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CHRISTMAS 2013
This issue has been funded by The Community Organisations Grants Scheme
Its celebration time. Our annual Christmas party takes place at the Woolston Club on December 8th. We have a wonderful line up of entertainment, marvelous raffle prizes, including a special free kids raffle, fabulous catering by the club, alongside our usual barbeque sausage sizzle. Come and join in the fun with members, family and supporters. Remember to reply to the enclosed invitation and help us cater for everyone. The Society provides this event at no cost to those attending and is gratefully supported by sponsors, donations and all those who buy raffle tickets, spin the chocolate wheel or purchase items from our baking and plant stall.

Christmas is also our time to especially thank those who have supported us during the year: We are so fortunate to have a wonderful extended renal community network of medical professionals and friends who go above and beyond the norm. So a special bouquet to staff of Christchurch Hospital Home Dialysis Training Centre and Nephrology Department, including ward 14; to our outstanding and generous group of KIC volunteers: Judy Giles, Chris Sparks, Anne Chambers, Jeanette Jones and Adrian Buttimore and to your dedicated, hardworking CKS committee.

Without the commitment and time they all give we would not be able to function as enjoyably and successfully as we do.

A few dates for your diaries:

Christmas Party – Sunday December 8th at The Woolston Club
Pot Luck Lunch - Friday March 28th 2014 - Medicine Management System

On behalf of Viv, myself and the CKS Committee we look forward to seeing you at the Christmas party, following which we wish you -

“A Happy, Healthy and Safe Holiday Season”.

Kate
The Christchurch Kidney Society Cordially Invites You to our 2013 Annual Christmas Party
Family fun & BBQ lunch.

Sunday 8th December
The Woolston Club,
43 Hargood St, Woolston
Time: 11.30am - 3.00pm

BBQ Lunch Provided • Cake & Plant Stall
• Bouncy Castle • Natural Magic
• Face Painting • Raffles
• Chocolate Wheel

Please RSVP by 27th November
Yes, we will be attending the Christmas Party & BBQ on December 8th
Family Name: _________________________________________
Number of adults: ______ Number of children:________________________
Children’s gender and ages please for Santa: _____________________________

RSVP to: the Christchurch Kidney Society, Level 1, 230 Antigua St, Christchurch
email: c.ks@xtra.co.nz or leave a message on Phone: (03) 379 5529
As we all know kidney failure has no bias and can affect any of us from any walk of life, race, religion, background and at any age. Recently we have had an influx of younger people starting dialysis and we have had several conversations with a number of them regarding their desire to meet with other patients in their age bracket. An important tool for getting through any challenging experience is peer support and so we put our heads together to come up with a way to connect our patients in a different way.

What we know is that in today’s world with the advance in technology, huge numbers of people connect via social media. So we have set up a Facebook group called ‘Kidney Failure Uncensored’ for our facebooking patient generation and their supporters. Although the group has been set up by us, the aim is for it to be taken over and run independently by its members once membership grows.

The idea of this group is to provide a safe, non-judgmental forum enabling members to discuss freely their experiences. As a group of people with shared experiences, we would hope that this will become a place that they can gain hope, strength and support from others in the same situation. The members could be currently on dialysis, facing dialysis in the future, have been transplanted or are a friend or family member of someone experiencing kidney disease.
To become a member you have to ask to join and then you are added to the membership. This group is solely for patients and their supporters so that means....no staff allowed! We wanted it this way so that people felt safe to be free with their thoughts and feelings and not concerned about their treatment being compromised at all. Not that this happens, but when you are a patient you feel pretty vulnerable and the aim of this group is to empower people and to enable them to have a voice.

Log on to Facebook and search Kidney Failure Uncensored in the search bar. If you have trouble finding it write this address into the web address bar: www.facebook.com/groups/kidneyfailureuncensored/

So go for it. Join up and make some connections!!

Becky Hayston and Sandy Neale
Changing Times at The HDTC

It has been a busy year in the Dialysis Service and along with that there have been some personnel changes. I want to let you all know who has come and who has gone. When you visit or phone us, you will possibly be talking with new people who may not know all your details, but given time, you will get to know them as just as you have done in the past with everyone else.

