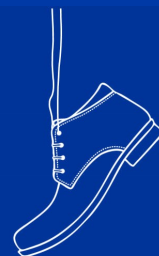


# ShoeString



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



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## Fiftieth Annual General Meeting

NOTICE is hereby given that the Annual General Meeting of the Dialysis & Transplant Association of Victoria Inc (Registration No A0012114V; ABN 40 628 284 998) will be held as follows:

**Date: Sunday 22 October 2023**

**Time: 2:00 pm**

**Venue: Ron Bromley Room, Level 1,  
79 Mahoneys Rd. FOREST HILL Vic 3131**

**Guest Speaker:** Kate Gale, our inaugural Sue Hatzimichalis Post Graduate Renal Nursing Scholarship recipient, will reveal details of the life of a Dialysis Nurse and how DATA has helped progress her skills and expertise through our scholarship.

**Afternoon Tea** will be provided. Please stay after the meeting for a cuppa and a chat. We look forward to catching up.

## OUR NEXT OUTING

Where: **POINT COOK RAAF MUSEUM**

When: 24th September 2023

Time: 12.45 PM Meet outside.

Cost: Free for all .

Where: 480-490 Point Cook Rd  
POINT COOK

RSVP: by 17th September 2023 either by phone or by email.

**\* You will need to fill in a Registration Form\* for this outing see Pge 9**

**You must let DATA know if you are coming.** Phone 9894 0377 Or email [info@datavic.org](mailto:info@datavic.org). **For further details. See page 9.**





# PRESIDENT'S REPORT

Good afternoon all.

I have been tied down with work and unable to contribute to DATA ShoeString this month but some of the items I would like to draw to your attention would be Grant a Dream for Kidney Kids. See details Page3 .My thanks to Steve Shuster for taking care of this matter.

The SHPGRNS We hope to have one of this year's winners to speak to us at the AGM.

We will continue with this Scholarship into 2024 which helps three trained nurses to continue

their renal education with a Post Graduate Renal Nursing Course.

We are working on making a donation to the Purple Bus which does amazing work for dialysis patients in the outback area of Australia. More details as they come to hand.

We are fortunate to be in a good financial position.

What we are lacking is man power. As the AGM comes closer we are aware that some member of Committee may resign. If you feel you could offer to work with the new committee please nominate



If you have any queries please speak to a member of Committee or myself.

Incidentally all current members of the committee must step down and if nominated, be re-elected, at the AGM .

Brendan

## FROM THE ARCHIVES

### ANNUAL GENERAL MEETING.

The Annual meeting will be held in the Leslie Jenner Nurses Home at 1:30 p.m. on Sunday 7th July, 1974.

The Guest Speaker will be Dr. D. Race, Chief Medical Officer of the Hospital and Charities Commission, who will give a short address on the "Methods of Funding the Home Dialysis Programme".

This talk should be of great interest to all and we would like to see as large a turn up as possible - including as many friends as you can roster.

### REPORT ON 1st ANNUAL GENERAL MEETING.

The guest speaker at our Annual General Meeting on Sunday 7th July was Dr. David Race, the Chief Medical Superintendent of the Hospital and Charities Commission, who gave us an insight into the operations of that Commission together with the roles of both the State and Federal Governments. We feel sure that all of those present enjoyed his talk, as was particularly evidenced by the number of questions asked by the audience, and we thank you all for the large attendance.

Special thanks to Dr. Mathews of the Royal Melbourne Hospital, Dr. Atkins of Prince Henry's and Mr. Ansell of the Australian Kidney Foundation for attending our meeting.

## First AGM 7th July 1974

Office bearers and committee were elected:

President: Ian Sutherland  
Vice Presidents: Ken Millen and David McKern  
Secretary: Brian Thomas  
Asst. Secretary: Helen Millen  
Treasurer: Alan Tait

First Patron: Professor Sir Lance Townsend





## Grant a Dream for Kidney Kids

Grant a Dream for Kidney Kids came about in 2023. It was instigated by DATA to:

Acknowledge that children and teenagers on dialysis need provision to take their mind off their treatment

Work with children's dialysis units and provide support for children and teenagers having dialysis

Provide a gift for children and teenagers on dialysis to make their stay more pleasant

Children who are on dialysis do not have it easy, whether it's a toddler or a teenager. Teenagers are defiant – they want to experiment, they don't want anyone telling them what to do

especially parents, they know everything. We can all recall our teenage years, when we were just trying to grow up. So a teenager on dialysis has it really tough, because there are so many constraints.

