

Shoe String

Newsletter for the Dialysis and Transplant Association of Victoria Inc.



Join us for Christmas in



GREYHOUNDS ENTERTAINMENT

Saturday 23 July 2016

6.00 pm

\$20.00 per person

This includes a 3 course Christmas dinner plus one drink

Greyhounds Entertainment, View Road, Springvale

RSVP ASAP as places are limited

See page 8 for booking and payment details

Book a table now!

JUNE 2016

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Thanksgiving**

DATA in Altona



Coffee and Cake in Altona

Everyone enjoyed the afternoon and DATA is hoping to have more social events on that side of Melbourne.

Go to page 10 & 11 for the full story and see who was there. Also read an article by George Said about DATA in Altona on page 7.



A new look Shoe String and a new editor

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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.

This newsletter may look a little different – that is because we have some new talent on board! Not to say that the old talent has gone anywhere – but Ros, Fay and myself are pleased to welcome (with open arms) Trudy Robson to the Editorial Committee. Trudy has more experience (and panache) than us and we look forward to working together.

Joan Eastwood

Hello, my name is Trudy and I am a Member of DATA and proud to be the newest member of the Editorial Committee and the designer of your new look Shoe String.

A little bit about me...I was very lucky to receive a new kidney in October 2012, my first & 'only' transplant!

Kidney disease is prevalent in my family with my father and 1 of his siblings and 3 of his five daughters (including me) with kidney transplants.

I was first diagnosed with Reflux Nephropathy in 2005, had surgery in 2009 to start PD, then when it stopped working in October 2010, I started Home Haemodialysis training which I did living by myself until I received the phone call of a lifetime - 'We have a kidney for you', October 31, 2012 - Halloween, can you believe it, but luckily it was not a trick but definitely a TREAT!!

I contacted the Editor of Shoe String early April this year stating the reason for my email was that I have enjoyed getting Shoe String in the mail over the years and would love to contribute to the newsletter by offering to give it a refreshed new look for 2016.

As a qualified Graphic Designer with over 20 years experience working in my own business, I relish the process of design and wanted to put it to good use towards something close to my heart.

I feel strongly that a new template updating the look & layout, including more photos and bigger photos where possible, adding prominent headlines and other graphic elements, will help to grow DATA's membership base, perhaps appealing to a much needed younger audience while maintaining its current members.

So let's see how it goes!!

Trudy



To keep Shoe String current and evolving, we'd love to hear from you - the DATA Community and share your 'Kidney' stories, news, photos, insights and adventures. Stories that inspire people, entertain them, inform them or offer intrigue or hope to other DATA members of what is possible.

If you have something to share, please email your stories to: editor.shoestring@gmail.com

Visit our website at www.datavic.org

The President's Report

This is probably the most challenging Presidents Report which, so far I have had to write.



John Podolak
0418 344 826

Firstly - the good news

1. Plans are being developed to replace the previously available accommodation in Blackburn for country members visiting Melbourne for treatment with hotel/motel type subsidised accommodation.
2. Applications for grants have been lodged with various bodies to support our present and future projects so that more and better help will be available to those in need.
3. New computer equipment is now in place to upgrade and improve our system. A new security and back up program is being installed. Charlie is liaising with our new IT support person Siva, and consulting with Joan and Ros to ensure that useful and successful components and previous procedures are not lost and that the excellent past efforts will continue.
4. Office Facilitator, Gwen Lever, is doing a great job and improving our office efficiency. Gwen has much to offer in the role of Office Facilitator.

Secondly - comments and apology

Presidents and Vice Presidents of any organisation are or should be responsible for the quality of the public image and the respect in which the organisation is held. (The buck stops with me).

Negative feedback was conveyed to Brendan and I and others from members and even non-members regarding page 7 in the previous Shoe String.

I am pleased to report that members of the Editorial Committee have apologised and assured us that all future issues of Shoe String will be checked by the Executive Committee prior to publication.

Thirdly - serious considerations for all members

To ensure that the future of DATA will continue grow and help those requiring assistance, I encourage and exhort members to come forward with new ideas and enthusiasm and offer to stand for General Committee and Executive Committee positions at the October AGM.

And finally on our right...

The wisdom of Adam Lindsay Gordon
– An Ozzi Poet the good news.

*Life is mostly
froth and bubble*

*Two things
stand like stone*

*Kindness in
another's trouble*

*Courage in
your own*

Special Effort Raffle

This year's Raffle prizes have increased considerably.

