

ShoeString



Newsletter of the Dialysis & Transplant Association of Victoria Inc.

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Vale Ros Ball



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Date of Nest Deadline

Vale Ros Ball

Ros Ball passed away peacefully in her sleep on 25th July 2022. She was 68 years old. Her life reads like a thick book. Ros was not one to sit still for long. She accomplished more in her 68 years than most would, in a couple of life times.

Ros's life with kidney disease began in childhood. At 8 and 18 years of age she had corrective surgery for reflux. She started Peritoneal Dialysis (PD) in 1987. Had a kidney transplant in 1988. Because of the aortic aneurysm repair

in 1997, the transplanted kidney failed. It was back to dialysis; first it was PD then haemodialysis. Ros commenced home haemodialysis in 2000 and nocturnal (overnight) in 2004. In 2010 with Charlie (Ros's husband) and the Austin hospital dialysis service technicians, a dialysis machine was installed in the family caravan. Ros and Charlie travelled widely once the caravan could support dialysis.

Ros was born and raised in Mansfield Victoria where she attended the local primary and high schools. After

(Continued on page 3)



President's Letter

As I write this I can feel that spring is in the air. How nice it is to wake up at 6.30am and see the sun start to rise. It may be me getting older but the winter definitely seemed much colder and wetter than I have experienced in Melbourne.

To add to it, I thought I had man flu but it ended up being Covid. Even after 3 vaccinations it still knocked me about. I was in bed for 10 days. I wonder how sick I would be if I hadn't been vaccinated. Fortunately that is all behind me now, and I am back on top of things.

Sadly we have lost our third Life Member this year in Ros Ball. See page 1 and 3. Ros made many

contributions to DATA over the years, including Editor of this magazine. She will be sadly missed.



ShoeString magazine celebrates Fifty Years this year which we will acknowledge at our AGM on 23rd October 2022.

There will be A DOOR PRIZE for a lucky attendee. Prize will be a week at either Yarrowonga or Rosebud. This was kindly donated by Steve and Linda Daws. So do come along and show your support

I would also like to thank all those who made a donation to our Association. Without these generous donations and the work of my fellow Committee Members we are able to provide social welfare and holiday homes rentals at extremely low rates.

Take care and enjoy the spring sunshine.

Brendan

Healthy Kidneys Education Project

Snippets from Filter Your Future Report to DATA August 2022

[PKD Australia Registry](#)

Yvonne participated in the first meeting for the PKDA Registry Consumer Working Group, held on 8th August. Participants with PKD discussed how to best increase the doctors understanding of the issues for Patients. PKDA is working towards the development of a Registry that will provide improved information.

[Otsuka Pharmaceutical 'Lunch n Learn' session](#)

Otsuka is the drug company that makes Tolvaptan, sold as 'Jinarc'; it's the only current treatment for adults with PKD. It is not a cure for PKD but slows down the development of fluid-filled sacs in the kidneys, which gradually prevents the kidneys from working. Yvonne has been on this treatment for the last few years and kidney function has amazingly improved. The Otsuka staff in Australia had invited me to share my patient experiences at their 'Lunch n Learn' session via zoom, and they were very interested to hear that when my treatment commenced, my eGFR was 50 (Stage 3A), and currently my eGFR has improved to 65 (Stage 2)! A good story indeed! The participants in the session were particularly interested to hear about the DATA-sponsored Healthy Kidneys Education Project.

Vale Ros Adcock

Yvonne joins with DATA members to express deep sorrow for the recent passing of our dear friend Ros. She was the instigator for DATA supporting the Filter Your Future Healthy Kidneys Education Project in 2017, and regularly offered her full support, ideas, and encouragement. Ros will always be remembered as a champion of kidney education and improving the lives of those impacted by chronic kidney disease. My sincere condolences to Charlie and Ros' mother, and DATA friends, at this sad time. Rest In Peace Ros.