Firstly, I have been appointed to the permanent position of Charge Nurse Manager for Dialysis Services. So I will be staying on for the foreseeable future.

Staff that have moved on:
Gillian Tait, Registered Nurse: Left in September transferring to the Neonatal intensive care unit.
Paul Fallen, Team Leader: Left in October. Paul is moving to Taupo where he will be running a Motel complex.
Jan Hughes, Administrator also left in October. She transferred to Site redevelopment to work as a Personal Assistant.
We wish Gillian, Paul and Jan all the best for their futures, and thank them for their contribution to Dialysis Services over their time spent here.

3 new appointments made:
Elaine Bartholomew is the new administrator, so many of you will be talking with Elaine when you place your orders.
Ashleigh House a Registered Nurse from Ward 14 started on November 11th and Paigen Lane a Registered Nurse also from Ward 14 will start on November 25th.
Both have Nephrology experience from the ward, and will spend time in both Home Training and Acute Dialysis over the next couple of months as they are trained in Dialysis. We welcome them into our team.

Wendy Cuthill
Nutritional Notes: CKD and weight management

The Plate Model

Palm size portion  ¼ plate

• A variety of foods = a variety of nutrients
• Make half your dinner plate non–starchy vegetables! Vegetables are low in calories and rich in vitamins and minerals
• Your meat/protein portion only needs to be the size of your palm
• Your carbohydrate portion only needs to fill ¼ of your plate. Carbohydrate foods provide a good energy source but eaten in high amounts can cause unnecessary weight gain
Weight loss occurs when...

energy expenditure is more than energy intake

BMR + Exercise + Activities of Daily Living > Food + Fluids

- Reduce total calorie intake by reducing consumption of foods high in fat and sugar
- Enjoy healthy eating
- Participate in activities that you enjoy

Decreasing fat:
Choose:
- lean meats
- low-fat dairy
- limit added fats in cooking
- avoid high fat foods - particularly snacks and fast foods

Decreasing sugar:
- Sugar is found naturally and as an additive to food
- Added sugar provides no additional nutrients, just empty calories
- Choose products with minimal added sugar such as wholegrain breads/cereals and fruit/vegetables
- Limit the intake of foods with added sugar including:
  - Jams  - Ice cream  - Sugary drinks
  - Cakes  - Muffins/biscuits  - Confectionery/chocolate

Alcohol:
- Avoid alcohol if not already included in your diet
- Males: 0 - 3 standard drinks/day, Females: 0 - 2 standard drinks/day
- 1 standard drink = 300ml beer, 100ml wine, 30ml spirits
- Aim for greater than 3 alcohol free days each week

Setting your Dietary Goals:
Where do you start?
- Make small changes as you can manage them
- Don’t change your goals until they have been achieved
- Remember small changes are sustainable so are more beneficial over a longer time period
In 2006, I donated a kidney to my husband. At the time I did not really appreciate just how many people in New Zealand need a kidney transplant and how few transplants are actually done each year. I decided to do some research into what might be done to increase NZ’s current rates of living donor kidney transplantation. In this article, I discuss a few of the key findings of the research.

Access to living donor kidney transplantation relies heavily on patients, and their families and friends having accurate information about living donation – the pros and cons for the potential recipient, the risks and benefits to donors, and the practicalities involved. Without this, patients may not realise a transplant from a living donor is an option for them, may not understand that this may well be the best treatment option for them, may not realise who could be a donor and may overestimate the risks to donors. Without information, family and friends may not even be aware that a living donor is needed or who could be a donor.

In my research, around one-fifth of patients on the waiting list said that no one from the renal unit had ever discussed living donor kidney transplantation with them. Many commented that discussions had been superficial, did not address their questions, were one-off or occurred only “at the beginning”. This raises questions about how actively living donor transplantation is promoted with patients, despite it being widely regarded as the preferred treatment for most people.

A major barrier is being able to find a willing and suitable donor. This is usually up to the patients themselves because most health professionals are unwilling to be directly involved in the process of finding living donors for ethical reasons. There is very little support, however, for patients in how to raise the issue of living donation with their family and friends.

