

# Shoe String

Newsletter for the Dialysis and Transplant Association of Victoria Inc.



**SEPTEMBER 2017**

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Trip of a lifetime

AGM

Human Services  
Support

Organ donation  
'Opt-out'





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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.

# Editor's note

The screenshot shows the Home Dialysis Central website. At the top, there is a search bar and a navigation menu with links: Home Dialysis Basics, Life@Home, Find a Clinic, Get Answers, News & Research, Professional Tools, and About Us. Below the navigation is a large blue banner with the word 'NEWS' in white. Underneath the banner is a section titled 'News Articles' with two columns of article previews. The first column includes articles like 'Kidney Health Initiative Involves Consumers' and 'In The Ides Of March: National Kidney Month And World Kidney Day'. The second column includes 'Will Home Be Where The Telehealth Is?' and 'Home HD Comes To Grafton, WV'. To the right of the news articles is a sidebar with a survey link 'Help us make better tools for YOU!', an 'Events' section, a 'Journal Watch' section, a 'News Articles' section, and a 'Newsletter' section.

## HOME DIALYSIS CENTRAL

- An American based site

**For anyone on dialysis, this is a fantastic and invaluable website to read and learn. One of the contributing editors is Dr. John Agar from Barwon Health Geelong.**

“At MEI, our passion is helping people with kidney disease live as well as they can. That means knowing as much as you can about your disease. And, it means taking an active role in your treatment. Home dialysis is the only type of dialysis where you HAVE to get training to learn how to care for yourself. That’s one reason we focus on it. The other is that more dialysis is more like having healthy kidneys.

People who dialyze at home tend to feel a lot better—and live longer. Many people don’t know that some of the first Americans who began dialysis in the mid-1960s are still alive today! For these pioneers, home treatment was the only treatment option.

At MEI, we believe home dialysis is good for you. It’s also good for providers and payers—and can even help ease the nursing shortage. It will take a long-term, focused effort to help everyone with kidney disease get access to home treatments.”

[www.homedialysis.org/](http://www.homedialysis.org/)

Take a look, cheers Trudy

**Visit our website at [www.datavic.org](http://www.datavic.org)**

# The President's Report



**Sue  
Hatzimichalis**  
**0412 469738**

Hi Everyone

Hope this finds you all well and keeping warm. As I am writing this it's only a couple of weeks left before winter is over (yeah!) and we start having some warmer weather!

As you may have read in the last SS, Nick was in hospital. Well he is still there but in rehab at Caulfield. He is in doing well but it will be a little while before he comes home as we need to do renovations to the bathroom so it is safe for him.

Thank you to all of you who have sent your subscriptions and raffles ticket books back. We really appreciate it and good luck in the raffle which will be drawn at the AGM on Sunday 22nd October, at Manchester Unity Hall starting at 2:00pm - see more details on page 9.

We had our annual "Xmas in July" dinner & trivia night on Saturday 22 July. Thanks to everyone who came and Ken & Kim Donnelly for all their hard work on the trivia but after 16 questions (of which I only knew 2 answers!) we unfortunately had to give up as it was too hard to hear Ken. See the full story and photos on pages 10 & 11.

Our next outing is going to be at D'Lish Fish in Port Melbourne on Saturday 23rd September. Fantastic seafood bayside at Station Pier. DATA will subsidise \$7.00 per person on the day. Everyone welcome. More details on page 7.

Anyway until next time, keep well, keep warm and stay happy!

**Sue Hatzimichalis**

*"good luck in the raffle which will be drawn at the AGM on Sunday 22nd October"*

## Tech Savvy Seniors

A Tech Savvy Seniors program has been developed by Telstra in partnership with the Victorian, NSW and Queensland Governments to give older people the opportunity to develop the skills and confidence to use technology for socialising, accessing important services or conducting personal business.

The program includes a number of self-teach videos covering topics such as; Mobile Phones, Home computers and Networks, The Internet, Social Networks & e-readers and Tablets. These videos can be viewed on-line or are available (on DVD) for hire from a number of libraries across Victoria.

