

ShoeString



Newsletter of the Dialysis & Transplant Association of Victoria Inc.

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Dialysis and Transplant
Association of Victoria Inc.

Registration No A0012114V

ABN 40 628 284 998



DATA goes to Yarrowonga



followed by afternoon tea at Yarrowonga Holiday Home

- When: Sunday 26th September 2021
Time: 11.45am for 12.00pm cruise & BBQ
Cost: DATA members \$15 a head,
non-members \$30 pp.
Where: Meet at 5 Coghill St. Yarrowonga
(DATA Holiday Home)
RSVP: 17th September 2021, phone 9894 0377
or email info@datavic.org
Covid Permitting

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ANNUAL GENERAL MEETING

We are hopeful that the AGM will be held on **Sunday 24th October 2021 at 1.30pm.** We also hope to be able to view the Thanksgiving Service 1991, which we had to cancel last month due to Covid19. We look forward to welcoming Celia Browne to introduce the video.

You are invited to attend the boardroom, Level 1, 79 Mahoneys Road, Forest Hill. Covid permitting.

We will present reports from all programs, and the financial report for 2021. We will select the new Committee for 2022. and award RJEAs recipients their grants.

All this is subject to change due to COVID restrictions at the time..

Please Watch the Web page &/or our Facebook page.



President's Report

Greetings to all

These are difficult and stressful times we live in. I keep saying to people, stay positive, stay safe and live for today. Victoria is in Lockdown Number 6 as I write this. Let's hope it is soon over and our lives can return to some normality. Being able to visit our family and friends. The Covid 19 restrictions have resulted in us having to cancel a number of our social events and have forced us to hold all our committee meetings for the last 12 months on Zoom. It has been a new experience for a number of us!

Much has changed with COVID so we must review how we do most activities—we are unable to go to the office during lockdowns. The ramifications are that we are unable print out envelopes for ShoeString. We cannot pickup or pack or post the ShoeString. Those of you who have provided us with an email address will receive ShoeString on line.

Hopefully as more Victorians get

vaccinated this will reduce the need for these hard and sudden lockdowns. Unfortunately these restrictions have meant a number of our members have had to cancel or postpone their holidays at Yarrowonga and Rosebud holiday houses.

Annual Subscriptions are due as of 1st July 2021. If you wish to contact DATA you can do so, either by phone (leave a message), or by email to info@datavic.org.

We plan to have our AGM on the 24th October, hopefully in the Board Room at Forest Hill,(see page 1 for details). We would like to invite all members to attend and we welcome nominations for the committee. As is usual at that time all Committee Members will step down and a new Committee will be formed. So if you feel strongly about DATA and kidney disease and believe you have something to offer, think about nominating for the Committee Please ring me to discuss.

If, due to Covid we are unable to meet

for our AGM, we will have a Zoom meeting and information of this will be made available to you. Watch DATA website or Facebook.

As always we welcome new members, and stories of your journey and hobbies for ShoeString. We also look forward to Covid permitted outings and catching up with all our friends in DATA.

If you have any queries, please don't hesitate to ring me or Secretary Sue Hatzimichalis, or any other Committee Member whose phone numbers appear on Page 8.

While we continue to navigate the impacts of Covid 19, we must continue to maintain Covid safe behaviour to remain safe and healthy.

Looking forward to Spring and some warmer weather.

Regards to all

Brendan Lowry

Words of Wisdom

When diet is wrong, medicine is of no use. When diet is correct, medicine is of no need.

Unknown

Tell me and I forget, Teach me and I may remember, involve me and I learn.

Benjamin Franklin

Volunteers Needed

We are looking for Volunteers to help with the packing of Shoe String.

We pack every second month at the office when we can.

Things are a bit more complicated now with Covid restrictions. We need to get to the Office to print the envelopes. Then the following week after printing we need to get to the Office again to pack the folded SS into the envelopes.. Once we are out of lockdown, if you think you could help in any way at all

please ring Joan Eastwood

Leave a message 0402 097 331

We are also **in desperate need of an Editor**. No previous experience necessary but computer skills would be an asset.