While most patients (85%) would accept a kidney if someone offered, most also find it very hard to approach people about being a donor. This might be
because they have some concerns about living donation (for example, impacts on the donor’s health or being worried that a donor would be financially out-of-pocket) or because they feel it is such a “big thing” to ask of anybody.

Nearly one fifth said they had not talked to anyone about living donation. Most patients would rather someone offered to donate without them having to raise the issue. However, people who had talked to other people about living donation were much more likely to say someone had offered to donate. Asking directly does not seem to be necessary. It may also be necessary to get information out to a very wide group of people because while people may be willing to donate, they may not be medically suitable or compatible with the intended recipient.

Often patients themselves turn down offers, either because they have concerns about the impacts of living donation on the donor, or because they have misinformation. For example, they might assume a potential donor would not be healthy enough (without them being tested) or assume someone is the “wrong” blood type, not realising that ABO-incompatible transplants or Kidney Paired Exchange (where two or more incompatible donor-recipient pairs are matched so they can “swap” kidneys) may be an option.

Options for addressing these (and other) barriers include: better education and information for patients and their networks; supporting patients to raise the issue of living donation; raising general awareness of kidney disease and living donor kidney transplantation; removing financial barriers for donors (especially reimbursement for lost income); better promoting NZ’s Paired Exchange scheme and making it easier to access; and making the work-up process easier for donors. National leadership, including a strong patient voice, is needed to make further progress on this complex and important issue.

This article is based on Paula Martin’s PhD thesis “Increasing the rate of living donor kidney transplantation in New Zealand: Developing an evidence base” available from Victoria University of Wellington. Paula can be contacted at paula.martin@vuw.ac.nz.
As we draw near to our much awaited annual Christmas party, it is always a time to remember those special to us, who are no longer with us. Bruce Grainger sadly passed away on the 23rd August. Many of you will know Bruce, as he played a very big part in our Christmas parties for many years. Bruce was formerly a committee member and most importantly our Father Christmas for a few years.

One year Bruce brought his T-bucket to the Christmas party and took kids for a spin around the carpark. Many people will recall chatting to Bruce and appreciate his amazing ability to listen and his wonderful outlook on life, despite the many challenges he faced.

Bruce was the “adult helper” at kidney camp in the North Island for a few years running. He was also enlisted to take South Island children safely to and from camp, which he did. The kids always returned home tired but happy. One year Bruce certainly didn’t return in the same condition as he went, as he broke his collarbone and ribs trying to beat everyone in the go-cart racing.

Bruce wanted to leave this world having made a difference. He was passionate about organ donation, even though that became impossible for him. I know he was a mentor to many and inspired people to stay positive, despite what they were facing, as he did.

Bruce will be sadly missed by us all, he did make a difference, and his sense of humour and smile were absolutely priceless.

Jo Houghton, October 2013
World Transplant Games in South Africa

The 19th World Transplant Games were held in Durban, South Africa from 28th July to 4th August 2013.

The New Zealand team consisted of 10 athletes and 9 supporters from all over New Zealand as far south as central Otago and north to Auckland. The team met up in Auckland and had a two day stay over at Perth before heading to South Africa.

We stayed in Durban and it was a very big eye opener for everyone. We weren't allowed to walk anywhere by ourselves for safety reasons, but everyone had a great time.

The New Zealand team competed really well at the games and the team returned with 5 Gold, 1 Silver and 6 Bronze medals. On the medal tally the New Zealand team finished 23 out of 49 countries, which is a great effort.

During the games there were a number of evening functions and day trips for athletes and supporters to attend, as well as having a nightly team meeting. On the final afternoon at the athletics the New Zealand athletes did the haka which is fast becoming a expected event at the games.

After the games a number of us did a 4 day wild life game safari park tour. It was really awesome to get up close with the wildlife in their natural environment.

If you are thinking of attending a future transplant games, a couple of dates coming up that maybe of interest to you are:

- The Australian Transplant Games, Melbourne from 26th September 2014
- 20th World Transplant Games in Argentina from 30th August to 5th September 2015.

You need to have had your transplant for a year before attending either of these, pass a full medical and have a current subscription to the New Zealand Transplant Games Association which is $50 per year.