As a service to members, DATA is offering to run group viewings of the videos at its Forest Hill office. If you are

interested in attending, call the office on 9894 0377 and leave your name and phone number.

### **Other training options include:**

**Broadband for Seniors.** Broadband for Seniors (BFS) helps older Australians get the skills they need to use computers and access the Internet. With BFS kiosks located all around Australia you can learn how to use a computer and surf the Internet free of charge.

Go to **[www.bfseniors.com.au](http://www.bfseniors.com.au)** to search for a kiosk near you. Alternatively call the BFS on 1300 795 897 to find out more.

Go-Digi. Infoxchange and Australia Post have joined together to create Go Digi. Go Digi is a national four year



digital literacy program with the goal of supporting Australians to improve their digital skills. To find out more visit **[www.godigi.org.au](http://www.godigi.org.au)**.

Australian Seniors Computer Clubs Association. ASCCA is the national peak body for seniors and technology. It supports computer clubs for seniors across Australia. To find out more about the locations of these clubs visit [www.ascca.org.au](http://www.ascca.org.au).

**DEADLINE FOR NEXT ISSUE 16 OCTOBER 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 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

### VACANCIES

- Aug 20 to 27
- Sept 3 to 10
- Sept 10 to 17
- Oct 8 onwards

Please ring NOW for November, December and January.

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](mailto: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

- Sept 10 to 17
- Sept 17 to 24
- Nov 12 to 19
- Nov 19 to 26
- Nov 26 to Dec 3
- Dec 3 to 10
- Dec 17 to 24

Why not enjoy a holiday in a great part of Australia metres away from Lake Mulwala. Cost is only \$180 per week for you and your immediate family. Call as I do get vacancies.

*Bookings at the Yarrowonga Renal Unit Ph: 5743 8189*

*Yarrowonga House Secretary Alan Rawson Ph: 9723 3019 Email: [fayal\\_rawson@hotmail.com](mailto:fayal_rawson@hotmail.com)*

# Trip of a lifetime

My name is Sandra Bell. For the past 11 1/2 years I have been on a haemodialysis program with Monash Hospital. This has included a mixture of nocturnal (at home) and then satellite haemodialysis.

One of my passions has always been travel which I have still managed to include in my schedules with haemodialysis. So when my son Paul asked me if I would like to go to England with him in September 2016, I jumped at this wonderful opportunity and of course said yes.

I had lived in England for 20 years and have not been back for 29 years. The dream to return had been with me for many years so how could I refuse such a wonderful opportunity.

The thought of organising the dialysis to England from here to me was daunting at first. However through a Kidney Health website I was able to find this company in England called 'Freedom Dialysis' which is based in Leicester. They were able to assist me in booking dialysis as a holiday patient. There were many emails to organize everything and in the end all the clinics I wanted were organised by them to the last detail. The clinics I attended were Hampstead London (Royal Free) and the Royal Berkshire in Reading.

Once these were organised I felt more confident in travelling to England. This of course involved Moorabbin Hospital too as they needed to do a lot of paper work on my behalf.

I was to be a holiday patient in these clinics. The staff at the clinics I attended were very professional and caring.

Apart from dialysis, my time in London was spent with friends and as well I explored some of my favourite places. These included the London Eye, Westminster, Camden market and Hampstead Heath. I also walked in areas in Hampstead where I had pushed the pram with my children all those years ago. It was a real memory trip.

We flew with Qatar airlines which was very comfortable especially as I was able to travel in business class and worth every penny!! My son Paul flew economy. Paul had organised wheelchairs for me so going through customs at Heathrow was a breeze.

For the two weeks that I was in England the weather was perfect. As there wasn't time to visit all my friends so I organised a reunion lunch at my favourite pub 'Angel on the Bridge' at Henley on Thames for 30 of my old friends who were able to come. It was a truly wonderful day and I didn't want it to end.

This trip was something I often dreamed about but never thought it would eventuate.

I would recommend the agency that did the organising for my dialysis and stay in England. They were excellent. There was a small fee required for their work. It was 70 pounds sterling.