Toddlers and young children on the other hand, want to be told that this will not last long. They want mom or dad to be with them, they get scared, they don't want to experience anything that is unpleasant, they want to be hugged.

So DATA steps in and tries to make their life a little easier while on dialysis. DATA wrote to the Children's Dialysis Units at Monash and the Royal Children's Hospital to ask how DATA could help ease the burden of dialysis for the children.



So far DATA has purchased:  
A laptop for a 17 year old boy studying year 11 through Virtual School Victoria who is on haemodialysis.

An iPad for a 13 year old girl, on Peritoneal Dialysis who needs to manage her dietary requirements very closely.

An iPad for the Monash Children's Dialysis Unit to distract children while procedures are performed.



From L to R: Steve Shuster, DATA Vice President, Mark Riyadh, Jinan - Mark's Mum, and Angela Lindsey, DATA Secretary

### DATA'S FIRST 'Grant A Dream' PRESENTATION

Brendan Cusack, Clinical Nurse Consultant advised DATA that Mark was in need of a Laptop for his studies.

Mark Riyadh is 17 years old and is originally from Iraq. He spent 5 years as a refugee in Lebanon. He can speak English well, but his mum Jinan has limited English.

He has been on dialysis for 6

years. The last 14 months, dialysis has been at the Royal Children's Hospital (RCH).

He needs a Laptop for his school work. He is completing his Year 11 studies with Virtual School Victoria as he is finding going to school difficult due to his dialysis regime. He gets taken by Patient Transport Ambulance to and from RCH three times a week on Mondays, Wednesday and Fridays.

DATA gave Mark a Laptop on 31<sup>st</sup>

July 2023 so he can continue with his studies. The Laptop can be for pleasure as well. He was given permission that while he is on dialysis he is allowed to pass the time by playing games or browsing the Internet.

We wish Mark all the best and hope that the Laptop will make his studies easier to cope with. But most of all we wish him best of luck when he receives a transplant.



# DATA Holiday Homes

The Rosebud & Yarrowonga holiday homes are for the use of DATA members and their immediate family, with 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.

**Amanda says :** Hello all, As we get closer to summer the Houses are booking up quickly. A reminder - as always, priority is given to Dialysis patients, then Transplants, followed by general members .

Cost is now \$220.00 a week and extra guest \$20.00 per night per guest Happy Holidaying from Amanda .

## Yarrowonga

Why not enjoy a holiday in a great part of Australia just metres away from Lake Mulwala.

**Vacancies :**

**2023 Sept 3rd - Sept 10th**

**Sept 10th - Sept 17th**

**Dec 17 th -Dec 24th**

**Dec 24th - Dec 31st**

**2024 Jan 14th - Jan 21st**

**Jan 21st - Jan 28th**

**Jan 28th - Feb 4th**

Cost is only \$220 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



**Please Remember  
To Take Your Key!**

## 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 :**

**Sept 3rd - Sept.10th**

**Sept 10th - Sept 17th**

**All of October**

**All of Nov**

**All of Dec**

**2024 Jan 14th - Jan 21st**

**Costs** \$220 per week. Extra guest is \$ 20 per night.

For HOUSE bookings please ring

Rosebud House Secretary

Amanda Pratt Ph: 9589 4894

**Have you stayed at either Holiday House in the last twelve months?**

**Tell us about your experience both good and bad**

**We would love to hear from you**



## Pepper's PKD Challenge

### About:

My name is Pepper Rae, I'm 13 years old, and I've been growing my hair since the day I was born. I have decided it's about time I cut it- but I wanted to do something big, and special, and support two causes at the same time

Firstly, I want to raise money and awareness for Polycystic Kidney Disease. Why PKD? Because my mum lives with this disease, and is currently stage 4- meaning she will be starting Dialysis very soon. PKD is a terrible disease that can be passed down from parent to child, meaning it's genetic. It forms cysts that are filled with fluid in the kidney, when you have this disease, it changes the size of your kidney and makes them larger. Pain can differ from nagging discomfort, dull aches and sometimes, severe stabbing pain, often the pain becomes worse when standing and/or walking, but mostly it makes you really, really tired...all the time!