We will train you on the job, If you are interested just ring. The Office and leave a message . Don't forget to leave your name, phone number, Shoe String and we will ring you back.





DATA's end of year Christmas Outing Sovereign Hill, Saturday, November 27th, 2021

The package will consist of :-

Entry to Sovereign Hill during the day on Saturday

Then at night we will enjoy Dinner at the Charles Napier Hotel in Sovereign Hill

followed by the Aura show.

Overnight stay at the Sovereign Hill Motel before driving back to Melbourne on Sunday.

So how much will this cost DATA Members?

Package 1. Entry, dinner and the show only \$135 per person.

DATA will pay half of this price so you pay \$67.50

Package 2. Entry, dinner, show and accommodation \$460 per couple.

Again DATA will pay half of this so you pay \$230 per couple

Package 3. Single room for yourself, entry, dinner and the show will be \$295

And DATA will pay half so you pay \$147.50

These are the basic prices for DATA Members but if you have friends that would like to come there may be a discount for them if we get over 20 people.

If you are a family with children there is a price on request, just phone Sue on 0412 469738

Reply Slip Sovereign Hill 27th November 2021

RSVP to the Office by 4th October 2021. A refundable deposit of \$100 is required at time of booking for packages 2 & 3.

Phone 03 9894 0377 & leave a message, email to info@datavic.org

Name _____ Phone _____

Please book me for :-

Package 1. Entry dinner show only - Number of people _____

Package 2. Entry dinner show double Accommodation - couple _____

Package 3. Entry dinner show single Accommodation – Single _____

- COVID PERMITTING-



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.

Yarrowonga

The house is only two houses from the lake. A walking track will take you around some beautiful homes, a skate park and playground. About 10 mins out of town is a place called Byramine Homestead and Brewery. Where you can enjoy a delicious platter or pick up some locally grown veggies. (Photos of the delicious platter and photo of sunset taken from the house are below)

Please be aware the landline service in the house is being disconnected.

Vacancies Yarrowonga

September: 5th till 12th

October: 3rd till 10th

Oct 17th till 24th

Both houses are Covid safe.

We have provided Sanitiser and cleaning products to assist in maintaining a covid safe environment for all.

Please advise Amanda if supplies run out.

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

For HOUSE bookings please ring

Yarrowonga House Secretary

Amanda Pratt Ph: 9589 4894



The Platter—mmmmm Yum

Rosebud

There is so much to do in Rosebud and surrounding areas in Spring.

Take a drive to Flinders and enjoy looking at the beautiful shops. Drive to Dromana and have fish and chips on the beach.

The house is heated and lovely to relax in with our new reclining lounge suite.

Please be aware the landline service in the house is being disconnected.

Vacancies- Rosebud

September

5th till 12th

12th till 19th

October:

10th till 17th

17th till 24th

24th till 31st

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

For HOUSE bookings please ring

Rosebud House Secretary

Amanda Pratt Ph: 9589 4894



Sunset at Yarrowonga from the house

**Please Remember
To Take Your Key!**

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, contact the hospital to confirm booking.
- • • Finally, ring to book the Holiday House



Healthy Kidney Education Project

Years 3 & 4.

1. Sugar Myth Busters



2. Sugar & Your Mouth



3. Healthy Wee, Healthy Me



4. Data Crunchers & Data Munchers



DATA & Filter Your Future working together educating children

Our new online lessons were launched in August 2021, a collaboration with [SugarByHalf](#) and [Cool Australia](#). A feature of these latest lessons is the addition of a Parent PowerPoint, suitable for inclusion in electronic school newsletters. Parents will find out why their children are learning about the kidneys and how they can have a healthier future.

This completes the development of online lessons for primary school education, a project begun in lockdown #1 2020 (Foundation, Years 1 -2), and finalised in lockdown #6 2021 (Years 3-6).

In the column to the left (Years 3 & 4), and to the right (Years 5 & 6) are the new lesson titles..

Yvonne Farquharson

Years 5 & 6.

1. Meet Your Kidneys



2. Healthier Choices



3. What's the Impact?



4. Plan for the Future



2021 PKD Awareness Day

Are you or other family members impacted by **Polycystic Kidney Disease (PKD)**?

