

Shoe String

Newsletter for the Dialysis and Transplant Association of Victoria Inc.



Join us to celebrate
Christmas

IN JULY

**Greyhounds Entertainment
Saturday 22nd July at 6.00pm**

- 3 course Christmas dinner with •
glass of beer or house wine
- Trivia by our Trivia Master Ken Donnelly •
• a raffle •

\$20.00 per person

RSVP by 15th July 2017

SO COME JOIN US FOR SOME FUN AND MEET OLD FRIENDS

Melways map 80 B11



JULY 2017

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Mouthwashes can help

Pier35 report

When was the last time you visited the city?

Join us at Federation Square for coffee & cake on Tuesday 22 August at 2.30pm

The venue is Beer Deluxe in The Atrium (opposite the Ian Potter Centre: NGV).

DATA pays for the coffee and you pay for the cake! (that includes tea or a drink).

Parking is available at Federation Square, but the cheapest option is to come in via public transport getting off at Flinders Street.

RSVP by 15 August 2017 by either calling the Office on 9894 0377 or emailing info@datavic.org.





Editor's note

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'Shoe String' denotes the feeling of life when it is turned up-side-down and that, with Kidney failure, Dialysis & Transplant, you sometimes have to pull yourself up by the shoe strings to get going.

The Dialysis and Transplant Association of Victoria, Incorporated, (D.A.T.A.) is a patient self help group made up of people with kidney failure and their families and friends.

Social days are held at regular intervals and the year culminates with the annual Christmas party.

2017 Special Effort Raffle



4000 tickets only at \$2.00 each

All books sold or unsold to be returned by Sunday 8 Oct 2017

Raffle drawn at AGM on Sunday 22 Oct 2017

Membership renewal

Membership renewal falls due on 1 July 2017

This year we have redesigned the DATA Membership Renewal form and you will see many of the sections are prefilled with your existing details.

The aim of prefilling the form is twofold. 1) It saves effort for our members. 2) It shows you what we have on record and gives you the opportunity to fix any errors. So please confirm all of your details are correct and if not, make any corrections on the form and send it back into DATA.

We are especially keen for you to check we have your current correct email address recorded as we head towards sending some information out to our members via email.

Please note there is a questionnaire on the other side of the renewal form and we would appreciate your effort to fill it in. It allows DATA to understand how you currently use online services.

Payment would be appreciated as soon as possible.

Anyone wishing to pay by direct deposit should contact the office for DATA's BSB and account details.

Visit our website at www.datavic.org

The President's Report

by Joan Eastwood



Sue
Hatzimichalis
0412 469738

Hello all.

Well, I have to report that Nick Hatzimichalis is currently in hospital. Unfortunately he developed gangrene in his toes, his foot became infected and though doctors tried, they were unable to get the foot to heel. He has had a below knee amputation of the left foot and leg. He is doing as well as can be expected. So our President, Sue Hatzimichalis has been busy one way and another.

We wish you well in the future Nick. Heaven knows you have had your share of bad luck and a few others' share too! So now it must be your turn for some good luck.

Sue, we hope you continue to be resilient and positive. We love and care for you both so hang in there! If we can do anything for either of you, please let us know.

Now is a good time to report on our other Committee members who are not 100%.

Hello to you out there, Christine Coleston. Christine joined our Committee in October last year and received a kidney transplant earlier this year. Unfortunately a few post-transplant problems sees her resting up at home for the next few months and taking

some time off the Committee. We wish her a safe and full recovery and hope you are able to overcome all the obstacles between you and good health.

Another member Paul Murphy, had shoulder reconstruction in February and is taking a while to spring back into action. Probably because he keeps overusing it with his guitar practice! That and other family pressures have convinced Paul to take leave of absence from Committee for a while. We will miss you Paul but I am sure you'll be back!

Mind you - there is no easy way out of being a Committee Member, so we expect to hear more of these two!

Our next outing is to Greyhound Entertainment for Xmas in July. Book early as places are limited and it's a fun night so come along and have some fun. Booking slip on page 6.

Your Committee continues to work hard for you as a DATA member - how and where best to offer financial support, how can we help those on dialysis and after transplants and what the needs are of our members.

Cheers
Joan Eastwood

*So please
make our day
and drop us a
line and tell
us what you
think.*

Have a laugh this winter



Q: What sits on the bottom of the cold Arctic Ocean and shakes?

A: A nervous wreck.

Q: What did the seal say when it swam into a concrete wall?

A: "Dam!"

Q: What did the big furry hat say to the warm woolly scarf?

A: "You hang around while I go on ahead."

Q: If you live in an igloo, what's the worst thing about global warming?

A: No privacy!

Q: What do you get from sitting on the ice too long?

A: Polaroids!

Q: Why are bad school grades like a shipwreck in the Arctic Ocean?

A: They're both below C level!

DEADLINE FOR NEXT ISSUE 14 AUGUST 2017

DATA Holiday Houses

The Rosebud & Yarrowonga holiday homes are for the use of DATA Members and their immediate family, with a Member present on all holidays booked.

