Otago Kidney Society Inc (OKS) – Autumn edition

OKS newsletter

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Welcome to the Otago Kidney Society (OKS) Autumn newsletter

President's message

A big welcome to 2024 from the OKS. We hope you all have had a nice break through the Christmas period.
The OKS has a few points of interest that we are organising that we would love you to become involved in.
We have importantly got World Kidney Health Day happening on March 14th. We are setting up a stand at the front of The Warehouse in South Dunedin, between 10:00am and 3:00pm. Please spread the word and come along if you can! The more support and help that we can get helps to bring awareness and lift the profile of kidney disease in our communities.

Our AGM is on the 26th March, at 5.30pm in the Dawson Room, Marinoto House in the grounds of Mercy Hospital.

Also, we have a luncheon in Gore, on Sunday, 7th April, which shall be subsidised by $10 per person by the OKS.

The OKS would like to ask any of you or family members that would like to join and help guide the OKS forward with ideas and joining in on our meetings, please reach out and contact any of us on the phone numbers above or the dialysis unit for information - we definitely need more arms and legs!

Have a wonderful start to 2024.

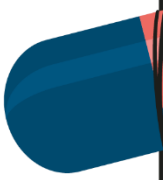
James Blair
President OKS

Events coming up

Lunch in Gore in April

Date: Sunday 7th April 2024 Time: 12:00pm – 2:30pm
Where: The Thomas Green Pub, Gore, see separate flyer

Kidney Health For All



Advancing equitable access to care and optimal medication practice

World Kidney Day
14 MARCH 2024

#worldkidneyday
#kidneyhealthforall
www.worldkidneyday.org

World Kidney Day is a joint initiative of
ISN IFKF-WKA

THE KAY BANNING MEMORIAL DONATION

On Friday the 23rd February 2024 the Otago Kidney Society Inc. received a very generous donation of $50,000. The donation was from Joanne Brooks in memory of her late sister Kay Banning who received services and support from The Otago Kidney Society.
Kay was a member of the Otago Kidney Society family and she had been a patient at Dunedin Hospital.
Joanne said "On behalf of my family, we are grateful for all the help and care Kay was given by the team at the Dunedin renal department. I am aware they were a big part of her life as 3 staff members came to Kay's service held in Mosgiel".
Kay Annette Banning passed away on the 15th May 2022 in Dunedin.
The Otago Kidney Society is pleased it was able to help and support Kay and is very appreciative of this donation, it will make a huge difference to the help and support that can be given to OKS members in the future.
Discussions and planning are underway on how to make the best use of this donation to make life easier and improved for OKS members.
If you have any thoughts or ideas on this, the OKS committee would love to hear them.

Christchurch Kidney Society

Christchurch Kidney Society have a variety of goods that are available for our patients to purchase:-

'Wristbands and Fistula Covers -the wristbands come in two sizes (21 cm and 24cm) and are printed with the words "No BP No Needles this Arm". The fistula covers are of various lengths and widths as well as colours. If you can spare a coin, to help us purchase additional material etc, that would be great—but not compulsory.'

'Fingerless Pairs of gloves, sizes S,M,L, made of UPF 40-50 Lycra are available at office. $4 for pictured length and $3 for usual glove length. Also available merino gloves for covering post skin lesion treatment. Concerning sun protection, from articles read, if specially treated fabric isn't available, it's best to choose darker colours, and tight-weave fabrics. Hold the fabric up

to the light, if you can see through it the sun can get through it.'

The Christchurch Kidney Society would also like any feedback on their gift packs for transplant patients and anything that could be added to make them better.

Please get in touch with Jo Houghton (Christchurch Kidney Society) 021 2860 309 or Natalie Brown (Otago Kidney Society) 027 454 3512,

Australasian Kidney Trials Network (AKTN)

The Australasian Kidney Trials Network (AKTN) operates under the Centre for Health Services Research at the University of Queensland's Faculty of Medicine.

The Network is a not-for-profit collaborative research group that designs, conducts and supports investigator-initiated clinical trials with the aim of improving life for people living with Chronic Kidney Disease (CKD).

To date, the AKTN has successfully completed eleven trials with more in development. Our research helps bring evidence to medical practice and in doing so improve outcomes for CKD patients.