Would you like to have the opportunity to connect with other PKDers across Australia and New Zealand?

On **Saturday 4th September**, we will get together to celebrate PKD Awareness Day. Last year, when we planned our first Zoom gathering, entitled, "Lockdown with PKD in Victoria", we could not foresee that in 2021 we would be facing the ongoing challenges of multiple lockdowns across Australia

and within the "on-again, off-again" Trans-Tasman Bubble.

Charmaine Green, the Manager of [PKD Australia](#), will co-host the online event with Yvonne Farquharson, the founder of [FILTER YOUR FUTURE](#). Charmaine will provide us with an update from PKD Australia. Yvonne will share some of her own PKD journey including education that has helped her to slow down the progression of her chronic kidney disease. Parents and family members who are supporting anyone with PKD, are encouraged to join us as we will also share some thoughts about talking

to your children about PKD (including adult children).

Our theme this year is '**Our PKD Journey**'. Please join us for our own Zoom PKD Bubble!

Time: Sep 4, 2021

11:00 AM Perth

12:30 PM Adelaide, Darwin

1:00 PM Brisbane, Canberra, Hobart, Melbourne, Sydney

03:00 PM Auckland, Christchurch, Wellington, NZ

PKD Australia

www.pkdaustralia.org

Register for the Event here

<https://www.eventbrite.com.au/x/pkd-awareness-day-together-tickets-167035239899>



Chapter Two: Darren's Story

This is Elaine and Ron's story

When Darren started getting sick during Oct/Nov 1998 he started feeling unwell with what we thought was the flu. It got worse over time, until he called us early one Sunday morning in November 98. We took him straight to Box Hill Hospital. It was busy in the waiting room but after a few hours of waiting we were taken into another room, and this room had a bed! Darren was feeling really bad, He was getting worse. Suddenly he grabbed a kidney dish and threw up into it. It was full of thick blood. That's when Ron & I started to panic! We called a nurse who was nearby and she got things moving. She called in another nurse to help move him into a ward. Once in the ward, they took a lot of blood from Darren, to find out what was going on. A doctor came and told us that Darren's kidneys had failed. The doctor also said it was lucky we had brought him in! We were very shocked to hear this. It was very scary and frightening. We left Darren there in the care of the Box Hill Hospital.

The next day, Monday, Ron got a call from one of the doctors who was caring for Darren. The Doctor told Ron that Darren would be transferred to the Alfred Hospital. The Doctor also said this was an emergency, and Darren would be transferred immediately. Elaine had been attending a meeting in the city in the morning followed by lunch. Ron had to ring Elaine and let her know what was happening. Fortunately one of her friends was able to go with her and find the correct tram to catch, which Elaine was happy about

as she was unsure of how to get there. They rushed to the Alfred. Elaine asked a lot of questions about the blood tests. The anxious parents were told that Darren had been diagnosed with a rare disease called Wegeners Granulomatosis which was mostly unknown at that time..

Over the next five weeks in The Alfred he had a lot of treatment such as dialysis, blood transfusions, plasma exchange, nearly every day and lots of other stuff like scans & x-rays.

Over the next few weeks, Darren started to get better. This was a great relief after all the worrying Elaine and Ron had been going through.



Darren came home just before Christmas which was great. Now he could recover at home. He did have to go into hospital every second day for blood tests but this gradually slowed down to every week, then longer. Thankfully, with the help of all the medications he was taking, Darren started to improve..

Life went on quite well for Darren until 2010, when he began to get sick again, in much the same way as before. He

was coughing up blood, so off to the Alfred again. Ron & Elaine learnt that he had the same disease again, but this time it was in the lungs. He spent two more weeks in the Alfred with more medications. After that, the next year (2011), he was back in hospital a few times with pneumonia. Darren's kidneys had deteriorated This was a concern for all of us.

In 2012 Darren started the year on dialysis so three days a week (Tuesday, Thursday & Saturday) Ron drove Darren to The Alfred for dialysis. Darren was soon able to have dialysis at Peter James Centre in Burwood This was much better because it was a bit closer to home.