Me (Sandra) and my son Paul on 'The Eye' (The London Eye)



Me (Sandra) and grandson Oliver at party at Henley-On-Thames

Of course, I especially thank my son Paul for initiating this trip and being so supportive to me at all times.

**Sandra Bell**

For more information go to:  
[www.holidaydialysis.co.uk](http://www.holidaydialysis.co.uk)

## Editors note...

Readers of SS may remember some time ago Sandra wrote an article for SS "It's alright to be on Dialysis" That article is now included in the information packs we send to our new members, if you would like a copy please ring the office and leave a message on the phone - 9894 0377.

*When travelling overseas some countries in Europe have reciprocal healthcare rights with Australia. For Sandra to use this in England, she just needed to prove she was a permanent Australian resident, by producing her Medicare card.*

*For more information on which countries have reciprocal rights with Australia see the Kidney Health Australia website (scroll down) or ask*

*your dialysis nurse to help you.*

*It is also strongly advisable to carry a doctor's letter with you in case customs make enquiries.*

*Travel Insurance. For further information look at the Kidney Health website under Travel or the site Sandra mentioned, Freedom Dialysis.*

*Happy Travelling, we hope to receive more stories from our members about travelling in Australia or overseas.*

## Did you know Bali has a holiday dialysis unit?

**The unit is in Nusa Dua and follows the same stringent infection prevention and quality control protocols as dialysis units in Australia. DATA member Greg Collette dialysed at the unit and has provided a detailed story. Read his report at <https://bigdandme.blog/?s=bali>.**



***'D'lish fish a family run fish and chip shop, offering some of the finest seafood in Melbourne'***

# Lunch at D'Lish Fish Saturday 23, September

Come along to our informal lunch at 12.00pm at D'Lish Fish in Port Melbourne on Saturday 23rd. It's Station Pier, Port Melbourne.

All DATA members are welcome. As we cannot book, it is suggested to order by phone before arrival. The menu is available on their website and I am happy to take down all your orders if you leave a message on the DATA office phone, so the wait won't be as long.

Can I please get your rsvp and order by Friday 22nd September, by contacting the office on 9894 0377 & leaving a clear and concise message, even repeating your

message, as our answering machine, like a lot of others, loses a bit of clarity.

People can have a walk around Station Pier, Princes Pier & around the beach. If they haven't been for a while it's nice to visit.

There is parking at a cost and tram 109 run is very close (approx. 30 metres) to D'lish Fish.

*Angela Lindsey*

<http://www.dlishfish.com.au>

**3/105 Beach St  
Port Melbourne VIC 3207  
Phone Orders : (03) 9646 0660**

## Organ donation 'opt-out' petition led by teenager who received two kidney transplants

*By James Hancock, ABC News, August 3, 2017*

Louie Hehir once missed out on simple things most children take for granted like sleepovers and swimming.

The 17-year-old from Geelong was born with kidney problems and received his first transplant at the age of five - but a few years later his body rejected the organ.

That meant he had to spend four years undergoing dialysis treatment, where a machine performs the role of the kidneys in cleaning his blood, before successfully receiving a second transplant.

Louie could not easily go on sleepovers because he needed to be hooked up to a dialysis machine at night.

Swimming would get the tubing in his stomach wet.

"I wouldn't wish that on my worst enemy, I felt alone during that time," he said.

"I can now go to school, go to sleepovers and that's meant I have this freedom that I didn't have before."

His friend Ryan Lambley, 14, was also born with renal failure and is connected to a dialysis machine three times a week for four hours.

The Royal Children's Hospital in Melbourne said it always had between 15 and 20 patients undergoing dialysis and a shortage of organ donors meant they faced a long wait for a transplant.

But Louie is passionate about speeding up the process and is heading to Canberra next week armed with a petition in support of an "opt-out" system for organ donation.

He has so far collected more than 1,200 signatures in support of the change and will present it to Minister for Aged Care and Indigenous Health Ken Wyatt.