Best Fluids Trial

Trial Summary

Kidney failure is a significant, expensive health problem. Kidney transplantation improves survival, quality of life, and is much cheaper than dialysis treatment for kidney failure. However sometimes kidney transplants from a deceased donor function poorly after surgery, and a period of continued dialysis is needed, a condition known as delayed graft function (DGF). In addition to complicating recovery, DGF can adversely affect long-term kidney function and the health of the recipient.

Intravenous fluids given during and after transplantation (usually sodium chloride, or normal saline) are critical to preserve kidney transplant function, but there is evidence that saline may not be the safest fluid to use due to its high chloride content.

The BEST-Fluids trial aims to find out whether using a balanced low-chloride solution – Plasmalyte – as an alternative to normal saline in deceased donor kidney transplantation, will improve kidney transplant function, reduce the impact of DGF, and improve long-term outcomes for patients. Participants will be enrolled, randomised and followed up using ANZDATA, the Australia & New Zealand Dialysis & Transplant Registry.

Trial Results: Simple changes to world practice for kidney transplants could deliver real benefits for recipients and reduce their need for dialysis by 25 per cent.

Upate from the Nephrology Team

Nephrology Service Update
Apologies to all for the infrequency of updates.

There has been a lot of development in the Nephrology service over the last 2 years.
In early 2022 Rob stepped down from the Clinical Director role for the service. He had fulfilled this role since arriving in Dunedin in 1989. At that point the service in Dunedin was very under developed and there was effectively no Nephrology service for Southland. Rob managed to develop the service, operate as sole Nephrologist for long periods of time and progress through the University career pathway to become Head of the Department of Medicine. As a service we thank him for his many years of dedication.
I took over the clinical leader role in an interim capacity in early 2022 and then formally in the middle of that year.
Funding was approved for an additional full time consultant position in 2022. There were multiple applicants for the role and interviews took place in December 2023. A decision was made to spread the role around which means that Tracey Putt has increased her Nephrology time from 0.5 to 0.8 FTE, Sine Donnellan has increased from 0.4 to 0.7 and Frederiek Heenan Vos has started with us in a 0.5 role.
With this we have changed how we work quite significantly. We now have a formal dialysis role where there is a named consultant looking after dialysis patients. With this we have instituted formal dialysis clinics. These will

progressively develop so that one of the dialysis nurses will be present at the clinic and we plan to evolve to formal multidisciplinary clinics where the renal social worker and the renal dietician will also be present. Currently we do not have enough social work or dietician time for this. We have begun a process for additional funding to allow this.

These changes have taken a bit of getting used to and we are continuing to evolve and try and make our systems work a little better.

With additional consultant time we started a new clinic for patients who are starting the dialysis and transplant education process (pre dialysis clinic). We plan to develop this into a true multidisciplinary clinic as we are able.

Southland clinic provision has increased from 22 full day clinics per year to 38 with dialysis and pre dialysis clinics included within this.

This does mean that you are more likely to see a different person each time in clinic. We like this as it means we all get to know you. If you would prefer to see the same person each clinic please let us know and we will try and facilitate this (though won't always be able to).

With additional consultant time we have also started to provide protected transplant work up clinics. Previously the main rate limiting step in transplant workup had been finding a clinic slot. This should now dramatically improve and shorten our transplant workup time. We are now able to provide transplant clinics in Invercargill.

Lynda (predialysis nurse educator) and Fiona (transplant coordinator) have started to travel to Southland to provide dialysis and transplant education.

Ideally we would like to be able to provide clinics throughout the Otago and Southland region particularly in Waitaki and Central. At this stage this is some way off.

In mid 2023 we received additional funding for 2 peritoneal dialysis nurse specialist roles. One based in Dunedin and one based in Southland.

Kath Go who has been working in the dialysis unit since 2017 successfully applied and has started the Dunedin based role. The Southland role was initially unfilled and we have not been able to attract a trained PD nurse specialist. We have made a decision to train someone into this role and have multiple applicants for this position and are currently working through a recruitment process.

The dialysis unit has had several staff leave and new staff start. I will leave it up to Blair and Lynda to introduce the new staff members.

As all of you who have experienced the dialysis know, the dialysis unit is not fit for purpose. We have had funding approved to develop a new dialysis facility in Dunedin. This is likely to be a 6-10 bed hybrid facility that will increase capacity until additional facilities are able to be developed near the new Dunedin Hospital. We are currently at a stage of drawing up plans for this facility and if all goes well this may be operational in the next 12 months or so.