- **First prize** is voucher of your choice to the value of \$800.00
- **Second prize** is voucher of your choice to the value of \$400.00
- **Third prize** is voucher of your choice to the value of \$150.00

Cost is \$2.00 per ticket, with 10 tickets per book with a total of \$20.00.

So please buy a few tickets. It is well worthwhile.

You will find your Raffle book enclosed with your Shoe String. If you do NOT wish to sell the tickets, please return to DATA, PO Box 159 Forest Hill 3131 at your earliest convenience. We may be able to pass them on to someone who would like to sell them.

If you are happy to sell them, please return the Butts with the name of buyer and phone details, by 9 Oct 2016 (on the Raffle book). You keep the ticket with no address on it.

The money collected is to be added on your Membership Subscription Renewal Form.

Raffle will be drawn at our AGM on Sunday 23 October 2016.

If you have any questions, please ring the office on 9894 0377, leave a message with your phone number and Gwen will call you back.

DEADLINE FOR NEXT ISSUE 11 AUGUST, 2016



DATA Holiday Houses

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

Both houses are equipped with a RO machine. 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 extra.

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

- July 10th onwards until September 11
- September School holidays are also free

I AM AWAY TILL THE 4TH JULY SO YOU CAN RING WHEN I RETURN TO BOOK THE HOUSE.

Lots of weeks free at the moment so please look at having a break and getting away to a very warm and comfortable house.

It would be nice to have some new families use the house.

Rosebud hospital is a lovely unit for those wishing to have dialysis at the hospital.

Rosebud House Secretary
Amanda Pratt Ph: 9589 4894

Yarrawonga

VACANCIES

- July 10 - 30
- All of August is VACANT

We are sorry to see that Ann and Frank Bonser, will be moving to Bendigo this month. Fay and I would like to thank them for all the help they have been to us over many years, ever since they came to a working bee and enquired if there was anything they could do for DATA about running the house.

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

DO NOT FORGET

If you need to dialyse at either the Rosebud or Yarrawonga 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

It is OK to be on Dialysis

I have been on haemodialysis now for over ten years. Initially I attended a satellite clinic and then I was trained for home dialysis which I did for eight years.

Due to the fact that I recently lost my husband, who was a great support to me on home dialysis, I have now returned to a hospital satellite program.

Renal failure is a life changing event for the individual, family and friends. Family dynamics may change, problems with relationships may occur as routines are disrupted and family members take on different roles.

For the individual with a diagnosis of "End Stage renal Failure" one can experience shock, disappointment, fear and eventually acceptance. This all takes time. My attitude today is very different to twelve years ago when I was first diagnosed.

Lately I have been aware of there being a lot of media coverage regarding kidney transplants. From my readings it seems to highlight that a kidney transplant is the ultimate. For example Jane Cadzow's article in the Age February 2016

For this reason I would like to put forward my thoughts that being on dialysis can result in very positive outcomes as well.

Costing for the treatment of a dialysis patient per annum it has been argued is a drain on the health budget, comparing it with a transplant which has an initial outlay but then provided all goes well for the patient there is a tapering off of costs per annum. It is argued too that following a transplant a patient may be able to return to full time employment whereas a patient on dialysis frequently is not able to do this. It is also argued that a transplanted patient has a much better quality of life.

From a personal perspective I have

enjoyed life to the maximum, in spite of requiring dialysis three times per week. I have managed to work around dialysis, and have enjoyed many trips away too, as well as keeping up with many many friends. I was happy too to be involved with the Red Bus Project. This project enables people to go to different places in Victoria where the Red Bus operates.

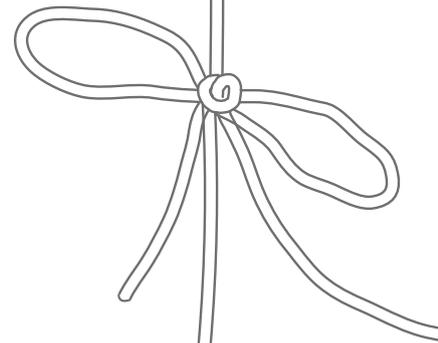
As a person who requires dialysis, I feel safe and confident at the clinic where I receive dialysis three times weekly. The staff are always very supportive.

I am very grateful to be alive and able to function within society in spite of the fact that I am kept alive by dialysis, and with my diagnosis I will never be able to receive a transplant. Dialysis has enabled me as an individual to continue functioning within society and enjoy life.