VALE ROS BALL *(continued from Page 1)*

completing 6th form in 1971 she started her nursing career in Wangaratta in 1972. Once qualified she came to Melbourne, then it was Darwin in 1977 for 12 months. After Darwin, Ros had a 10 month break overseas travelling through Asia, Europe, Canada and America. When Ros returned home she qualified as a midwife, and then completed a Neonatal Intensive Care (NIC) course. She worked in the NIC Unit at the Mercy Hospital caring for premature babies.

She met Charlie in 1991 at a bush walking club and they married in 1999. Since then, Charlie has always been by Ros's side, especially after her eyesight diminished in 2009.

Ros joined DATA in 1989. She was a member for over 30 years. Joined the committee in 2006. Was president, then secretary, then both president and secretary, then secretary again. Ros also looked after the holiday home in Rosebud for a few years as well as being an editor for Shoestring. While being on the committee, Ros organised holiday dialysis in Lorne, Orbst and Myrtleford. Ros was also on the subcommittees for Filter Your Future and the Sue Hatzimichalis Post Graduate Renal Nursing Scholarship. As said before Ros was never one to sit still.

Ros commenced her charity work at an early age. She was involved in Junior Red Cross at High School and was president for a while. In later years, she volunteered with the Wesley Mission, visiting an elderly lady once a week. She participated in a program to house wards of the state while

they were being prepared for independent life.

In addition to her contributions to DATA, Ros was involved with the Big Red Kidney Bus and was a consumer participant for Kidney Health Australia. She also spent a number of years



as a renal patient representative on the DHHS Renal Health Clinical Network (RHCN). She always wanted a better deal for people on dialysis.

We will miss her, remember her hard work and dedication.

Sincere Condolences to Charlie, Ros's mother, and also her many DATA friends.

TWO SPECIAL DATES TO REMEMBER

Do not forget we are going to Yarrowonga on Sunday 11 September, (that is next Sunday if you read this immediately and my calculations are correct) for a cruise on Paradise Queen on Lake Mulwala. If you live up that way and can't make the cruise maybe you could join us at Yarrowonga Holiday Home for Afternoon Tea. You should book in IMMEDIATELY through the Office if you want to go on the **cruise**. No need to book if you want to come to afternoon tea.

Another date to remember is 50th celebration of Shoe String. That is on 23 October 1 pm at the Office Forest Hill. I am so looking forward to catching up with old friends. It will be a casual afternoon maybe a short video to get us talking, then AGM business being conducted last. If you want to contribute any memories I will see you there.

Joan Eastwood



DATA Holiday Homes

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.

The House s are now open for CHRISTMAS BOOKINGS.

Preference is given to Haemo Dialysis and PD patients

Please leave a clear message on my answering machine, with return phone number and I will get back to you.

Thanks Amanda

Yarrowonga

We have a new shower chair, reading lamp, and Coffee table at Yarrowonga.. See below.

Vacancies

October 2nd to October 9th

October 16th to October 23rd

October 23rd to October 30th

November 6th to November 13th

November 13th to November 30th

Cost is only \$200 per week for you and your immediate family. Call as we do get vacancies.

Bookings at the Yarrowonga Renal Unit Ph: 5743 8189



Sunset from DATA House Yarrowonga

Rosebud

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.

Vacancies

October and November, except for one week, the week of October 30th to November 6th is taken .

Costs \$200 per week. Extra guest is \$ 20 per night.

For HOUSE bookings please ring

Rosebud House Secretary Amanda Ph9589 4894

And Yarrowonga House Bookings

Amanda Pratt Ph: 9589 4894





Letter from Steve

To: Editors ShoeString
<editor.shoestring@gmail.com>

G'day DATA,

With the upcoming 50th anniversary of DATA I thought that I would take this opportunity to briefly reflect on the impact that DATA has had on me.