Alongside this we are in the process of writing a case to develop a combination incentre and training unit in Southland. There is recognition from Te Whata Ora Southern that that this is a required facility and a realisation that this is an absolute requirement for the dialysis service going forward. This is a quite big project and is likely to take some time to progress.

Ricki-Lee Earwaker from Invercargill has started with us a consumer representative and attends our departmental and quality meetings. Many thanks to Ricki-Lee for her input and support over the last 12 months.

Overall, the service is going through a period of generally positive change. Many people are involved in this, and I thank them for their efforts.
As many of you are aware Maria Thompson in the office goes above and beyond in putting patients care first and we thank her for this.

John Schollum

Update from the Dialysis Unit

Dialysis Service update February 2024.
It has been quite some time (April 2020) since there was an update from the dialysis service – too long, sorry.
Newer Team members
There have been a lot of changes in the team since I last wrote.

We have had Hannah Campbell (EN), Bronwyn Kett (RN), Majit Nizar (Renal clinical physiologist – RCP), Astrid Haanen (RN), Paula Herbert (EN), Courteny Harris-Fletcher (EN INV), Hashim Mir (RN), Joanne Turner (EN) all leave us to move on to other opportunities. The good news is that Astrid and Paula are still available to help casually which is very much appreciated. Also, we have welcomed several fabulous new team members – Madhivanan Devaraj (RCP

from Hawkes Bay) who joined us I August of 2023, Jayson Del Rosario (RN) commenced September last year. Along with Linnet Cungihan-Richardson (June 2021) who many will know, Ann Lee joined us October 2022 and Janel Javier shortly before Ann in September of 2022. More recently Dennis Mathew (RCP INV) from the UAE commenced November 2023 in Invercargill with Teri Crosbie. Most recently Adriana Brouwers (RN) for the Netherlands and Matt Slemint (new grad RN) both commenced in January of this year. We have been very fortunate to have such quality team members join us. We are still currently recruiting for a further nurse for Bronwyn's vacancy and hope to appoint into this soon.

Very sadly Beverly Carnegie our health care assistant passed away in October of last year after becoming unwell. Bev was known to many of you and had been with us since 2009. It was a shock for the team and many of you who knew Bev to hear this.

Lieny Manson, who has been the unit receptionist since joining the service in 2010 has been appointed into the role of Healthcare Assistant. This has made for a smooth transition and change following such a tragic time. This does mean that there is a clerical vacancy that we are seeking to fill as soon as we can and miraculously Lieny is managing to keep this work ticking over while learning a new role and taking on additional training for this.

We were thrilled to be able to appoint Kathleen (Kath) Go as the first Clinical Nurse Specialist (CNS) for the service in Peritoneal Dialysis (PD). Many of you will know Kath and we are looking forward to how this role, and another (CNS PD) role for Southland (yet to be appointed) will provide so much more support for those on PD as well as for staff in the outlying areas and in primary care.

We remain very grateful to Kerryn Dyer (Dietitian) and Sophie Smith (Social Worker) for all the support they do offer to the service which is significant given the amount of time they have allocated for this.

Of course, in this time both David McArthur and Ian Bowen, dialysis clinical engineers since the beginning of time both retired. Personally, I could not envisage how the service would continue with out them but, both Joseph Thomas and Marvin Gomez have stepped in and are very ably continuing to provide this service.

Model of Care

As some of you will be aware there was an evaluation of a two-shift model late last year. While this has been reviewed there are no immediate plans to progress with this and this along with other initiatives such as dialysis clinics with nursing and medical combined will be discussed further as part of the future service planning process. Many of you may well be wondering, with the new Dunedin Hospital building, what is happening for the dialysis service. While there will be a fully "plumbed for dialysis' medical high dependency unit and a smaller co-located acute dialysis unit in the new main hospital block, the dialysis service itself is not included in this project. There is a lot of effort being made to find a longer-term solution for where the dialysis service will be located and more will be said when there is something to share.

Something that is being worked on is seeking feedback more intentionally from those on dialysis during training, whether the individual is incentre or at home. We hope to have more to say about this towards the middle of the year so that there is the opportunity for feedback from you all in a planned way.