Countries including Spain, France and Singapore have already made the switch to a presumed consent model, where citizens are automatically donors unless they officially record an objection.

Currently, Australians wishing to donate their organs and tissue after death need to include their name on the national register and donations do not go ahead if families strongly object.

Louie said the views of a donor's family would still be respected under an opt-out scheme.

"If the opt-out policy were to go ahead the Government and hospitals would always ask the next of kin's permission if they are willing to go ahead with the decision of the loved one," he said.



'Opt-out may not boost donor rate'

Dr Cathy Quinlan from the Royal Children's Hospital backed the opt-out model, saying it would make the organ donation process even easier.

"I come to that as somebody who is really busy, I have four kids and a very busy job, and even though the process to actually sign up to be on the donor registry is really straightforward, quick and easy, I think a lot of people just don't get the time to do it," she said.

# HUMAN SERVICES SUPPORT

Did you know that people suffering with Renal disease can get support from the Government's Human Services Department. Based on your circumstances, you could claim the Disability Support pension and other financial assistance plans. It is all very easily accessible online and by phone. Below is just a bit of a guideline. See website for more.



[www.humanservices.gov.au/customer/services/centrelink/disability-support-pension](http://www.humanservices.gov.au/customer/services/centrelink/disability-support-pension)

## Disability Support Pension

Financial help if you have a permanent physical, intellectual or psychiatric condition that stops you from working.

### Eligibility basics

- at least 16 and under age pension age
- have a permanent medical condition that prevents you from working 15 hours or more per week within the next 2 years
- under the income and assets test limits

Pension rates per fortnight	Single	Couple each	Couple combined	Couple each, separated due to ill health
Maximum basic rate	\$808.30	\$609.30	\$1,218.60	\$808.30
Maximum Pension Supplement	\$65.90	\$49.70	\$99.40	\$65.90
Energy Supplement	\$14.10	\$10.60	\$21.20	\$14.10
TOTAL	\$888.30	\$669.60	\$1,339.20	\$888.30

## Other payments

### ESSENTIAL MEDICAL EQUIPMENT PAYMENT

A yearly payment to help with energy costs to run medical equipment or medically required heating or cooling.

#### Who can get it

You can get this payment if you or the person you care for:

- needs heating, cooling or certain equipment for their medical needs
- has a Commonwealth Concession Card, and
- pay for running costs

#### Home Dialysis Machine covers:

- Home dialysis
- Machine assisted peritoneal dialysis equipment (cyclor or heater)
- Kidney dialysis machine
- Intermittent peritoneal dialysis machine

- Haemodialysis machine
- Peritoneal-dialysis machine

#### How much you get

The most you can get is \$154 each year.

**For this payment there are a few forms that need to be filled out by yourself and your GP - it's a bit of a hassle but be persistent and you will get the dollars!!!**

### ONE-OFF ENERGY ASSISTANCE PAYMENT

From 26 June 2017, we'll pay eligible recipients a one off Energy Assistance Payment. This will help with rising energy costs.

#### Eligibility

To get this you need to be residing in Australia on 20 June 2017 and getting:

- Age Pension
- Parenting Payment Single
- Disability Support Pension

### RENT ASSISTANCE

A regular extra payment if you pay rent and get certain payments from us. See website for rates.

### MOBILITY ALLOWANCE

A regular payment to help with essential travel costs if you have a medical condition that means you can't use public transport.

There are 2 different payment rates:

- the standard rate of \$94.10 a fortnight, or
- a higher rate of \$131.60 a fortnight

**There is also Telephone Allowance and Sickness Allowance.**

**For more information and details and to see if you are eligible please visit:**  
[www.humanservices.gov.au/customer/services/centrelink/disability-support-pension](http://www.humanservices.gov.au/customer/services/centrelink/disability-support-pension)

# Promoting Exercise on Dialysis

**Don't depend completely on the medications your doctor prescribes for you such as phosphate binders and calcitriol "to keep your bones strong". As well as taking these prescribed medications, take responsibility and do some exercise.**

A research was conducted by Deakin University in 2015 using Resistance band exercises for patients during dialysis. Resistance bands come in different colours indicating the level of resistance. Benefits of engaging in regular exercise to build strength and endurance was shown in preventing risk of developing conditions i.e. obesity, high blood pressure, back pain and muscle tightness. 'The expected benefits of engaging in a

regular exercise program include, but not limited to: weight loss, improved blood sugar control, increased strength, power and flexibility, improved mental health, lower risk of other chronic disease progression and increased independence'. It also helps to kill the "boredom" on dialysis.

