

Shoe String

Newsletter for the Dialysis and Transplant Association of Victoria Inc.



Subsidised
Accommodation
for Country
Members



The Ron
Jones
Educational
Awards

Autumn Picnic
at Caribbean
Gardens &
Market



JANUARY 2017

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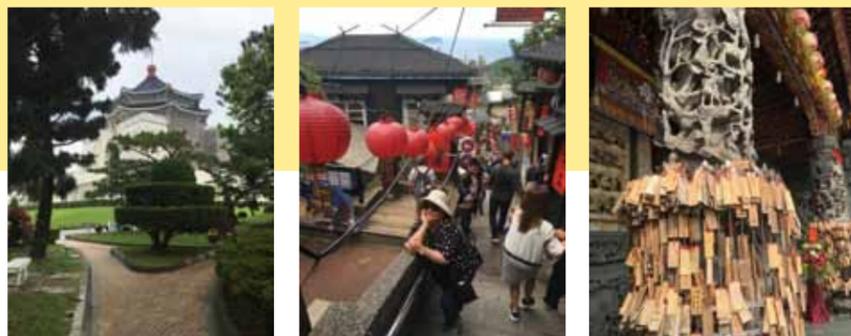
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Editor's note



Travelling after a Transplant

Hello readers,

I recently travelled to Taiwan and Hong Kong and wanted to share my fabulous holiday with you to highlight that you can travel after a transplant and not be put off by our multiple medications, packing, customs and travel insurance and...

I love travelling overseas and I hadn't had an international holiday for over 10 years due to kidney failure and then years of dialysis. I couldn't wait to walk through those double sliding doors at Tullamarine, get a stamp in my passport and start my adventure in a foreign land! The whole idea of a different country, different smells, tastes, sights and experiences - what a buzz!

10 days in Taiwan and 4 days in Hong Kong were amazing. I shopped online for great flights and super deals on accommodation and you can really save. Yes it takes some planning, but not ridiculous amounts and it's worth it.

Here are some tips:

- Check with the country's embassy before you travel, regarding what meds you can and can't take
- Definitely get a letter from your Renal Consultant explaining your medical condition/s and the meds you are taking
- Take 2 sets of your daily tablets as weekly doses (I use those plastic weekly tablets packs - perfect for this). One for your carry-on bag and the second in your suitcase, so just in case either piece of luggage goes missing in transit
- Take all of your transplant meds in their packs as well - advised by 'Aus Gov Smart Traveller' but you can limit the number of blister sheets
- Take extra of your anti-rejection meds - these are the 'really' important ones that cannot be missed, but trust me when I say, they can be sent via express international courier to your hotel in 2 days - what a relief!
- Be prepared in advance that your travel insurance is going to be a lot more due to our health, and budget for it. I was very happy with 'Insureandgo' but you have to speak with them on the phone as well to explain your health circumstances. Check them out here: www.insureandgo.com.au
- Register your travel plans with Smart Traveller- www.smarttraveller.gov.au
- In hot places, rest up in the heat of the day - I always went back to my hotel around 2-3pm for a rest and even a nap!
- DRINK DRINK DRINK bottled water
- And have a super dooper fantastic holiday - that's a MUST!!!

Trudy Robson

Visit our website at www.datavic.org

The President's Report



Sue Hatzimichalis
0412 469738

Hi Everyone,

I hope you all had a Merry Xmas & a Happy New Year! How is everyone coping with the heat? Like me? Not too well and I'm not even on dialysis!

Nick & I have just come back from Sydney where we spent NYE on a barge right in front of the harbour bridge with fantastic views of the fireworks with all their magnificent colours as they burst into spirals. Oh what a way to bring in 2017!

Nick did dialysis at RPA (Royal Prince Alfred) in Sydney, and they have a wonderful NUM Kim, who keeps one of the chairs available for 'holiday' patients. They have a unit of 33 chairs but you must book early as they do get booked out really quickly. I booked Nick's chair in May 2016.

Well, just a little bit about what I have been up too since I last wrote one of these reports. Nick at this stage is very stable with his last hospital visit being in September 2015 for Influenza B (that year was the only year they didn't cover all the strains, just his luck - and B was one of them). He was in ICU for 5 days and then home - one of his shorter hospital visits to say the least!