World Kidney Day

While not directly involved personally in the planning and preparation for this I am aware that there are staff and members of the OKS who are actively involved in arrangements for this, and I do want to express my thanks for all that is being done in this regard.

As a service we are very grateful for the support the patient support groups do offer.

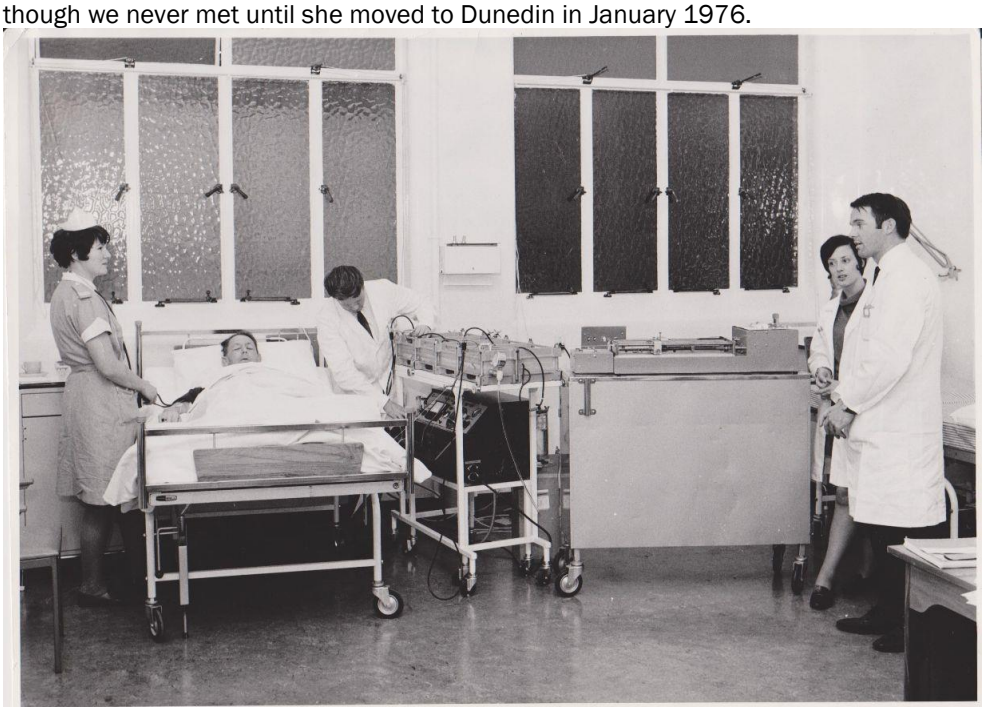
All the very best, on behalf of all the dialysis staff

Blair Donkin
Charge Nurse Manager.

At the end of last year, we farewelled Maree and we will miss her dearly and thank her for working so hard to make our lives better.

Dear Members
Natalie has asked me to give a little background to the beginning of the Otago Kidney Society (OKS) and a little history of nursing in the Dialysis Unit. For those of you who don't know I made the decision to move to Christchurch in December. It was a very difficult decision to leave Dunedin, family and friends. Amongst those friends are colleagues and patients who I've had long associations with through the Dialysis Unit and OKS. Thank you so much for the flowers and champagne.
Many of you will not know but the original name of the OKS was the Kidney Cottage Club (KCC). It was established in 1976 after a robust discussion I had with the then Nephrologist Tony Hocken regarding holiday dialysis for Haemodialysis (HD) patients. I'm sure there are some of you out there who still remember Tony with fond affection. He had told me in no uncertain terms our patients were not allowed to visit other units and I was not to accept patients from other dialysis centres. It was very hard to win a discussion with Tony who had a great way with words. I think every doctor enjoyed his referral letters. The discussion ended with him saying "you find a solution" hence the beginning of bringing together a wonderful group of patients and colleagues to form the KCC. This may sound harsh but to give Tony his due you need to know a little background and history of the early days of dialysis.
Tony had been working in the UK in the late 60s early 70s and came to Dunedin in 1974. There had been increasing breakouts of the Hepatitis B virus in HD units there. Two HD units in Edinburgh had a very sharp outbreak. The death rate among renal patients was 24% and 31%in staff members. It was only from 1971 that blood banks screened for the Hep B virus and in those days before you had Erythropoietin (EPO) patients required frequent blood transfusions. The positive result for screening the virus was the hepatitis rates dropped 25% for patients receiving blood transfusions. Later came more sophisticated testing of blood for transfusions so be reassured it is ok if you need one.
Then in 1981 more good news for renal patients, the FDA approved a sophisticated HepB vaccine for human use. Liz and I were really happy too as previously we had to have a blood test every month to ensure we were negative. This was to protect us and you the patient. There was a stigma being a dialysis patient in the early 70s because of the hepatitis outbreak, a little like the aids epidemic in the 80s. In London I remember when staff at British Telecom refused to go into dialysis patients homes. I also remember us teaching a hepatitis positive patient in isolation virtually by an intercom system. The room was like a glass cabin. How things have changed and all for the better. Technology over the years has improved to make your dialysis safer and more physiological comfortable and efficient. I think one thing that hasn't changed are the patients. I will mention my observations later.
The first dialysis unit at Dunedin Hospital was opened on July 9th 1970. It was situated around by the kitchen in the old Dunedin Hospital. It later moved to a purpose built dialysis unit on the ground floor of the hospital but patients went to Christchurch for HD training until 1974. I was appointed Charge Nurse or "Sister" in 1975 after returning from the UK late in 1974 and got the home programme going as a viable option. Previously in 1973 I undertook a post grad certificate on Dialysis