When I was first diagnosed with renal failure the year was 1983 and I was 19 years old. Suddenly I found myself on dialysis and my life had changed forever. I was a patient at Prince Henrys Hospital and was training to do haemodialysis at home when I first became aware of DATA. One of the dialysis nurses handed me a copy of Shoestring and as I read it (while attached to my dialysis machine) I came to the realisation that I was not alone and there were many people in a situation similar to myself. This sense of community has stayed with me since that moment.



Over the next 40 years or so I have had many fulfilling interactions with DATA. This has included several visits to the Op Shop in Box Hill to deposit old clothes, books and toys as well as making several

purchases - the most notable was of a pair of yellow trousers that were often worn on the golf course where fashion and style were not a requirement!

The sale of raffle tickets was also an annual occurrence and I delighted in selling tickets to many family, friends and workmates. On one occasion I was even fortunate enough to win the 3rd prize which was a beautiful hand made quilt!

It is very difficult to travel and have a break from the regular requirements of dialysis and over the years I am most grateful to DATA for providing me (and my family) with the opportunity to get away from this routine to enjoy a holiday in the DATA Holiday Home in Yarrowonga. I first visited there in 1989 and I remember cruising along the Murray River in a paddle steamer which was not only exciting but also relaxing. It was also a treat to go over the border to NSW where pokies were legal and the RSL Club was the only place to visit!

Over subsequent years I was fortunate to receive a transplant and I didn't return to the DATA house until 2013, a mere 24 years since my first visit!! I was on haemodialysis again and this time stayed at the DATA house as I was dialysing overnight and was able to enjoy the holiday without too much interruption. Over the next 8 years we travelled to Yarrowonga regularly during the school holidays and on every visit felt extremely appreciative to DATA for giving us this opportunity and for making countless special memories.

My most recent interaction with

DATA seemed to be a "full circle" moment. When I first joined DATA in 1983 Ron Jones was the Editor of Shoestring. Last year my son Frederick, (who is now in Year 8 at school) was presented with the Ron Jones Educational Award. This special moment encompasses all of my interactions with DATA and is symbolic of just how fortunate I feel



to have been supported by DATA for most of my life.

Thank you DATA - and Happy 50th!

I have included a pic of 5 copies of Shoestring - 1 from each decade of my DATA membership - as well as a pic of Frederick with his certificate from DATA

Cheers,

Steve Kiellerup

ED. Thank you Steve for this great story.



Come and Celebrate ShoeString's 50th Anniversary

When: Sunday 23rd October 2022
Time: 1.00pm. To be followed by
49th Annual General Meeting of Dialysis & Transplant Association
Where: Level 1, 79 Mahoneys Rd. Forest Hill
Cost: Free
RSVP: 17th October 2022, phone - 9894 0377 or
email - info@datavic.org

Last Social Outing for the Year:

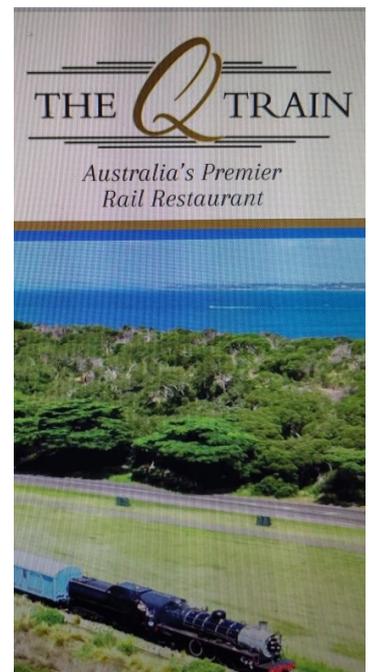
Australia's Premier Rail Restaurant, The Q Train

When: Sunday 4th December 2022
Time: 10.30am
Where: Docklands
Cost: \$50 (train lunch) + \$25 (ferry & bus) for DATA members & carers; \$120 (train lunch) + \$50 (ferry & bus) for non members
RSVP: 25th November, phone 9894 0377 or email info@datavic.org

Sail from Docklands to Portarlington, bus to Q Train, 3 hours on the train, bus to Portarlington, ferry to Docklands.