I have endeavoured to highlight the fact that one can function in a positive way and live a productive life as a person requiring dialysis.

For the reasons described it would be great if dialysis which is the treatment required for many people with renal failure could have a more positive public exposure.

Thank you Sandra Bell for your thoughts and encouragement. Sandra is planning a trip to England and we hope that Sandra writes another story, this time about her trip to England.



...I have enjoyed life to the maximum, in spite of requiring dialysis three times per week.

Another accommodation unit for Kidney Health Australia (KHA)

In 2014, with the assistance from a philanthropist, KHA was able to buy a brand new unit in Brunswick, Melbourne. This unit is spacious and comfortable and close to the Royal Melbourne Hospital.

This unit is specifically for use by the Royal Melbourne Hospitals kidney transplant patients and family, who

travel from the country and need accommodation. This unit has proved to be a success and in high demand.

Now KHA has similar accommodation in Adelaide. So a big congratulation must go to KHA on this achievement.

www.kidney.org.au

Paired Kidney Exchange, record Breaking Year



The Australian Paired Kidney Exchange organises kidney transplants when a person in urgent need of a kidney has a loved one willing to donate their kidney but has an incompatible blood or tissue type. With the help of a complex computer program, the recipient – donor pair’s details are placed into a pool and are matched with other donor – recipient pairs until each is matched with a suitable swap.

On the 19th November, 14 simultaneous operations were carried out to remove kidneys from their donors before the organs were couriered across town or flown interstate to be transplanted into recipients.

The Austin Health, Monash Medical Centre, Royal Melbourne Hospital and in NSW Westmead Hospital, Prince of Wales and John Hunter hospital were all involved. This would have meant the organising and coordination of day, and time, for operating on the donors, transporting the organs to local and interstate hospitals and then transplanting the organ into the recipient.

Not only was the Austin Hospital involved with the paired kidney exchange, The Renal Transplant Unit, carried out a record 50 transplants in 2015 an almost five-fold increase from a decade ago.

Assoc. Professor Frank Lerino said he felt fortunate and proud to be part of the exchange.

“To see our health system working in such a collaborative way is just fantastic. It’s a great thing to see patients having the opportunity to have a renal transplant where they would otherwise be on a transplant list for long periods of time”.

Thanks to the Austin Hospital for sending in their story.

Further information can be found at www.donatelife.gov.au and type into their search box paired kidney exchange.

Would you like a holiday on the Mornington Peninsula this winter?

At Rosebud Hospital Renal Dialysis Unit, we offer an all year round holiday Dialysis program and we have some vacancies over the winter season. With the DATA holiday house in Rosebud nearby and equipped for a holiday, it's perfect in all seasons.

There is still plenty to do on the Peninsula, even when the sun isn't shining. Come and see the beautiful scenery with lovely drives around



the bay. Discover hidden arts and crafts, wineries and galleries in and around Redhill, Flinders and Arthurs seat. Treat yourselves to beautiful gifts at the weekend markets or in the boutiques of Sorrento and Mornington or on those dark evenings' rug up and watch a movie at the Dromana drive-in.

To enquire and make a holiday booking contact Rosebud Dialysis

Unit via email:
holidayatrosebud@phcn.vic.gov.au

For more information go to:
www.peninsulahealth.org.au/services/services-f-m/medical-services/rosebud-haemodialysis-holiday-program/

Contact Amanda Pratt at DATA for more details on the Rosebud holiday house bookings.

DATA plays by the rules

Many of you may recall previous articles concerning a proposal to update DATA's rules. I thought it was time to give you an update and provide some background for our newer members.

On 26 November 2012 the Associations Incorporation Reform Act 2012 (Vic) (AIR Act) came into effect. It replaced the Associations Incorporation Act 1981 (Old Act) and introduced new items that must be covered by an associations rules i.e. there are now 23 Scheduled Items compared to 17 in the Old Act.

All associations were notified of the change by Consumer Affairs Victoria (CAV) and subsequently the DATA committee established a sub-committee to review DATA's rules. There were presented with

3 legitimate options. The first was to do nothing and leave the rules unchanged. This option was dismissed as the committee would need to be constantly aware of all discrepancies between the rules and the act and make sure that the requirements of the act were applied in precedence to the rules. The second option was to adopt a set of model rules that had been prepared by CAV. This was ruled out as the model rules did not fully fit DATA's requirements. The final option, and the one that was adopted, was to prepare a new set of rules.