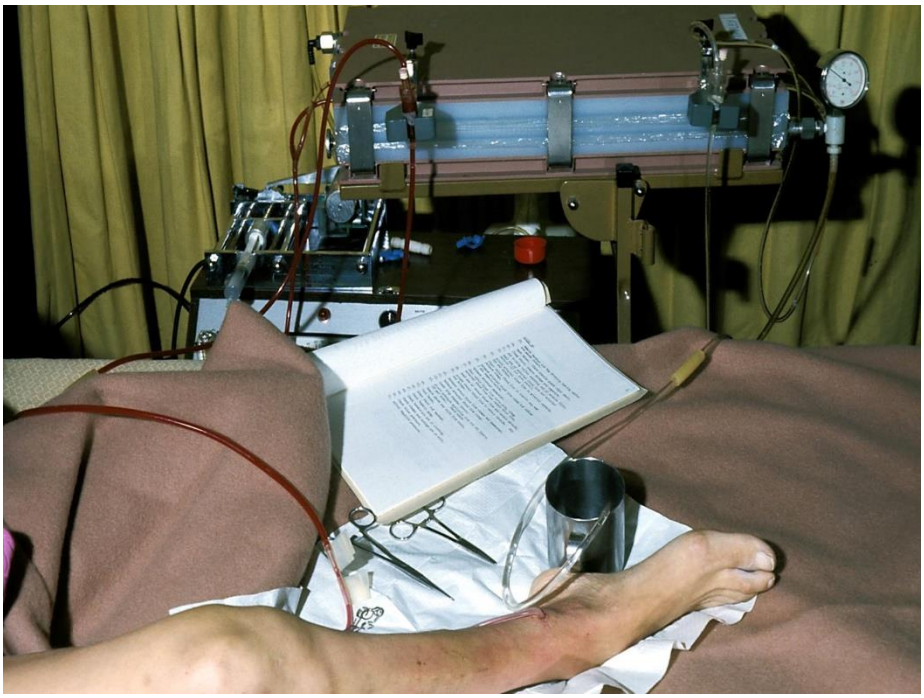
and Transplantation at the Royal Free in London. Coincidentally Liz Edwards had completed the same course 2 years prior to me though we never met until she moved to Dunedin in January 1976.



1st dialysis treatment in the original Dialysis Unit in Dunedin Hospital, 1970

The Royal Free had a very large HD unit. It had an in centre and a home training unit. Some of the incentre patients had been on HD 10 years. The first long term HD treatment was in 1960 in Seattle in the USA so these patients commencing dialysis in 1963 were true pioneers. To survive 10 years in those days was miraculous. I know my and Liz's passion for nephrology came from meeting those patients and our own patients in the Dunedin unit. Their humour, stoicism, discipline and living life to the full was in part to pay respect to all the patients on the journey with them who didn't last so long. They lived close to death on a regular basis. They would come in late afternoon, set up their machines and dialyse for 10 hours and some would go to work the next day.

