risks of death, morbidity, hospitalisation, and poorer quality of life compared with people with CKD living in urban areas.

The study explored the experiences and perceptions of rural and remote patients and families in relation to accessing health services for kidney disease in New Zealand.

The researchers spoke to 35 participants - 26 people with kidney disease and nine caregivers and assessed the impact of having dialysis and accessing specialist nephrology services when you lived further than 100km from the nearest dialysis or transplant centre.

Five themes or trends were identified from the research. The five themes and related subthemes were intense psychological impact of rurality; pressure of extended periods away from home; services not designed for rural and remote living; suffering from financial losses; and poor communication. In this research we found that many of the participants were emotionally exhausted from constant travel, stress, and lack of support they received. For some participants this resulted in an embedded and unresolved trauma.

The research also revealed that some patients expressed grief and guilt as they felt they were a burden because of relocation, travel, extended periods away from home, needing assistance with home dialysis and financial pressures. For many, their partner or children had to give up work or education to support them with transportation or responsibilities at home. The burden of care damaged relationships, constrained finances, and caused household stress. In some situations, children were removed from schooling as they needed to travel with the patient out of town, resulting in a sense of guilt. For many participants the long days travelling away for dialysis training or treatments, waking up at 5am and returning in the evening, was physically demanding and left the participants feeling "absolutely worn out". Many participants were also frustrated about being told that they had no choice but to travel or relocate and felt a lack of understanding by health professionals about the wider implications of relocation.

The rural patients also felt that they were missing out on family occasions and interactions with children and grandchildren.

The following diagram illustrates all of the findings from this research:

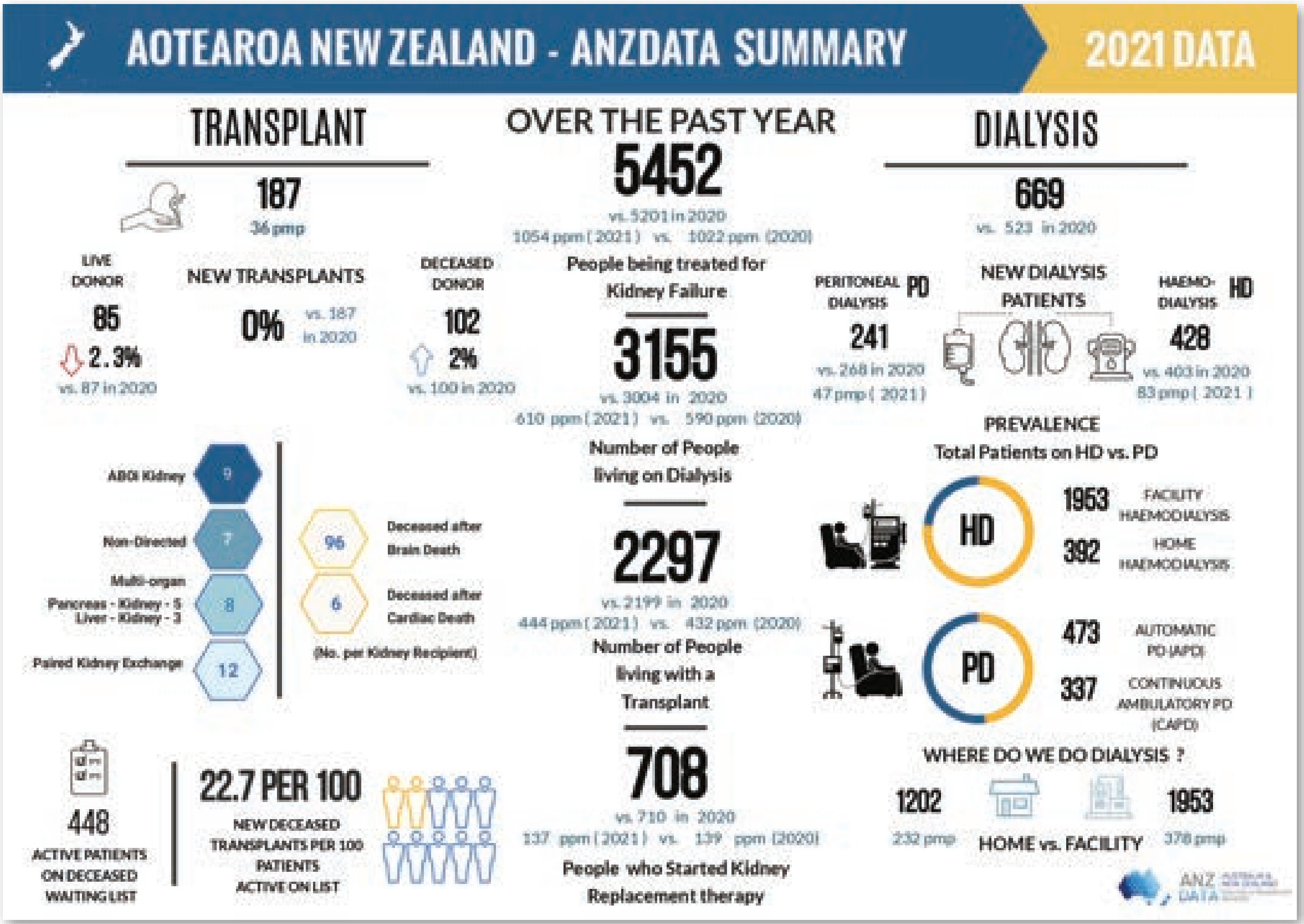
NATIONAL RURAL HEALTH CONFERENCE 2022 (NRHC 2022)