*With thanks to The Home Therapies Center, Austin Hospital, Repatriation Campus for this article.*



***Teddy Roosevelt... "do what you can, with what you have, where you are"***

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## World Transplant Games 2017



On 30th July I attended Transplant Australia's VIC/TAS Christmas in July Luncheon held at RSL Box Hill, where I met members of the successful Australian Transplant Team who recently returned from the World Transplant Games 2017, held in Malaga Spain from 27 June to 2 July.

The International Competitors came from the following groups: Kidney, Liver, Bone-Marrow, Heart and Lung - totaling 2,200 athletes from 60 Members

Countries.

We congratulate the Australian team who finished the Games with 26 Gold, 27 Silver, 18 Bronze and came 6th overall.

The sports our competitors competing in were road race, volleyball, table tennis, golf, squash, swimming, kyack, ten pin bowling, badminton and athletics.

I met up with Chris Tew who is a member of both DATA and Transplant Australia who won a Gold in discus, Silver in shot put and Bronze for the javelin. Chris talked out her experience and how she enjoyed the Games.

In the Australian Team the youngest was 12 and oldest was 73.

Winter Transplant Games will be held in 2018 in Anzere-Arbaz in Switlerland and next Summer Transplant Games will be in 2019 Newcastle On Tyne in England.

17th Australian Transplant Games will be held on the Gold Coast Queensland from 30 September to 6 October 2018.

Recipients of solid organs, tissues and corneas can participate .

Donor's families, living donors, and supporters can participate in some events.

As a recent Transplant Recipient, August 2016, I have decided to be a competitor for the Victorian Team in the upcoming Transplant Games in 2018

If you would like more details just contact me and I will be only too happy to assist you.

See you on the Gold Coast!

*Peter Collins*

# Notice of Annual General Meeting

**Notice is given that the Annual General Meeting of the Dialysis & Transplant Association of Victoria Inc will be held on Sunday 22 October 2017 at 2:00pm at Manchester Unity Hall, 8 Main Street Blackburn.**

The post AGM dinner will be a “Volunteer’s Dinner” by invitation only to acknowledge the practical contributions made by volunteers over the past 12 months. Details will be sent with invitations.

## **The ordinary business of the meeting will be:**

1. To confirm the minutes of the previous Annual General Meeting and the Special General Meeting held on 23 October 2016.
2. To receive from the Committee reports upon the activities of the Association during the preceding financial year.
3. To receive and consider the financial statement submitted by the Association to members in accordance with section Part 7 of the Associations Incorporation Reform Act 2012 (Vic).
4. To receive and consider the Auditor’s Report and Reviewed Accounts on the financial affairs of the association for the last financial year.
5. To confirm or vary the amounts of the annual subscription and joining fee.
6. To determine, by resolution, the requirement, if any, to have the current year’s financial statements reviewed or audited in accordance the act.
7. To elect officers of the Association and the ordinary members of the committee.
8. To consider any other business.