The sub-committee decided to use the model rules as the basis for DATA's new rules and set about the long and complex task of adapting the model rules to DATA's

requirements. The objective was to ensure the obligations of the act were met without altering the overall objectives of DATA. The exercise has taken longer than expected due to unforeseen disruptions but is now nearing a key milestone. A draft set of rules is ready for review by the committee and will be scrutinised by our solicitor. We will then be ready to call a special general meeting with the aim of passing a special resolution to adopt the new rules.

All members will be sent a copy of the proposed rules and any other necessary documentation. So keep any eye on your mailbox.

Ros Ball

DATA is trying to set up a branch in Altona

On Australia Day In 2014 I was made Citizen of the Year and I am well known in my municipality. This is to make the point that I am well known in my community and I am not short of social contacts in and around Altona. However this year owing to haemodialysis taking 6.5 hours of my time, every second day, I cannot attend many social functions as I would like.

On my non-dialysis days I attend to appointments with doctors, do some gardening, fix things in the house and so on. Although I would like to, I am unable to go to DATA functions as they are too far from where I live. A

couple of weeks ago DATA members came to my area. What a delight; I enjoyed meeting old and new friends. Although I felt sad that only two other members were from the western suburbs. There must be many, many dialysis patients in my area that are not aware of DATA and if they do, they would consider the travel a real impediment.

So for my sake, and others like me, we decided that we could have our own support group with a DATA branch right here around my area. We have a population greater than Tasmania on this side of Melbourne. Hurray, DATA in Altona!

I have been communicating with the DATA committee through Ros, our Secretary, and it seems to all of us a good idea. We need to work out how we progress but good will is evident and so is success.

Watch this space!

George Said

While George does the leg work in Altona DATA needs to sort out the legality and such. This may take a little time. Those of you who live in the western suburbs please feel free to contact George on 9398 2921.

Ros Ball

Subscriptions are now due and yes, they have gone up to \$15.00

You will find your subscription form for 2016 - 2017 on a loose page with this Shoe String. Please fill in ALL the details and return to DATA with your cheque or money order or credit card details. All items: Membership, Special Effort Raffle collection and any Voluntary donations, can be included in one payment, but please fill in ALL the details on the Subscription Form.

Post to DATA, PO Box 159 Forest Hill, 3131. Thank you.

Join in the fun at Christmas in



GREYHOUNDS ENTERTAINMENT

Saturday 23 July 2016

6.00 pm

\$20.00 per person

This includes a 3 course Christmas dinner plus a glass of beer or house wine

There will be a lucky door prize and we plan to have some trivia with our Trivia master Ken Donnelly. Bring a simple gift or two to pop in the basket by the door to be distributed during the evening by Mr Claus.

Remember – Christmas presents are never what you wanted....I remember I gave my teenage boys a tea towel each one year – they were not terribly impressed!.....so have a bit of fun! Prize for the most original present.



Christmas in July 2016

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: _____

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Signature: _____

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

ABN: 40 628 284 998

A woman's pet parrot hadn't talked for days, so she took it to a veterinarian to see what could be wrong.

He laid the parrot on his exam table and checked the bird with his lab equipment. After a few minutes, he let her know her parrot was dying.

"Oh no," she moaned, "Don't you have any other test besides those?"

"Yes, I have two more tests," the vet said. He whistles, and out trots a Labrador Retriever.

The dog approaches the parrot, sniffs it for awhile, then shakes his head to indicate the bird is dying.

The vet then leaves and returns carrying a cat. The cat nudges the parrot, licks it, and shakes its head to show the bird is dying.

"I'm sorry," said the vet. "Your bill is \$200."

"\$200 to tell me that my parrot is dying?" replied the woman.

"Well, if you'd accepted my first diagnosis, the bill would have been \$20. But after the lab report and the cat scan, it's \$200."

Have a laugh



What do you call it when a Mosquito flies into a fan?

Pesticide

How come oysters never donate to charity?

Because they are shellfish

You are on a horse, galloping at a constant speed. On your right side is a sharp drop off, and on your left side is an elephant traveling at the same speed as you. Directly in front of you is another galloping horse but your horse is unable to overtake it. Behind you is a lion running at the same speed as you and a horse in front of you. What must you do to safely get out of this highly dangerous situation?

Get your drunken tush off the Merry-go-round!

Top 5 Tips to make your Dialysis more successful

Although dialysis is lifesaving, it can be tough. The good news is, there's a lot you can do to feel better, avoid infections and enjoy more energy. Take control of your health by following these tips:

1 Consider home dialysis

More treatments, an option with home dialysis, makes you feel better. You'll also enjoy a more flexible schedule and greater independence.