When your kidneys don't work properly, it starts to

change your blood pressure, which then affects your heart, circulatory system and liver. It can cause aneurysms and serious heart conditions and chronic fatigue. With this disease, the only known treatment is dialysis, which is a treatment which is usually done externally to the body, which filters your blood and does the job your kidneys should be doing. Mum will do this until a healthy kidney can be found and transplanted.

This disease is slow, and will cause your kidney failure and eventually shut down. I am raising money for the Dialysis and Transplant Association of Victoria, because they do such an amazing job supporting and taking care of my mum. My goal is \$2000.00 and I pledge to cut at least a foot and a half of my hair with my scout group on the 18th of December!!

But where will my hair go, you ask??

I am donating my hair to an awesome charity that can make my hair into wigs for kids with Cancer.



### Please come forward

*Although we have made attempts to locate you through My Cause, we have been unsuccessful. Please make contact with our office so we can thank you personally for your courage and resolution to benefit others.*

***DATA received \$ 2,287.00 from My Cause***



## Judy & Phillip Smith's Travel Tales

Six weeks ago my husband Phillip and I set off on a holiday in Victoria and NSW in our caravan.

I had been quite unwell following Immunotherapy, Covid - which is deciding to stay with me but gradually improving and a disastrous fall on our kitchen floor where I split my forehead open requiring a few days in hospital and 23 stitches as well as cutting my arm at the same time. Unfortunately I lost my confidence to be in the house on my own and walking without a four wheel frame was out of the question. Phillip decided we needed a break away from medical appointments and we managed three and a half weeks by utilising Telehealth with my Nephrologist, Plastic surgeon and GP.

Medical issues solved, the next hurdle was getting me up the steps of the caravan.....nothing beats Phillip and he set about making a ramp along with a hand rail for me.



Our first couple of stays were in Wagga Wagga and Temora visiting relatives, and from there we spent three nights exploring Cowra. Such an interesting town with beautiful gardens and museums depicting sad stories of POW camp sites, cemeteries and stories of struggle and survival.



We left Cowra and drove to Dubbo enjoying the many pieces of Silo Art along the way. The Royal Flying Doctor Service was most interesting and informative, as were the beautiful old buildings in town.

A couple of years ago, during the drought, we had driven as far as Lightning Ridge where we encountered dust storms, very little if any livestock and dry river beds as far as the eye could see.

However, on this trip the scenery was certainly different with sheep and crops in the paddocks, hundreds of wild goats prancing around and water in the rivers. Such a change! The size of the stations along the highway are huge and spread for hundreds of kilometres, surely a somewhat lonely life however I hear life in the outback is never dull.

From Dubbo we drove to Bourke. We had explored there previously but enjoyed searching the area again and visiting the cemetery where Fred Hollows is laid to rest. Such beautiful tributes to this marvellous man.

On through the cotton fields to Cobar an amazing mining town for an overnight stay. We had not been to Cobar before so spent quite a bit of time there learning the local history and enjoying the well preserved old buildings.

Our next stop was a night in a tiny settlement called Wilcannia which is on the Darling River and the camping ground is beside a Billabong. Wilcannia is the turn off point to White Cliffs a famous opal mining town but unfortunately time did not permit us to visit



## Judy & Phillip Smith's Travel Tales

there however there is always a next time. The camp site manager lit a camp fire at sunset and sang and played his guitar. He supplied nibbles and the dozen or so caravan occupants took a drink and a chair to join in a lovely happy hour chatting amongst ourselves about our travels.

The roads are so straight and the rich red land flat but there is always something to see. Arriving in Broken Hill, after setting up camp we made our way to The Palace Hotel which was used for filming Priscilla Queen of the Desert for a drink and the obligatory photo shoot beside the extra large jewel encrusted high heel sandal.