Both houses can facilitate haemodialysis machines. For those members on home dialysis, please contact the House Secretary to discuss if your hospital technician can supply and install a dialysis machine in the house for your holiday.

We are sure you will appreciate that Members on haemodialysis find it very difficult to holiday, so we often prioritise them over PD and Transplant Members. But there are always vacancies so please don't hesitate to ring and check.

Friends and extended family are welcome to join the DATA Member and they must pay \$20 per person per night.

Please note, you are responsible for the

cleaning of the houses when you leave which does include bathroom w/wand toilet, so we expect the houses to be left neat and tidy for the next holiday makers and please do not leave any food.

No pets allowed with Guide dogs being the exception.



Rosebud

VACANCIES

- Vacant except for the week July 9 to July 16

It's a terrific place to holiday so take full advantage of the vacancies and book in a week or even just a weekend to get away.

Bookings at the Rosebud Hospital Renal Unit must be done online email to: holidayatrosebud@phcn.vic.gov.au

For HOUSE bookings please ring Rosebud House Secretary Amanda Pratt Ph: 9589 4894

DO NOT FORGET

If you need to dialyse at either the Rosebud or Yarrowonga Renal Units, please do the following:

- Contact the hospital to check the availability of booking a chair
- Check the vacancy dates of the Holiday House
- Then ring to book the Holiday House
- Finally, contact the hospital again to confirmation your dates and book in

Yarrowonga

VACANCIES

- July 16 to 23
- Aug 6 to 13
- Aug 13 to 20
- Aug 20 to 27
- Aug 23 to Sept 3
- Sep 3 to 10
- Sept 10 to 17
- Sept 17 to 24

But I do get vacancies so give me a ring.

Bookings at the Yarrowonga Renal Unit Ph: 5743 8189

Yarrowonga House Secretary Alan Rawson Ph: 9723 3019 Email: fayal_rawson@hotmail.com

Ken Smith

A sad story or perhaps a not so happy story



As told to Ros Ball

Ken has been on the DATA Committee so long he can't remember when he first joined. (According to ShoeString archives it was in November 1999).

About 10 years prior to this Ken's wife Fay suffered from severe diabetes, which ultimately led to her developing renal disease. It was up to Ken to help his wife with the insulin injections. When Fay required peritoneal dialysis, Ken learnt how to perform this procedure on his wife.

Meanwhile Ken was trying to but could not continue working as a truck driver, and bus driver. Caring for Fay made this very difficult for him.

Ken believes that Fay had a lot of issues with dialysis and never came to terms with it.

Their younger son offered to donate a kidney, but unfortunately at the time Fay was not well enough to go ahead with the transplant surgery. After 10 years suffering diabetes and several years suffering renal disease Fay was admitted to hospital, where she died 5 weeks later.

Ken had often tried to get Fay to be more mobile and active. He found this very difficult and frustrating and was disappointed that Fay was not able to respond to his encouragement.

Ken discovered DATA a short time after Fay died through a friend who had developed renal disease. Upon talking to a committee member, Ken started to understand more about renal disease and the depression that can overtake people. He also became aware that people with renal disease may not look ill. Ken was motivated to learn more about the illness to help support his friend with dialysis, who has since had a successful transplant.

Joining the DATA Committee Ken quickly found a roll in being Santa Clause at the DATA Christmas Parties,

giving out gifts and lollies. This was a role he really enjoys and over the years many photos were taken of children sitting on Santa's knee.

Currently, Ken visits Dialysis Units in his area to promote DATA and distribute copies of ShoeString. If he visits your Unit, do say hello!

Note: Renal disease is often referred to as the silent killer, because symptoms are so vague.

This is not a happy story with a happy ending and is a reminder renal disease can be overwhelming.

If you require help adjusting to renal disease ask your doctor for a referral to a psychologist.

There is no shame in having difficulty coping.

OR ring

LIFELINE 13 11 14

BEYOND BLUE 13 1300 224

DonateLife Annual Service of Remembrance

The Service of Remembrance was held on May 28th 2017 at the Collingwood Town Hall. The building was beautiful and majestic. The change of venue was because of maintenance works being carried out at RMIT. The Collingwood Station was very close making it easy for those using public transport to get there.

The Service was organised by Donate Life, Victoria following in the same format as previous year with two Transplantees and two donor families talking about their journey. Obviously it is not only kidneys but heart, liver, lung and cornea transplants that are

represented. This year we heard from the mother of a child who received a liver transplant at 3 years of age. We next heard from a cornea transplant recipient and her struggles before she had her transplant.

It is always a very sad story when it comes to Donor families and this year was no exception. One donor family represented by the sister felt very strongly that her family would feel much peace of mind knowing that the donor had at last contributed to a world in which she had required so much care. The last speaker spoke of the discussion in the family around

the dinner table as to the possibility of organ donation. This proved to be very beneficial knowing her son's wishes when several years later she had to make that decision. Then not once but twice she was confronted by the same question, when her husband suffered a brain haemorrhage. She was able to say yes to organ donation, knowing that these were their wishes.