I went back and studied Clinical Hypnotherapy and other natural therapies so I can help people to 'stop smoking' & 'lose weight' amongst other things. I now run a very small but busy therapy room in Sydney Road, Brunswick and I love it.

I'm excited to be back in the seat as DATA President again and I am very dedicated & enthusiastic to getting lots of projects up and running for DATA, like I use to do. Offering support to anyone on the committee that comes up with brilliant ideas is paramount...and we strongly encourage ideas from our Members like you, so please read the article called Revitalising DATA from Ros asking you to think about what you want from your DATA.

You can either ring the office or write down your ideas and post them or drop us an email at info@datavic.org with your suggestions and we will take them to the committee and let you know the outcome... so in the words of Captain Picard on Star Trek - "we'll make it so No 1" (if we can).

We are thrilled to announce that applications are now open for the Ron Jones Educational Awards 2017, see page 6 for the application form and more details. What a wonderful award for young students.

Our Autumn picnic is shaping up to be a really great day at Caribbean Gardens and Market on 26 March. I have been there before and had a fanatstic day, so I'm sure you will enjoy the venue and it's variety of activities.

Great news, as a registered charity with the ACNC - Australian Charities and Not-for-profits Commission, DATA can now proudly display this logo.



Finally, we are offering our Members accommodation assistance when anyone needs to travel more than 100kms for medical treatment. You will find that story on page 5.

Cheers Sue

I am a little kilo, I am deep within your veins. They try to remove me, but I soon come back again.

I am a little fluid, "one Kilo" is my name. And when I come in on you, it really is a shame.

I am a little kilo, and when I say bye-bye. The cramps that I do leave you would make a grown man cry.

I am a little kilo, my friends are Two and Three and if you go above them, murder it will be.

I live in cans and bottles and please be of no doubt, that when I get inside you, it's hard to get me out.

I am a little kilo, my story is now told. So do not put me on you, for I really am a load!

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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.

DEADLINE FOR NEXT ISSUE 10 MARCH 2017

Perfect holiday destinations



Rosebud

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.

Please note, as transplant and PD patients have more freedom and options to travel, priority is given to those Members on haemodialysis as

this is often the only way they can get a holiday.

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 and 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

Rosebud

We do get cancellations so please ring to check.

We have replaced the broken dvd player and installed new laser light on the roof in the bbq area, so it will no longer leak.

In the next few months, some trees will be cut back from the house and I will be getting quotes for new curtains/blinds in the house.

I recently found a broken outdoor chair on inspection of the house. We realise that accidents happen, so please ring me to report any damages.



Yarrowonga



Yarrowonga

Yarrowonga

Weather is perfect at Yarrowonga this time of year, so give me a ring to book a holiday.

You will need to book early if you are wanting to dialyse at the Yarrowonga Renal unit. Do not leave it until you are about to go to Yarrowonga Ring the hospital book in and ring me to confirm.

Thanks again to the Techs at Monash, who took Dialysis machines up during the holidays to Yarrowonga for members on home dialysis from Monash, Box Hill, Alfred and St. Vincents hospitals. Very much appreciated. Also thanks to the Austin.



Yarrowonga

VACANCIES

Vacancies

First week available from

• April 23

Taking bookings up to June 2017.

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

VACANCIES

• Feb 12 to Feb 19

• Feb 26 to Mar 5

• Mar 19 to Mar 26

• Jun 18 to Jun 25

• Jun 25 to Jul 2

Bookings at the Yarrowonga Renal Unit Ph: 5743 8189

Yarrowonga House Secretary Alan Rawson Ph: 9723 3019

Email: fayal_rawson@hotmail.com

What do you do when the Doctors say 'You must come to hospital for treatment or you need to come in every day for blood tests and you live a long way away?'

We used to be able to book into Blackburn for a night, a week or a fortnight, but circumstances have changed and we are no longer able to offer that solution. The Committee understand your feeling of frustration, and we are trying to remedy this.

DID YOU KNOW that you (DATA Members) can apply to DATA for assistance with your accommodation

Subsidised Accommodation for Country Members

costs when you have to travel over 100Km for medical treatment and have to stay overnight (conditions apply). When you have established the date of your next hospital visit contact the DATA Office and request an application form. You will be notified of DATA's decision as soon as your request has been processed.

Other avenues of support are VPTAS (Victorian Patient Transport Assistance Scheme). Just put VPTAS in your search engine and there it is. You can apply to VPTAS as well as DATA.