The five nights spent in Broken Hill were fabulous. So many interesting things to see and do. We visited railway, mining, gem and art museums, a Jewish museum and the amazing Miners Memorial set on the highest point of Broken Hill overlooking the township, a sobering experience. Broken Hill is the home of artist Pro Hart, a yummy ice cream shop which also sells proper malted milks which required two visits, and sand stone free standing sculptures in the Living Desert State Park.

Silverton is a mining ghost town about half an hours drive from Broken Hill whose old buildings are now art and craft shops. It boasts a fabulous rustic hotel and a large tribute to The Mad Max film which was produced there. Dusty and desolate with grass tufts scattered around, there are many donkeys free



roaming the town. To complete our day, we joined with other tourists on the hill of Mundi Mundi outside Silverton armed with rugs, chairs, nibbles and wine to

watch a most beautiful sunset.

Reluctantly we left Broken Hill and drove to Mildura for four nights. What a surprise, as we settled in we discovered The Big Red Kidney Bus in the caravan park, sponsored by the Rotary Club of Croydon. It proved to be busy with people coming and going for their dialysis throughout the days.

We spent a couple of days with my Primary school girlfriend and her husband as they toured us around the town and outlying area, my god daughter and her family and relaxed in the sunshine with a book. Unfortunately the day we left Mildura it was pouring with rain so a wet pack-up and an unpleasant drive to St Arnaud caravan park to spend an evening with my cousin and her husband.

As we drove home the next day relaxed and ready to face the onslaught of medical rounds, an ACAS assessment and a Carpal Tunnel operation (which I had last week and another to follow when it's healed) we reflected on the beautiful country in which we live.

We have already started to plan our next adventure.

Judy Smith



This is a picture of Judy checking out the Big Red Kidney Bus.

*Editors : Thanks Judy for this interesting story , we can't wait to read the next instalment.*



## RECENT OUTINGS

### Visit to the Museum

On the 25th June a small group braved the cold weather and attended the Melbourne Museum and exhibition Fantastic Beast: The Wonder of Nature.

The exhibition was a mixture of actual animals and the creatures of the Wizarding World.

Following the exhibition we were free to wander around the Melbourne Museum which included Dinosaur, Triceratops: Fate of the dinosaurs, The First Peoples exhibition and Marvelous Melbourne to name just a few exhibitions on display.

Following our walk around the exhibitions we all met back at the Café for a drink and something to eat.



### Christmas in July

Here we all are at the Watsonia RSL where we enjoyed a lovely midday meal on 23 July ... We had the traditional meal of ham, turkey and vegetables followed by plum pudding with custard & cream.. It was a small crowd but a good mix of old and new DATA members. Ken Donnelly very kindly donated a door prize of a voucher for French Island Vineyards Restaurant which was won by Nicole.







## FUTURE OUTINGS

Where: **POINT COOK RAAF MUSEUM**

When **24th September 2023**

Time **12.45 PM Meet outside.**

Cost **Free for all**

Where: **480-490 Point Cook Rd  
POINT COOK**

RSVP: **by 17th September 2023**

by phone or by email.



**\* You will need to fill in a Registration Form\* for this outing. See details below.**

**Please let DATA know if you are coming.** Phone 9894 0377 Or email [info@datavic.org](mailto:info@datavic.org)

\* If you are interested in this outing you must go on line and fill in the Registration form. You need to know CAR REGISTRATION. And number of people travelling in that car.

**To book :** type into your Search engine: [airforce.gov.au/community/visit and learn/raaf-museum/plan a visit](http://airforce.gov.au/community/visit%20and%20learn/raaf-museum/plan%20a%20visit).