The day ended with afternoon tea and much chatter.

Joan Eastwood

Christmas in July 2017



Name _____ Mobile /Phone _____

Number attending @ \$20 per person _____ Any dietary requirements _____

TOTAL \$

I enclose my Cheque / Money Order (circle one) made payable to DATA Inc.

No cash through the Post thank you.

I wish to pay by Credit Card: VISA MASTERCARD

Card number:

Expiry date: Card Verification Code:

Amount: _____ Date: _____

Cardholders Name: _____

Signature: _____

RSVP by 15 JULY 2017 by either:

Mailing to: The Treasurer DATA, PO BOX 159, Forest Hills 3131 | or calling the DATA Office on 03 9894 0377

Office Use Only

Date Rec: __ / __ / __ Receipt No: _____ Date Banked/C. Card __ / __ / __ Date M'ship updated __ / __ / __



Mouthwashes can relieve upper GI symptoms in CKD patients (bad taste)

In a study, 66% of patients found sodium bicarbonate beneficial, with 40% preferring it to other mouth rinses.

A novel and inexpensive way for chronic kidney disease patients to relieve their upper gastrointestinal symptoms without medication is to rinse with mouthwashes that dilute saliva and/or displace bitter-tasting compounds, such as urea, a new study finds.

Karen J. Manley, MSc, a renal dietitian from Austin Health in Victoria Australia, tested 4 mouthwashes in random order on 42 pre-dialysis patients with stage 4-5 CKD from an outpatient renal clinic. The rinses included sodium bicarbonate salt citric acid and de-ionized water, each in a 500 mL solution.

Patients had complained of more than 1 of the following symptoms: poor appetite, nausea, lack of taste,

vomiting, and dry mouth. All patients reported poor appetite, most noted taste changes, and half complained of nausea and dry retching.

Saliva testing confirmed increased concentrations of urea, potassium, and bicarbonate and higher pH levels. Investigators also assessed patients for individual genetic sensitivities to bitter and other tastes (e.g., salty, sour, sweet) and classified patients as non-tasters, tasters, or hyper-tasters.

"Water mouth rinses generally improved all symptoms including dry mouth, taste changes, nausea, and dry retching, while sodium bicarbonate was found to be more effective in improving taste changes, nausea, and dry retching," Manley told Renal & Urology News. "The salt solution was beneficial in improving nausea and dry retching.

Citric acid improved dry mouth and taste changes, but some patients found it increased nausea and dry retching."

Most patients (66%) found sodium bicarbonate beneficial, with 40% preferring it to the other mouth rinses, according to results published online ahead of print in *Nephrology*. Manley explained that sodium bicarbonate cleanses receptors on taste buds and may favourably alter mouth pH. The mouth rinses also may be beneficial for chemotherapy and pregnancy patients.

DATA assisted Karen in carrying out this research by giving her a grant

www.renalandurologynews.com/chronic-kidney-disease-ckd/section/625/

Ros Ball

Lunch at Pier 35

We are supposed to have regular meetings at Altona DATA once a month. However once we held a couple of these meetings and got to know one another, it was time to do something different. Thanks to Alan Thompson we did have something different; we played bowls. After that event I was reluctant to invite people for a meeting.

We were fortunate that Hobsons Bay City Council had given us a grant and so it was not difficult to spend some money. Pier35 offers inexpensive

lunches seven days a week as well as a magnificent view of the Yarra, the start of the Maribyrnong River and the West Gate Bridge. We were also pleased to see a couple huge cargo ships glide past us going upstream.

Now you would think the Altona Branch would have enjoyed lunch together with a couple of guests. Not so. The DATA committee (the eastern suburbs one) decided to join us and share the cost with the Altona Branch. This resulted in an offer of a free lunch for all members.

The result was a magnificent day for around thirty DATA members, carers and guests.

What a day! I know that it was enjoyed by all, 'cos no one complained, and most had complimented the organisers by word of mouth and by email.

The problem now remains how do we top this one for our next get together. I think deep thought and a few prayers are urgently required.

George Said



Dates to remember



Christmas in July

22 July - see front page & page 6

Coffee & cake at Federation Square

22 August - see front page

Fish & chips at Station Pier

Saturday to be set in September - TBA

AGM

22 October 2017

Check the DATA website for updates to our list of activities.

Some web pages of interest

www.homedialysis.org/news-and-research/blog

www.nwkidney.org

www.peninsulahealth.org.au/

www.worldkidneyday.org

www.cari.org.au

www.australiandialysisbuddies.org

www.greendialysis.org

www.transplantaustralia.org.au

www.homedialysis.org/news-and-research/blog

www.bigdandme.wordpress.com

Our thanks to all who contributed to this edition

Why not spread the word and pass this copy on?

Shoe String is always looking for stories to publish. If you have a story to tell and you're not sure where to begin, our Editors would be more than happy to assist you in writing your article.

Or if you have any ideas of issues you would like to see covered, contact us.

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The views expressed in the editorial and the contributed items, are those of the authors and are not necessary the opinions of D.A.T.A. Inc.

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