There is a website called www.hospitalsaccommodation.com you can use to assist you to find the most appropriate accommodation near to your hospital.

Autumn Picnic at Caribbean Gardens & Market



Keep 19 March 2017 free for DATA's Autumn Picnic at Caribbean Gardens & Market. This exciting venue has something for everyone!

For the kids there is mini golf, train rides, jungle cruises, beach buggies, army tanks, a chairlift and more! You can also peruse the Market where there's over 1,000 undercover stalls with a great variety of products.

And then there is Lake Caribbean and the beautiful gardens to enjoy a relaxing afternoon in while sharing the company of other DATA Members.

We plan to kick off the afternoon at 12 noon but you can arrive at any time to start your day of fun.

DATA has booked Gazebo D, so just bring some lunch, a chair and your enthusiasm and we'll have a fabulous day.

There is plenty of free parking onsite and DATA will assist with funding some of the days' activities.

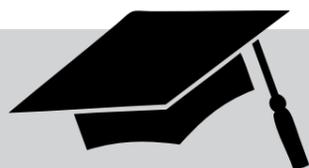
Please ring the DATA Office for more details.

We'd love to see you there.

**1280 Ferntree Gully Road, Scoresby.
Tel: (03) 9756 5000.
www.caribbeangardens.com.au**



Ron Jones Educational Awards



These awards offer a fantastic opportunity for students between years 7 to 11, to shine.

Applications for the The Ron Jones Educational Awards, are now open, so fill out your Application form below for a chance to win fabulous prize money.

Assessment is based on the Applicant's school reports together with essay on the topic of 'My Chosen Career'.

There are two levels of Awards to be won. One Award is based on excellence and scholastic ability and three Awards for encouragement.

The Ron Jones Educational Awards honour the memory of a founder and long time dedicated worker for DATA, Mr Ronald N Jones, AOM.

- Applications must include a handwritten essay of 300 words entitled 'MY CHOSEN CAREER'.
- Please include the Applicant's previous year's school reports.
- Applications must be received no later than the **30 June 2017**. Winners will receive awards at the AGM in October 2017.
- Please fill in this form using Block Letters.

RON JONES EDUCATIONAL AWARDS APPLICATION FORM

Please complete this form and forward it to:

The Secretary, D.A.T.A. Vic Inc. PO Box 159, FOREST HILL 3131

STUDENT'S DETAILS

SURNAME _____ GIVEN NAMES _____

ADDRESS _____

POST CODE _____

DATE OF BIRTH _____

HOME PHONE _____ MOBILE _____

PRESENT YEAR OF SCHOOL _____

SUBJECTS STUDIED _____

PARENTS / MEMBERS DETAILS (if Applicant Member is under 18 or a child of a Member)

Financial Member of DATA?

YES NO

SURNAME _____ GIVEN NAMES _____

ADDRESS or same as Student _____

POST CODE _____

HOME PHONE _____ MOBILE _____

SIGNATURE OF STUDENT _____

SIGNATURE OF PARENT _____

My essay on "MY CHOSEN CAREER" and last years school reports are enclosed.

YES NO

That Dreaded Itch

Being told not to scratch is no advice on how to cope with itching!

It is generally believed that high phosphate levels causes itchiness, but there could be other causes as well.

Ureamic toxins can build up and irritate the nerve endings in the skin.

Uncontrolled balance of calcium and phosphate may result in crystals being deposited into the skin.

Magnesium can also build up and deposit crystals into the skin.

Heat will aggravate the skin.

What you can try and do

- Take your prescribed phosphate binders with meals
- Try to stay out of the hot weather and away from heaters
- Use a moisturising cream on dry, irritated skin
- Use a soap containing a moisturiser, or try showering without soap
- Use soap made for sensitive skin
- Wear breathable clothing and use cotton bed sheets to avoid sweat accumulation
- Avoid using washing detergent with enzymes.
- Consider using oatmeal bath products.

Itchy Cream Recipe (provided by the Ballarat Unit many years ago)

Give this recipe to your pharmacist.

0.5% phenol

0.5% menthol

0.5% Olive Oil

Make up in a Sorbolene base and use as required.

Please let us know how well this cream works.

Altona Branch of DATA Vic

Dear friend,

We hope you have had a happy time during Christmas and we wish you a happy new year.