- ♦ **October outing** will be the Annual General Meeting 22. October 2023 See Agenda AGM Below more details Page 1.
  - ♦ **November Outing** will be a surprise. Please keep the date free --That's. Sunday 26th November.2023
- Our plans are a little bit hazy yet but we are working on something special. **Please Keep the Date Free.**



## AT THE CHOCOLATERIE

Chocolaterie at Yarra Valley is a beautiful place on a nice sunny day. Melbourne gave us a very pleasant Sunday afternoon on 27th August. Eight DAATA members & friends has a lovely day at the Chocolaterie. The scones are not big they are huge. After a bite to eat we all headed for the tasting. The chocolate was all nice, it's hard to choose a favourite. We tasted chocolate coated nuts, cookies & cream, rocky road as well as several more samples. We all went home with bought chocolate for later, but how much of the chocolate did not make it home. If you haven't been to the Yarra Valley Chocolaterie you must go, especially if you are a chocoholic.





## The Kidney Project Update.

The Kidney Project in USA is developing a bio kidney which has been tested in pigs and should be available for human testing in several years. ShoeString printed an article from Mark Wolfenden in January 2023 about the Kidney Project.

### **Kidney Project update from Mark Wolfenden**

Bo from the Kidney Project has written with some exciting news. They have been awarded USD \$ one million dollars, prize money which will be a massive shot in the arm for the Project.

I have asked Bo for some more specifics around the milestones they hope to achieve with this much needed injection of funds, which I'll share with you when he responds.

Dear Mark,

I'm reaching out to share some exciting news regarding The Kidney Project. Dr. Shuvo Roy and The Kidney Project team were just awarded their fourth prize from KidneyX, a public-private partnership between the U.S. Department of Health & Human Services and the American Society of Nephrology that was founded to accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases. The Kidney Project is the only group among kidney innovators to have won four prizes! This year's KidneyX Prize of \$1 million was awarded to advance The Kidney Project's prototype bio-artificial kidney toward a human scale, with manufacturing and, ultimately, clinical trials on the horizon.

This important prize would not be possible without the support and advocacy of you and other Kidney Project supporters. Thank you!

More info on the prize can be found [here](#).

<https://pharmacy.ucsf.edu/news/2023/06/scaling-bioartificial-kidney-ucsf>

Additionally, The Kidney Project and Dr. Roy continue to be recognized for this important work in various publications. You can read more in [this Nature article](#) - <https://www.nature.com/articles/d41586-023-00653-6> about the project's potential to significantly improve the quality of life for dialysis patients that highlights Dr. Roy as one of the top 12 innovators in the Bay Area.

Once again, thank you for helping to get The Kidney Project to this point! The work isn't done, with a number of important milestones ahead to reach the first in-human clinical trials. This important work isn't possible without continued support and advocacy.

Please do not hesitate to reach out if you want to learn more. We look forward to providing future updates as The Kidney Project continues to hit milestones and builds towards the world's first implantable kidney.

Bo O'Hare

Senior Director of Development      UCSF



# Trivia Page, Bits & Pieces.

*Smart is when you believe only half of what you hear.*

*Brilliant is when you know which half to believe.*

Leather is "rated" based on its texture. Cows with abundant water sources typically have softer hides, rated "A". But hides from cows living in hot, dry climates are typically **D Hide-Rated**.

Do you know what would have happened if it had been three wise women instead of three wise men?

They would have asked directions,

Arrived on time

Helped deliver the baby

Cleaned the stable

Made a casserole, and,

Brought practical gifts.

Pass it on to the wise women in your life!!!



### Peter's Trivia

DID YOU KNOW that fleas can jump two hundred times their body length and can accelerate fifty times faster than the space shuttle.

### Peter's Trivia

Did you know babies are born with about 300 bones, but by adulthood we have only about 206 bones.

### Peter's Trivia

Did you know the phrase 'rule of thumb' is derived from an old English law which stated that you couldn't beat your wife with anything wider than your thumb.



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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 13 OCT 2023

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](mailto:editor.shoestring@gmail.com)**

Shout out to all the sickies from DATA. Elaine Hennessey has been in hospital & after Care most of the month. Darren H had his share as well, with chest infection and a few days in hospital. I am sure Ron will be glad to see her home.

Another one is Mischelle & Brian Wallis have been having a hard time over Xmas 22 and Mischelle spent some considerable time in hospital. I hear you are back on track now, Mischelle. Stay well.

Send us your articles for ShoeString Thanks to Judy Smith for her article on page 6 & 7..

Thanks to my co- Editors Gwen & Angela .

See you all at the AGM