Held in Christchurch Cities Te Pae Convention Centre in September, a group from KHNZ attended the National Rural Health Conference 2022 to spread awareness about the importance of early detection and prevention of kidney disease.

Kidney Health NZ staff at the National Rural Health Conference 2022

Patient voice advocate Claire Christie was also on hand to speak about her personal experience with dialysis and kidney disease.

ANZDATA 2021 – AUSTRALIA AND NEW ZEALAND DIALYSIS AND TRANSPLANT REGISTRY



AOTEAROA NEW ZEALAND - ANZDATA SUMMARY **2021 DATA**

TRANSPLANT

187
36 pmp

NEW TRANSPLANTS
0% vs. 187 in 2020

LIVE DONOR
85
2.3%
vs. 87 in 2020

DECEASED DONOR
102
2%
vs. 100 in 2020

ABOi Kidney 9
Non-Directed 7
Multi-organ 8
Pancreas - Kidney - 5
Liver - Kidney - 3
Paired Kidney Exchange 12

96 Deceased after Brain Death
6 Deceased after Cardiac Death
(No. per Kidney Recipient)

448
ACTIVE PATIENTS ON DECEASED WAITING LIST

22.7 PER 100
NEW DECEASED TRANSPLANTS PER 100 PATIENTS ACTIVE ON LIST

OVER THE PAST YEAR

5452
vs. 5201 in 2020
1054 ppm (2021) vs. 1022 ppm (2020)
People being treated for Kidney Failure

3155
vs. 3004 in 2020
610 ppm (2021) vs. 590 ppm (2020)
Number of People living on Dialysis

2297
vs. 2199 in 2020
444 ppm (2021) vs. 432 ppm (2020)
Number of People living with a Transplant

708
vs. 710 in 2020
137 ppm (2021) vs. 139 ppm (2020)
People who Started Kidney Replacement therapy

DIALYSIS

669
vs. 523 in 2020

NEW DIALYSIS PATIENTS

PERITONEAL DIALYSIS PD
241
vs. 268 in 2020
47 pmp (2021)