April 2014 was nothing out of the ordinary, Darren was getting ready for lunch, prior to dialysis. Suddenly, Darren got a call from his doctor at the Alfred telling him that they had a kidney that matched his blood type! had to stop and drop everything and drive him in. We all went in to the Alfred On arrival we (Ron & Elaine) were told to go home because it could be a while before he was operated on. We got a call the next day saying the transplant was a success and Darren is doing well in ICU. Went in to see him and all the doctors were all around him and when Darren woke up he looked around and he threw up three times all over himself !! After that Darren started to improve and was sent home after about two weeks. He has been going well ever since which is a great relief for Darren and us .-

Ron & Elaine

Words of Wisdom

'Do not pray for an easy life . Pray for strength to endure a difficult one '



ITEMS OF INTEREST

I am still walking my 10,000 steps per day . It has now been fifteen months of daily walks. I had a challenging day recently - It rained nearly all day so I did my walking all around the house. It is much nicer walking outside in the fresh air. It must be awful for people quarantining in a hotel with no access to fresh air.

Craft Corner

I am still knitting-**of course**

I've knitted a dog jumper for my daughter in law's schnauzer, and it fits I am going to make another one in pink for Guoguo. *She is a beautiful dog who loves honey toast.*



Hi & Bye From Angela

WEBSITES you might enjoy:

have you looked at DATA'S site lately? www.datavic.org

Website— www.cari.org.au

CARI Guidelines or mission is to improve the quality of care and outcomes for patients with kidney disease in Australia & New Zealand by facilitating the development and implementation of trustworthy clinical practice guidelines based on the best available evidence and effectiveness.

Website— <https://www.homedialysis.org>

Home Dialysis Central is a one-stop online source of unbiased information about home dialysis - in all its forms - for people with kidney disease, their families and the healthcare professionals who provide kidney disease care.

Polycystic Kidney Disease – PKD.

Polycystic Disease is a lifelong genetic disease. As the disease develops cysts appear on both Kidneys and the kidneys themselves enlarge, often up to five times their normal size, leading to kidney failure.

PKD is the most common life-threatening genetic disease and affects more than 25 thousand Australians and

millions worldwide, representing a significant burden on the health care system. It accounts for 6% of new patients requiring renal replacement therapies.

The progression of PKD is relentless. For the PKD victims that develop kidney failure, dialysis and transplantation are the only available

treatments.

“Knowing that you are likely to end up with Kidney failure is like having a ticking time bomb” PKD patient said.

You can find out more about PKD on their web site

www.pkdaustralia.org

What is worse than raining cats and dogs?

Hailing taxis.



Why don't koalas count as bears?

Because they don't have the right koalafications.

The Maths Class

Applebee, the 6th grade teacher, posed the following problem to one of her math classes:

"A wealthy man dies and leaves ten million dollars. One-fifth is to go to his wife, one-fifth is to go to his son, one-sixth to his butler, and the rest to charity. Now, what does each get?"

After a very long silence in the classroom, little Morris raised his hand. The teacher called on Morris for his answer. With complete sincerity in his voice, little Morris answered, "A good lawyer."



Dialysis and Transplant
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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.

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 Yarrawonga, 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

Hi there to all the sickies , special shout-out to Judy and Phillip Smith, Hope you are both feeling MUCH better. Hello to Ros who has been struggling with aches and pains, hope you are feeling 100% .

In the article 'An Apology' we mentioned the firm Kidney Buzz. There seems to be a problem with delivery, so Ros will chase it up and let you know next issue. We apologize for any inconvenience. Also in the last Shoe String we forgot to mention that article about Peritoneal Dialysis was from the ARCHIVES, and some things have changed.

Send us your letters about: What you did in Lockdown #6. I washed a couple of windows, did some gardening, cleaned the shower, tidied up the ironing room which included emptying the ironing basket .and worked on Shoe String. Now you send us your list or make a list of things you wish you had done!

It appears that we will have to email most ShoeStrings, and the posted Shoestrings will be late. We are unable to access the Office at Mahoneys Road so cannot print envelopes. We are sorry for this and hope to be back in business soon.

Cheers Joan Eastwood