If you would like any more information please feel free to contact me on my email: saraford@clear.net.nz or my home number (03)9802073.
CKS GRAEME COX YOUTH EDUCATION TRUST

It has been a very quiet year for the Trust. The audited financial statements of the Trust have been filed with the Charities Commission and the Trust is in a good financial position to continue to assist young people with chronic renal failure. Our financial year was very successful with the Charity Dinner held in September 2012.

We were very lucky to receive a donation from the Sefton Kowai Women’s Institute, North Canterbury Branch and Noeline Cox ran a very successful “lotto bonus fundraiser”. Everything helps to boost our funds and soon we will look to organise another fundraising event.

Please contact the CKS if you have any questions about the Trust and what it covers, as we would love to assist young people through 2014 to reach their educational goals, or pursue an activity of interest to them.

Most of our trustees will be attending the annual Christmas Party and we would be more than happy to chat with you if you have any questions.

We wish everyone a safe and happy Christmas.

Jo Houghton / Treasurer
CONSUMER COUNCIL REPORT October 2013

“Nothing About Us Without Us.”

It is a while since I have submitted a report giving an update on consumer council activities.

Very soon the CANTERBURY HEALTH SYSTEM’S QUALITY ACCOUNTS will be published the main target audience intended to be consumers. This year all health boards have to publish such a document & the Health Safety & Quality Commission have guidelines for these.

Copies are being sent to all GP surgeries with copies earmarked for each waiting room. This set of Quality Accounts along with those of 2011-2012 are also available on Canterbury DHB, updated website, www.cdhb.health.nz Feedback is important. You can provide feedback by E-mailing qualityaccounts@cdhb.health.nz

The consumer Council was involved in their production. FACILITIES DEVELOPMENT has remained a major focus mainly with the redevelopments at Christchurch & Burwood Hospitals. Consumers have been consulted widely & beyond the council and the Design Lab models show new ways of designing hospital rooms for the future with benefits for patients & families to the fore.

In addition to council business at each meeting we have a speaker from an aspect of the way the Canterbury Health Services function.

Examples include Wayne Reid Refugee & Migrant Health Manager, Pegasus Health discussing Interpreter Services/Asian/Refugee Issues

Did you know that there are around 170 cultures in Christchurch who speak around 80ish different languages? A number of migrants do not have a GP. Pegasus Health have put out a booklet explaining New Zealand’s Health Care system for refugees & Migrants.

It is important that interpreters are trained qualified & used.

Bruce Penny & David Kerr spoke to us in November about particularly HEALTH INFO which is an important source of information for consumers to use. It is constantly being reviewed to find & update information to improve the experience & knowledge of those receiving health care. (http://www.healthinfo.org.nz) they also recognize the need to cater for people who are not computer literate. GP’s are to encourage people to use the site.

This is just a fraction of the Council’s activities & consumers are represented widely on Committees such as the Fall’s Steering Group, Clinical Board, Infection Prevention &Control Committee & eSCRV The Shared Care Record View. eSCRV is a secure data place for electronic patient information available through Health Connect South, the Canterbury Health system’s principal information system enabling clinicians secure access to a person’s latest patient information enabling them to deliver better & safer care.

Consumer Council meetings can be attended by the general public.
The CKS has recently been in correspondence with dialysis patient, Aleksandra Dermont and we were delighted when she sent us some information and photos of her recent holiday cruise

“The journey was wonderful. We went from Passau (Germany) to Krems (Austria), Budapest (Hungary), Vienna (Austria), Bratislava (Slovakia), Melk (Austria). Every day we stopped at another place. In Budapest we stayed overnight and that was truly special, because Budapest is so beautiful at night with all the lights shining.

Diaysis was every second day (because of the excellent food on cruise ships people eat much more than they should :-) But that was OK for me, as I ate and drank too much too...they organized it perfectly, so everybody could do all excursions - on the evening when we were in Vienna three of us went to a classical concert and the staff waited for them to come back at 11 p.m. to have short dialysis then and one more dialysis the next evening.

The captain, the barmen, of course the doctor and the nurses, everybody spoke English too, they even did an introduction about the ship in the English language.

You have to bring with you the medicine you need for dialysis.

The costs are 299 Euros for one treatment, plus the costs for medicine, such as EPO.