There are approximately ten individuals who have expressed interest in the creation of an Altona Branch of DATA Vic.

We are VERY happy to announce that the first meeting has been organised and hope to see you, your partners/carers at the meeting.

Here are the details:

Date: Saturday 4 February

Time: 2.00 to 4.00 in the afternoon

Place: Louis Joel Arts & Community Centre, Cnr of Sargood & Queen Sts Altona vic 3018

Refreshments will be served and we look forward to meeting you at this informal meeting.

George Said george3018@gmail.com

Convenor 03 9398 2921

We need your help to REVITALISE DATA in 2017

In the mix of services offered by DATA, the holiday homes are well utilised, the newsletter is popular and our accommodation support program for country members is getting off the ground.

As we start 2017, the Committee is looking for more ways in which DATA can provide further practical help and support for those suffering renal disease.

Some suggestions that have been put forward include, donate equipment, such as blanket warmers or televisions to renal units, start a subsidised holiday program for dialysis patients and organise group holidays.

We would love to hear what you, the Members, feel is important. So if you have any ideas put them in a letter, send us an email to info@datavic.org or ring us on (03) 9894 0377.

Ros Ball



The DATA Trophy is awarded

Winners at the Transplant Games in 2016

On the left: The 2016 DATA Award for the Transplant Games was awarded to Nigel Goldsworthy.

Nigel had a kidney transplant in 1974! The DATA Award is presented to a member of the Victorian team who is

on Dialysis or a Transplant recipient who demonstrates outstanding sportsmanship.

Nigel is pictured with the Transplant Australia Vic/Tas Chairperson, Roxanne Kavanagh.

On the right: GOLD GOLD GOLD! 3 winners at the Darts competition. From left: Mary (liver), Fiona (kidney), Karen (kidney).

The "Thank You" shirt is dedicated to Donor families & living donors.



Stay Cool when it's Hot

Heat in summer, can be a challenge when you're on a restricted fluid diet. You may feel especially thirsty on a warm day, but you have to be careful about the amount you drink. Health complications can occur from drinking too much.

The extra fluid that builds up in your body between dialysis treatments can cause swelling which can increase your blood pressure and strain your heart. It can also collect in your lungs making you breathless and cause strokes.

- Use ice blocks in your drinks and treats like icy poles.

- Sip beverage's slowly allowing you to savour the drink longer.
- Swallow your tablets with an allocated drink.
- Suck on jubes to help quench your thirst, or chew chewing gum.
- Try freezing berries and grapes for a cold refreshing snack.
- Remember to keep your salt intake

low, because salt will increase your thirst.

- Keep out of the heat.
- If you initially fail don't admonish yourself, but just try to get back on track.

With thanks to the Kidney Centre Seattle newsletter.



Have a laugh



Father William

"You are old, father William," the young man said,
 "And your hair has become very white;
 And yet you incessantly stand on your head —
 Do you think, at your age, it is right?"

"In my youth," father William replied to his son,
 "I feared it would injure the brain;
 But now that I'm perfectly sure I have none,
 Why, I do it again and again."

"You are old," said the youth, "as I mentioned before,
 And have grown most uncommonly fat;
 Yet you turned a back-somersault in at the door —
 Pray, what is the reason of that?"

"In my youth," said the sage, as he shook his grey locks,
 "I kept all my limbs very supple
 By the use of this ointment — one shilling the box —
 Allow me to sell you a couple."

"You are old," said the youth, "and your jaws are too weak
 For anything tougher than suet;
 Yet you finished the goose, with the bones and the beak —
 Pray, how did you manage to do it?"

"In my youth," said his father, "I took to the law,
 And argued each case with my wife;
 And the muscular strength, which it gave to my jaw,
 Has lasted the rest of my life."

"You are old," said the youth; one would hardly suppose
 That your eye was as steady as ever;
 Yet you balanced an eel on the end of your nose —
 What made you so awfully clever?"

"I have answered three questions, and that is enough,"
 Said his father; "don't give yourself airs!
 Do you think I can listen all day to such stuff?
 Be off, or I'll kick you down stairs!"

My husband was waterskiing when he fell into the river.

As the boat circled to pick him up, he noticed a hunter sitting in a duck boat in the reeds. My husband put his hands in the air and joked, "Don't shoot!"

The hunter responded, "Don't quack."