Depart Docklands 10.40am, arrive Docklands 5.40pm

Q Train travels along the historic Bellarine Railway between Drysdale & Queenscliff





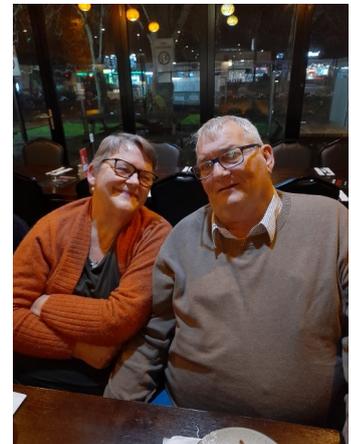
Christmas in July



Saturday 23rd July 2022, DATA members gathered at Mitcham Hotel to celebrate Christmas in July. According to legend, Christmas in July was first celebrated at a summer camp in 1933 in North Carolina, USA. In Australia, Christmas in July has been around since the early 1980s. It's celebrated in July as it is the coldest month in the Southern Hemisphere. North Carolina is in the Northern Hemisphere but their summer is in June/July/ August.

Anyway 16 people gossiped, laughed, ate and drank. The Christmas dinner had 3 courses and between the courses some people disappeared to the pokies room, some informed us of the AFL scores (does it only happen in Melbourne) and some of us just chattered. After the meal it was just coffee or tea, no green tea, decaf or oat milk was available. Still, everyone had a drink to finish the evening. Everyone received a present – there were handmade Christmas cards, bottles of wine, cutlery wraps, microwave bowl holders and more. Two couples were new to DATA social events – Judith and Graeme Lauder, Mischelle and Brian Wallis, we hope to see them again soon. An enjoyable Saturday evening at a warm and pleasant venue.

Angela Lindsey for the Social Committee



EXERCISE FOR PEOPLE OVER 60

IF YOU'RE NOT OVER 60, PASS IT ON TO SOMEONE WHO IS!

Begin by standing on a comfortable surface, where you have plenty of room at each side.

With a 2 kg potato bag in each hand, extend your arms straight out from your sides and hold them there as long as you can. Try to reach a full minute, and then relax.

Each day you'll find that you can hold this position for just a bit longer.

After a couple of weeks, move up to 5 kg potato bags.

Then try 10 kg potato bags and eventually try to get to where you can lift a 50 kg potato bag in each hand.

Then, hold your arms straight for more than a full minute (I'm at this level).

After you feel confident at that levelPut a potato in each bag.



A duck, a skunk, and a deer went out to dinner at a restaurant.

When it came time to pay Skunk didn't have a scent,

Deer didn't have a buck and so they put it all on Duck's bill.



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Association of Victoria Inc.

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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. Vic. Inc.

DEADLINE FOR NEXT ISSUE 04 November 2022

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 event.

We own and run two holiday homes for use by our members— One is at Yarrowonga, the other at Rosebud.



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



From The Editors

CONTACT US ON EMAIL: editor.shoestring@gmail.com

Thanks to all who contributed to this Shoe String. We do have a vacancy on staff for an Assistant Editor. If you are interested in this position please leave your name & number at the Office. I will ring you back.

All carers must be doing fine I didn't hear from anyone,. See July Shoe String for details. Call at any time I will ring you back, if you leave your number.

We also have several vacancies on Committee so do consider it, if you are able. You probably have a lot to offer so come on have a go! Cheers Joan Eastwood

Dates to Remember

September 11th Sunday BBQ at Yarrowonga see page 3

October 23rd Sunday -50th Anniversary of Shoe String and AGM 79 Mahony's Road Forest Hill.

December 4th -Ferry trip & 3 Course Lunch on Q Train .