They have 8 places on the ship.

You have to book the dialysis prior. The doctor offering this is Dr. Peter Rittich from Hamburg. This is his website: http://www.schiffsdialyse.de
The site provides information in English too - he is very kind and always doing the best for us. On the website you can find other cruises worldwide. I did one from Fidschi to New Zealand and Australia six years ago.

Here is the website from the ship, the name of the ship is MS Mozart. http://www.dertour.de/kreuzfahrten/dertour-mozart/
Its in German, but the staff from the service hotline speak English and Dr. Rittich can help you with the booking too. This page is in English: www.eurorivercruises.com/fleet/mozart.html

I love cruising, its a bit expensive but it is worth every euro.

I wish you all the best and I hope the information I sent will inspire you all to do that fantastic journey.

Aleksandra
SNIPPETS

Viv’s CKS Pot Luck Lunch Round-Up:

Michelle Allan, dietician, spoke to the group about nutrition and kidney disease and how it is important to maintain a good nutritional status to provide sufficient energy, and to maintain a healthy weight. It’s not just weight gain but also weight loss that can be a problem. Some of you may need to follow specific diets due to diabetes, high cholesterol, or high potassium but everyone should maintain a varied diet to provide a variety of nutrients, and salt should be restricted. The Kiwi way of piling the plate with meat, whilst delicious no doubt, is not the healthiest! See ‘The Plate Model’ for a more nutritious layout. Also added sugar provides no additional nutrients just empty calories so limit the intake of foods with added sugar such as sugary drinks, ice-cream, cakes, and jams. Check out the ‘Healthy Food Pyramid’ in the Autumn Renal Messenger to see how to balance your day’s food. If in doubt contact the nephrology dieticians for advice. The new renal dietician Hilary Dumbleton can be reached on 364 0622.

Fortunately the lunch on the table was fairly healthy fare! Always great to catch up and share news and information.

Thanks to Michelle for coming along and sharing the useful information!

Next Pot Luck Lunch

March 28th 2014—Medicine Management System

Bring your own lunch or something to share and enjoy with other members and supporters.

Govan Seminar room, 1st floor, 40 Stewart St, Christchurch.

Disclaimer

While every care is taken to insure the accuracy of information, views expressed in the Renal Messenger are not necessarily those of the Society. Articles by non professionals are intended to interest and inform and are not intended as medical or dietary advice. This information should come from the medical professionals involved in your care.
Help us make our Christmas Party
a success!

We need donations for the sales table
baking and plants to sell.

If you can help contact us at the KIC
Phone 379 5529
Email c.ks@xtra.co.nz

THANKS

The Christchurch Kidney Society acknowledges support from these organisations
CKS Mobile Dialysis Unit

Take you off on your long awaited (aren't they always) holiday weekend or plan a spring break. Our Mobile Dialysis Unit is fully equipped for all dialysis needs and bookings can be organised by phoning Kieran Smith or Selwyn Heatley at The Home Dialysis Training Centre Phone 364 0610.

Hire Charges: The current fees are as follows:
(all include GST, insurance and road user charges)

1. New Zealand dialysis patients: $200 bond plus $50/day.

2. Overseas dialysis patients: $500 bond plus $125/day ($NZD).

Conditions of use apply, bond and hire fees must be paid in full by either cash or cheque at least 2 weeks prior to picking up the vehicle.

Note: The Christchurch Kidney Society will consider the reduction or waiving of these fees for any dialysis patient under the care of the Nephrology Department, Christchurch Hospital, for whom payment would be a burden.
To discuss this option please contact the Renal Social Worker, Christchurch Hospital Ph (03) 364 0420.

Bookings and general enquires should be directed to:

Dialysis Services,
Christchurch Hospital,
Private Bag 4710,
Christchurch 8140,
New Zealand
Telephone: (03) 3640-614
E-Mail:
selwyn.heatley@cdhb.health.nz
kieran.smith@cdhb.health.nz
The Renal Messenger by Email

Would you prefer to receive your Renal Messenger by email as a PDF file? Each printed copy costs us around $1.70 to print and post. In view of the fact that more of our members now have access to email we would be pleased to email the Messenger to those members who would prefer to receive it this way.