by authority of the Committee

## **COME ALONG AND HAVE YOUR SAY**



### **DATA AGM 2017 RSVP**

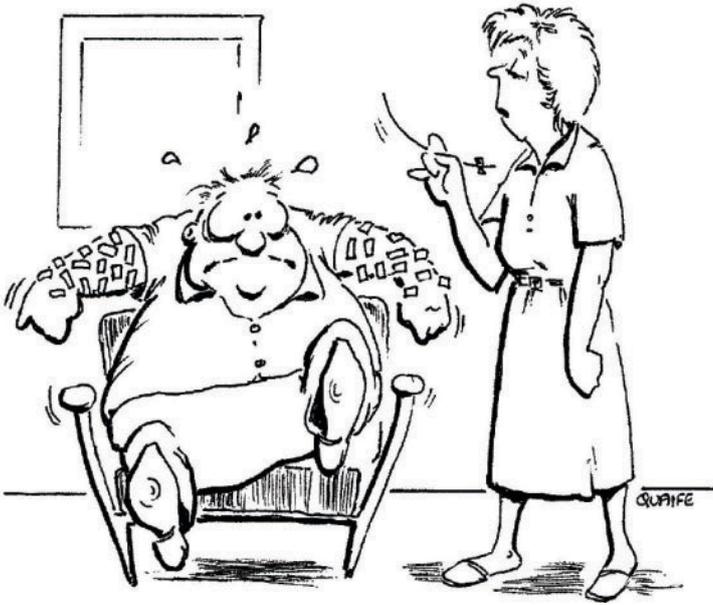
Yes, I will be attending the Annual General Meeting on 22nd October 2017 at 2.00 pm

Name ..... Phone .....

Number of people attending .....

Register by email to: [info@datavic.org](mailto:info@datavic.org) or phone 9894 0377 or return this slip to PO Box 159 Forest Hill. 3131

# DATA Christmas in July 2017 'wrap up'



Don't worry, I'll find a good site soon.

## Have a laugh



Mr. Smith—we'll have to watch your blood pressure.

The DATA Christmas in July was held on Saturday 22nd at the Greyhounds Entertainment in Springvale. There were familiar faces as well as new ones. There were 25 DATA members, family and friends who attended the function. We all had fun and laughter.

It was different this year, as we didn't have the function room. Our group was in a corner but it was still noisy. Ken Donnelly, the trivia master, needed help to repeat his questions for the further tables. Only 16 questions were asked due to the noise (Ken prepared 30 questions). One of the questions was – name a country in Asia (there are 3) that begins with K. Easy everyone thought, Korea. There is no such country – it's either North or South Korea. The 3 countries are – Kuwait, Kyrgyzstan and Kazakhstan. Congratulations Doug Lindsey for winning the trivia, he had 11 questions correct, excellent effort.

We had a raffle and lots of tickets were sold. Main winners were – Violet Sixtus, who won the hamper and Alan Stayner, who won the bottle of wine. There were lots of small prizes as well.

It was Val Anderson's birthday on the day, so we all sang happy birthday. Val is a friend of Joan Eastwood. Joan a DATA member, has been on the committee for many years.

For only \$20, the 3 course meal and a drink was very good value. It tasted alright as well.

Thanks to Ken Smith and his daughter, everyone received a bag of lollies at the end of the night.

Next year we'll try somewhere different for our Christmas in July.

*The Social Committee*



# Dates to remember



## Fish & chips at D'Lish Fish at Station Pier

Saturday 23 September at 12.00 pm

## 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](http://www.homedialysis.org/news-and-research/blog)

[www.nwkidney.org](http://www.nwkidney.org)

[www.peninsulahealth.org.au/](http://www.peninsulahealth.org.au/)

[www.worldkidneyday.org](http://www.worldkidneyday.org)

[www.cari.org.au](http://www.cari.org.au)

[www.australiandialysisbuddies.org](http://www.australiandialysisbuddies.org)

[www.greendialysis.org](http://www.greendialysis.org)

[www.transplantaustralia.org.au](http://www.transplantaustralia.org.au)

[www.homedialysis.org/news-and-research/blog](http://www.homedialysis.org/news-and-research/blog)

[www.bigdandme.wordpress.com](http://www.bigdandme.wordpress.com)

<https://scribeschool.net/urinary-excretory-system-info-for-scribes.html>

## 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.

Write to: The Editor, Shoe String

PO Box 159, Forest Hill 3131

Email: [editor.shoestring@gmail.com](mailto:editor.shoestring@gmail.com)



@DATA - Dialysis & Transplant Association

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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.

DEADLINE FOR NEXT ISSUE 16 OCTOBER 2017