2 Watch your fluids

The most common reason people on dialysis visit the hospital? Too much fluid. Stick with your limit!

3 Exercise and eat well

Living health life style is key to feeling good on dialysis. Exercise regularly and follow your low salt, kidney friendly diet.

4 Attend all appointments

Your doctor monitor's your pathology results and checks your medication and keeps your health top of mind. Make appointments with your doctor a priority.

5 And, of course, be on time for dialysis and stay for your full treatment

With thanks to Northwest Kidney Centers' newsletter 'Kidney Connect'.

Northwest Kidney Centers, USA, promotes the optimal health, quality of life and independence of people with kidney disease, through patient care, education and research.

Check out their website www.nwkidney.org

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.

In our thoughts

It is with sadness we report that Geoff Fletcher passed away 17 April 2016 after a long struggle with kidney disease.

A Celebration memorial was held in May to reflect on Geoff's life. Several members of DATA Committee were privileged to attend

Geoff was a vibrant and enthusiastic person who loved his family, sailing and the yacht club. Though a quietly spoken man, he always got his message across. He was a compassionate man. He was always ready to help DATA although we were only one of the groups he assisted.

He was an Electrician by trade and always ready to fix things electrical at Queen Street Blackburn. He looked after Blackburn for a few years letting people in and checking them out after their stay.

Geoff will always hold a special place in the hearts of all of us at DATA.

Our sincere condolences to his wife Jan and family.

We also say goodbye to good friends Sheila Baxter who died in April and Jacqueline Jenner who died in May.

Sheila and Jacqueline were both well known to us and we will miss their phone calls usually about holidays but it was always good to have a catch up chat.

Joan Eastwood

Donate Life Thanksgiving Memorial Service

This service is specifically for those who have received a transplant to recognise the contribution of families who allowed and enable transplants to occur.

The service started with a Welcome and a quick mention of the 25 years since the first service. A choir sang and then Celia Browne spoke about her family. This was printed in the last Shoe String "Transplantation from Two Angles".

More people spoke of their experience with donation be they donor families or recipients. It was a very moving day and I expect many people were near to tears by the end. In memory of loved ones people were invited to light a candle. The service finished off with the choir singing a gentle and moving song.

To complete the day, tea and coffee was served allowing people to meet others who attended the service. Lots of our car stickers with 'Don't take your

organs to heaven, heaven knows we need them here' were put out on the tables and taken by many people. I have never seen our stickers taken up with such enthusiasm before.

As you may remember, DATA actually performed the very first Memorial Service 25 years ago with a special flag.

Donate Life did find the first flag used for the first service, and were happy to give it to us. It is a picture of flames in the middle and 2 doves done mainly in reds on a white background. IF YOU KNOW who designed and made this flag, it would be lovely to have this information for our records.

Please note, this is a secular service, not a church service. There is no connection or reference to any religion.



By Ros Ball

Coffee and Cake in Altona

It was a great day and we all enjoyed the good company and the good coffee and food with DATA subsidising the cost. DATA rarely holds social gatherings in the Western suburbs and this was a good opportunity to do so. We must give a big thanks to George Said for helping organise the day and suggesting the venue.

There were 10 people present and with so much to talk about - comparisons with

each other about hospitals, treatment and dialysing, time flew by. Cars were a discussion point too, especially as Alan drove a left hand drive American car to the function.

As the afternoon went so quickly I missed a walk along the beach.

DATA is hoping to have more social events in that area. See the article on page 7.



Above: Charlie Ball, Alan Puli and Ros Ball

Left: On left: Charlie Ball, Alan Puli, Joan Eastwood, Maroula Said and Sophie Drwecki. Right: Peter Wilson, Ros Ball, Kathy Day, Ernie Herbert, Kaitlyn Stevenson and George Said.

Dates to remember



Christmas in July

23rd July 2016, 6.00 pm
GREYHOUNDS ENTERTAINMENT

Next Shoe String packing

25 August 2016

Annual General Meeting

Dialysis & Transplant Association of Victoria inc
23 October 2016, 2.00 pm
Venue TBA

Some web pages of interest

www.nwkidney.org

www.peninsulahealth.org.au/

www.worldkidneyday.org

www.cari.org.au

www.australiandialysisbuddies.org

www.greendialysis.com

www.transplantaustralia.org.au

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

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



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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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