We would like to thank the 68 members and supporters who have already chosen delivery by email, it has already resulted in a cut to the print run with associated savings to the CKS.

We now produce 375 hard copies each issue which are distributed to members, interest groups throughout the country and around the hospital. Of course we will continue to do this, but if we could further, reduce hard copy print numbers our savings would be even more significant.

To subscribe by email please let us know at c.ks@xtra.co.nz with “Email me the Renal Messenger” in the subject line.
Humour: RETARDED GRANDPARENTS

(this was actually reported by a teacher)

After Christmas, a teacher asked her young pupils how they spent their holiday away from school. One child wrote the following:

We always used to spend the holidays with Grandma and Grandpa.

They used to live in a big brick house but Grandpa got retarded and they moved to Batemans Bay where everyone lives in nice little houses, and so they don't have to mow the grass anymore!

They ride around on their bicycles and scooters and wear name tags because they don't know who they are anymore..

They go to a building called a wreck centre, but they must have got it fixed because it is all okay now. They do exercises there, but they don't do them very well.

There is a swimming pool too, but they all jump up and down in it with hats on. At their gate, there is a doll house with a little old man sitting in it. He watches all day so nobody can escape. Sometimes they sneak out, and go cruising in their golf carts!

Nobody there cooks, they just eat out.

And, they eat the same thing every night --- early birds.

Some of the people can't get out past the man in the doll house. The ones who do get out, bring food back to the wrecked centre for pot luck.

My Grandma says that Grandpa worked all his life to earn his retardment and says I should work hard so I can be retarded someday too.

When I earn my retardment, I want to be the man in the doll house. Then I will let people out, so they can visit their grandchildren.

Merry Christmas
APPLICATION To The Christchurch Kidney Society Inc.

FOR:

☐ Membership
☐ Renewal of Membership

I/We, Name: Mr/Mrs/Ms/Dr)

Address: ..........................................................

Phone: (    ) ..................................................

Email: .........................................................

(Include your email address if you would like us to keep you informed about any events/information for which falls between issues of our newsletter.)

Hereby apply for membership/renewal of membership of the Christchurch Kidney Society (Inc.), and enclose an annual subscription and/or donation.

Membership (includes immediate family)  $ 15.00  (inc. GST)

Donation (no GST, no obligation)     $ .........................

Total Enclosed: $ ______________

If you prefer to pay membership directly to the CKS Inc. bank account:

Westpac Bank: 03 1591 0025801 000. Please include your name and initials in the reference. Please complete and return this form to the society to enable us to update our records and correctly receipt your membership with any donation you may wish to make.

Please tick all that apply:

o New member  o Dialysis Patient  o Existing member  o Transplant Patient
o Renal patient  o Supporter

I/We agree to abide by the rules of the Society.

Signature: .........................................................

Please mail this completed form to: CKS, Level 1, 230 Antigua Street, Christchurch. Attn: Membership Secretary
The Christchurch Kidney Society (Inc.)

Kidney Information Centre
Level 1, 230 Antigua Street
Christchurch 8011

Phone: (03) 379 5529
Email: c.ks@xtra.co.nz

CONTACT LIST

Patron: **Professor John Morton**
President: **Greg Beach**
          Ph: (H) 3515401
Vice President: **Jo Houghton**
          Ph: (H) 981 9160       Cell: 0212 860309
Secretary/Field Officer: **Kate Hay**
          Ph: (W) 379 5529
Treasurer: **Roger Sandford**
          Ph (W) 366 6264

Committee:

* Helen Bickers       Cell 027 416 7188
* Noeline Cox        Ph: (H) 338 9902
* Pam Crawford       Ph: (H) 351 3279
* Deanne Dowding     Ph: (H) 338 5622       (W) 338 3334
* Sara Ford          Ph: (H) 980 2073       Cell: 027 531 2111
* Judy Giles         Ph (H) 366 8054
* Roger Sandford     Ph (W) 366 6264
* Kathy Tuu’u        Ph (H) 351 3401

Nephrology Associates: **Dr John Irvine**
                      **Dr Nick Cross**

Field Worker/Membership: **Viv Smith**
                     Ph: (W) 379 5529