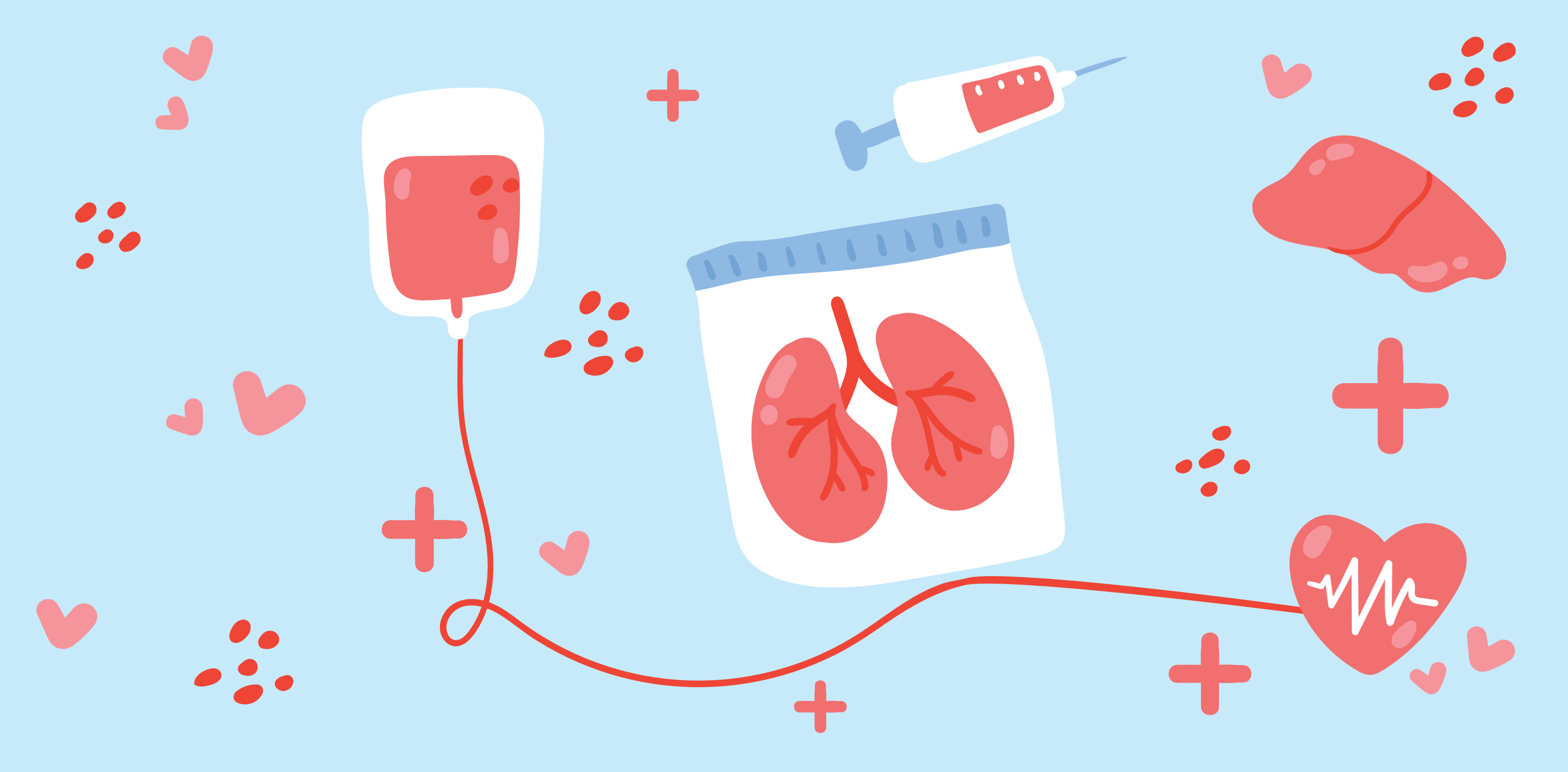
HAEMO-DIALYSIS HD
428
vs. 403 in 2020
83 pmp (2021)

PREVALENCE
Total Patients on HD vs. PD

HD
1953 FACILITY HAEMODIALYSIS
392 HOME HAEMODIALYSIS

PD
473 AUTOMATIC PD (APD)
337 CONTINUOUS AMBULATORY PD (CAPD)

WHERE DO WE DO DIALYSIS ?
1202 232 pmp
HOME vs. FACILITY
1953 378 pmp



Thank you to the following organisations for their support:

- Green Cross Health
- The Kingdom Foundation, proudly managed by Perpetual Guardian
- WG Johnston Charitable Trust
- R O Dixey Trust
- Massey University
- Vernon Hall Trust Fund
- Havelock North School
- Te Kowhai School
- Hamilton Library
- Palmerston North Library
- Wellington Library
- Havelock North Library
- St Mary's College, Wellington
- Ucol Masterton
- Pak 'n' Save Wainoni
- Eastgate Mall
- Wintec
- Genesis Energy
- Stroke Foundation
- REAP Centre Masterton
- Stabicraft
- Kiwi Beverages NZ

Support Kidney Health New Zealand

Yes, I want to join the fight against kidney disease and support Kidney Health New Zealand

I/we would like to donate: ☐ $100 ☐ $50 ☐ $30 ☐ Other: ____________

Payment type: ☐ Mastercard ☐ Visa

Card number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Card expiry date: / / Name on card: ____

I would like: ☐ A Receipt for my donation ☐ Information about Gifting to Kidney Health New Zealand in my will

☐ Information about Kidney Donations/Transplants ☐ To become a member of Kidney Health New Zealand

Name: ____

Address: ____

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.
Or direct deposit to ANZ Account - Kidney Health New Zealand - *06 0501 0280602 00*

Kidney Health
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