Building the Kiil Dialyser in the Dunedin Dialysis Unit 1976


A patient connected to a Kiil Dialyser in the 1970s

There were home training patients also, who learned to build, pressure test and sterilize the artificial kidney. It was a very labour intensive procedure and if the pressure test failed they had to start all over again!! Many people lived in very small houses with little land. One solution was for a crane to drop a porta-cabin in the back yard for a dialysis machine. The photos of the artificial kidney are from our dialysis unit at Dunedin Hospital in the 1970s. Then Dialysis moved from a purpose built unit to a 4 bedder room in 4C in 1981. This was a disastrous move. I had moved to Australia from 1978 to 1982 or I may have had a falling out with management at the time. Unfortunately, the decision was made with no nursing input. The only positive out of the move was the unit started using hollow fibre artificial kidneys because of space restraints. It was the end of building the kill. The tragedy of that move is since then there has never been a purpose built Dialysis Unit at Dunedin Hospital. Make sure the next one is!!

There is so much interesting history in the development of Dialysis throughout the years and too much to write here. I know Liz has some interesting material and that could be for another newsletter.

Now back to the KCC. People who know me well are aware of my love of travel and holidays. I had just returned from my big OE. I couldn't comprehend being told or telling someone they could never go on holiday. I got together a motivated group of patients to form the 1st KCC committee. Kevin Sawyer, Alison Burgess, Molly Harrington and Liz Whyte.

We approached hospital management for some unused property in Central Otago. They offered us the old nurses home at Cromwell Hospital. It was a brick cottage with 3 bedrooms but required labour and money to make it habitable and to accommodate a dialysis machine. We set up a subcommittee for fund raising. A small group like us would never be able to fund the whole project, so it was suggested to me I speak to the Ravensbourne Lions Club who were looking for a project. This was scary having never done public speaking. Off I went to the Ravensbourne Hotel and spoke at their meeting. Obviously it was very successful. They said they would approach the Cromwell Lions and get it done as a joint project covering all the labour costs. We were on our way.

We all had lots of fun with fundraising activities and working bees, which included, dine and dance, raffles, cake sales and barbecues. We used to sell the cakes and raffles outside the pay office in Hanover Street. Those were the days of real money in brown envelopes. We had a captive market. The Cromwell Lions were very hospitable and one of them offered us motel accommodation for free when working on the cottage. Everyone knew how to party after a hard days labour.

Opening of The Kidney Cottage, Cromwell January 1978. Maree standing by blue door

The KCC opened on 28th January 1978. I remember this as it was my first wedding anniversary. First it was exclusively for Dunedin Hospital patients use which included Southland, Central and Waitaki. If it was not used by patients the next priority was Dialysis staff and then other hospital staff. After the developments I mentioned earlier regarding Hepatitis B vaccine and testing we were later able to offer holiday dialysis to patients around the country and later from around the world. It was a very popular facility and was devastating when the Southern District Health Board decided to sell off Cromwell Hospital and our cottage in 1990.

The Friends of Dunstan Hospital formed in 1992 and sometime after that we were given another old nurses home for a dialysis facility. Unfortunately this time we were only allowed to use it as a holiday dialysis facility and not be able to do renovations and make as a holiday home as well. Like the Cromwell facility I think the Dunstan facility is still well used in summer. I would encourage all home HD patients to use the facility if you can. It's the old adage "use it or lose it".

Being a member of the OKS until my move to Christchurch has been a great transition in letting go from work into retirement and retaining wonderful relationships. The journey living with renal failure is not easy and some journeys are more bumpier than others. As I said earlier there have been many changes mostly for the better but patients remain the same. I nursed for 47 years, 33 of those years caring for renal patients. From my observations over the years when you get the news of requiring dialysis you run the gamut of many emotions. When you are shown options for treatment you're bewildered, anxious, sad, scared, feel you're too dumb to learn all that. Your automatic reaction is to want to do it in hospital where you feel safe. My experience is patients get over all that then thrive.

Home HD should always be the first option for HD patients. For a few this isn't an option but I will tell you what I observed over the years. Longer hours and more sessions mimics the real kidney better. You cannot have these options in a hospital unit. This gives you better control of your fluids and electrolytes which allow you to lead a fulfilling and longer life.

You can participate in sport, school, work and community.

You don't lose precious time with family but have time to be more involved with them and their activities.