When asked for his name by the coffee shop clerk, my brother-in-law answered, "Marc, with a C." Minutes later, he was handed his coffee with his name written on the side: Cark.

A woman called our airline customer-service desk asking if she could take her dog on board.

"Sure," I said, "as long as you provide your own kennel." I further explained that the kennel needed to be large enough for the dog to stand up, sit down, turn around, and roll over.

The customer was flummoxed:

"I'll never be able to teach him all of that by tomorrow!"

After an impromptu song, our pastor asked the church pianist, "What key did I sing that in?"

The pianist replied, "Most of them."

The Editorial Committee would like to apologise if we offended you with our choice of jokes.

Our aim is merely to add a bit of light-heartedness in a glum world and we do not intend to offend. We will endeavour to be more selective in the future.

The Big Red Kidney Bus holiday memories

Dear Ros,

In February I had the pleasure of holidaying at Anglesea on this beautiful bus.

I was diagnosed in 1994 with CKD and lasted until 2004 before I had to go on to Peritoneal Dialysis. During that time we were able to travel all over Aust. Across the Nullarbor and as far North as Cairns. We have flown to the King Island and all that time our product was sent ahead where we could pick it up and continue on our way. Many times our product was sent into caravan parks where were parked.

This all ended when we had to go to Haemodialysis. Trying to find available chairs up the coast was near impossible. The first two years we managed to get into public hospitals and annexes. The following year we wanted to go to Sth West Rocks up near Coff's Harbour. Getting there was the hard part, instead of driving a few 100 kms we had to do over 700kms a day as there were no chairs available along the coast. We did manage one chair at Yarrowonga, the one that is used for the holiday house. They were just beautiful and it made our trip a little easier. We could at least have another day or two to get to Port Macquarie.

But then I read about the Big Red Kidney Bus and booked for Anglesea. What a delight, all I had to do was book the caravan park instead of spending hours on the phone trying to find a chair.

The holiday was fabulous, we had four other couples follow us and it was as if we had a normal holiday with friends. I had not been swimming in summer for many years as we live in the country and it is a three hour drive to the ocean.

This bus has given us the freedom and flexibility to go wherever it goes. I thank Kidney Health Aust every day as they were paramount in getting this bus up and running and are promoting another one in West Aust. My daughter lives there and if it comes off we will fly over to Perth to visit. What a great thing to be able to say.

To all of you out there who have not thought you could holiday. Throw off your shackles and take advantage of this bus. The girls are beautiful and full of fun, and you get 1.1/2 days of holiday without worry.

Helen M Williams



DATA CHRISTMAS PICNIC 2016

The annual DATA Christmas picnic was held on Saturday 3rd December at Halliday Park, Mitcham. It was very busy in the park.

The weather was perfect for a picnic, sunny and warm. Although it was a small gathering, everyone enjoyed themselves and it was a lovely relaxing afternoon.

There was plenty of Joan Eastwood's slices to share. This year Joan made a caramel as well as lemon slice. The small meringues with the option of cream and strawberries, were just beautiful and very popular. Lion's Christmas cake was cut into slices and shared with a fruit platter being the healthy option! Tea and coffee didn't go astray either.

The Christmas Party raffle had four prizes:

- Eleanor Allan won the hamper
- Vicki Abbatangelo won the Himalayan lamp
- Angela Lindsey won the iced Christmas cake
- Sue Hatzimichalis won the angel statue.

Winning a raffle prize anytime is great, but it's even better at Christmas time.

We hope to see you all at the next Christmas Party.

Angela Lindsey



Carer's Group

Are you caring for someone who is on dialysis or has had or needs a transplant? Life can be challenging for those who care for someone ill.

Sometimes it can help to talk to others who are also carers to share experiences and let off a little steam.

Transplant Australia runs a Carer's Group where people can come along and chat together. Meetings are held approx. every 6 weeks and there is no

cost to attend, and you do not have to be a member of Transplant Australia. Generally a Counsellor is present if anyone requires a private chat.

Meetings are held at the Yarraville Footscray Bowling Club, 339A Francis Street, Yarraville.

If you wish to be added to the contact list, please contact Karen Knuckey nuckster@ncable.net.au. Emails are only sent regarding dates for meetings.

Any enquiries contact Karen on 0423 021 984.

Dates to remember



Autumn Picnic at Caribbean Gardens & Market

March 19, 2017

Some web pages of interest

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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