The bonus is you have the opportunity to use the dialysis holiday facilities the different regions offer.

I loved my 33 years in dialysis and met wonderful and different patients. There were the overly disciplined patients, not many, one I told "you can wash your hands too much" I never ever thought I'd say that to a patient. Not attending special occasions because their peritoneal bag exchange was due. Then there were the patients that went by the book and did very well. Then there are the ones who think they can cheat the system a little so have a few ups and downs on the way and then see the light and stay on track. Then there are the patients that feel they only have control if they buck the system and unfortunately don't do so well. I also want to state that there are patients who do everything right but through no fault of their own just can't win over their bodies failing condition. So on finishing this article I will give you my pearls of wisdom and wish you all the very best health for now and long into the future.

Turn up to every outpatient appointment.

Get your prescriptions and medications on time. Never run out.

Do your Dialysis prescribed treatment to the letter.

Keep to fluid and diet restrictions.

Stay engaged with your family, friends and community and it will help lighten the burden

For patients wondering why I have not spoken about Peritoneal Dialysis (PD) it is because it was not performed in Dunedin until 1989 when Rob Walker came to Dunedin as a young Nephrologist. Liz, Dawne and myself were thrilled to offer this treatment to a more varied group of patients. We all know that PD is a great option for travel!!

I would like to end my contribution to the OKS newsletter by acknowledging patients and colleagues from the past who have made a significant contribution to the OKS since its inauguration.

Anita Lloyd
Adele Hastie
Bruce Davie
Hazel Jones
Jock Alison
Brent Edwards
David Bell
Noelene Clarke
Glen McLennan
Shane Boyle

I want to acknowledge your present committee for their commitment to the society and to you. Please support them. You can do this by attending AGMs, they are now on zoom, give feedback and ideas on how they can support members and I emphasise consider joining the committee

James Blair
Karen MacLeod
Natalie Brown
Philippa Pringle
Liz Edwards
Lynda Anderson

I want to say a big thanks to Ian Bowen and Dave McArthur for their support in World Kidney Week every year
I have loved working with you all past and present members of the OKS and all my wonderful colleagues in the Dialysis Unit.

Maree would love to hear from you here email is Mareejones48@xtra.co.nz, cellphone number 022 393 2165.

Staff Photo 1990s: Left to Right: Rob, Liz. Benita, Maree, Bob Young (technician), Noeline Bridge (Nephrology Secretary), & Dawne

Kidney Health
NEW ZEALAND

Prevention • Support • Research

KHNZ kidney resource project – an update

After seeking feedback from the kidney community throughout New Zealand, Kidney Health New Zealand is now beginning the process of creating a suite of education resources which will be accessible and in a variety of formats.

Feedback was received from patients, whanau, and allied health and healthcare professionals working with kidney patients. Some of the common themes around the formatting of the resources include the need for more information to be translated into a wider range of languages, more graphics and less words, consideration of English as a second language for many, small amount of information at a time, in other words layers of information and consistency of wording throughout the resources ie. kidneys instead of renal. Consideration will be given to ensure accessibility to the resources for all, planning is underway to establish a national repository for education resources, including access for those without data and those less IT savvy.

The design will include a selection of short videos clips, podcasts, booklets, flip charts, brochures and fact sheets which will contain information for those affected by kidney disease, those at increased risk, newly diagnosed, kidney replacement therapies, supportive care and information for caregivers. The information will range from what to do when the GP tells you your kidneys aren't working properly, managing medication, treatment options through to managing fatigue, anxiety, anger and what can I as a caregiver do to support my person.

Work will be done to ensure this Information is accessible for GP's and Practice nurses to enable the information to be printed out for their patients to take away with them. Many of these resources will be useful for Primary Care and support their learning too.

The KHNZ resources design will be consistent throughout with cultural considerations at the forefront, the ability to update these resources regularly will be a priority to ensure they remain current and a reliable source of information for all.

Co design of these resources is critical, and we will be seeking input and feedback from patients, caregivers, healthcare teams working with kidney patients. This will be done by way of focus groups, either via Zoom or Face to Face, emails, and regular updates.

It is important your voice is heard, after all these resources are for you, and those who want to understand kidney disease and support those impacted by the disease and its treatments.

I welcome your feedback at any time, you can email Carmel at carmel@kidney.health.nz or call me on 021 460456, or 0800 543 639.