

ShoeString



Newsletter of the Dialysis & Transplant Association of Victoria Inc.

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Dialysis and Transplant
Association of Victoria Inc.

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Yarra River Cruise

On a drizzly Sunday morning, 28th April, 24 DATA members and friends braved the Melbourne weather for the Melbourne River Cruise. It was a cold day but everyone was rugged up. The hour journey from Federation Square to Gem pier in Williamstown was smooth and there were many sights to see as pointed out by the captain. Lunch at the Custom House was enjoyable and the meals were big.

The Maritime Museum was a great hit. It was free to enter and there are many things to see.

1. Steve Irwin flagship docked at Williamstown was used by the Sea



Shepherd Conservation Society to campaign against whaling.

2. The Bluestone morgue was constructed by convicts. Apparently, ghosts frequent the morgue.

It was an enjoyable day overall. It was nice to see some different faces.

See you at the next outing.

Social Committee

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Forthcoming Events

COFFEE & CAKE is our next outing on May 14th at 2pm at **STUDLEY PARK BOAT HOUSE**. 1 Boathouse Road Kew, OR

COFFEE & CAKE 2pm on Friday 24th May at **BUNDOORA HOMESTEAD**

7 Prospect Hill Drive Bundoora. RSVP to the Office 98940377 by 17th May.

RAAF MUSEUM at Point Cook

On Sunday 23rd June at 12.30pm. Entrance is at 430-490 Point Cook Road. Point Cook.

There is no cost but please be aware that adult visitors are required to produce a photo identification and sign in, to gain entry.. RSVP 17th June to 9894 0377

CHRISTMAS IN JULY DINNER is planned for 27 July. Please keep this date free. More details in next edition of Shoe String.

All of these outings can be replied to by the due date to the Office

Phone 03 98940377 or

Email: info @ datavic.org



President's Report

Hello, Hello, from in front of my fire place, hope you are all keeping well and warm!

We had a wonderful day on the ferry to Williamstown on Sunday 28th see front cover for photos.

LAST NOTIFICATION for RON JONES EDUCATIONAL AWARDS. If you have school age children Year 6 to 11, please get them to put in an application. See page 5 for the Ron Jones Application. Applications close on 30th June 2019. The winners will be presented their awards at the AGM in October.

Here are my nags....nags are the things you do to your partner or children to get them to help around the house for you....so DATA needs some help around the "ShoeString" house...

1. We need you to write about your experiences of being a carer or going on Dialysis whether it is haemodialysis, PD, Nocturnal, Home Dialysis, or even a Transplant recipient, they are all treatment for Renal failure and we all have the same issues but we feel so alone,

your story could help someone come to terms with their diagnosis. We all know there is someone worse off, but in the family of Kidney Disease it is nice to know you could have the same problem as the guy next to your dialysis chair....so please share your story!

2. We always need volunteers to fold and pack ShoeString, so once again please help. More people make the job smaller and time goes really fast. We normally do this on a Sat/Sun afternoon, just ring the office and leave a message and Gwen, our office administrator, will let our editorial committee know.

3. Please join us on our outings, we have a wonderful time and we would love to see new faces at these days, we have so much fun. The next outing is Coffee & Cake on Tues.14th May 2pm at **Studley Park Boathouse** and / or on Friday 24th May to **Bundoora Homestead 2pm** see Details page 1

4. My last nag for the month is, if you are going to join us on our outings please RSVP on or before the deadline date and only RSVP to the



Sue Hatzimichalis 0412 469 738

office phone number or email address so Gwen can add you to the list. She will then confirm or cancel as necessary and let me or Angela know the numbers!

Gee, you are lucky, I had only four nags, so until I see you or hear from you, keep warm, and stay out of trouble, like I will!

Cheers from

Sue Hatzimichalis

Words of Wisdom

Sometimes you just need to talk about something not to get sympathy or help but just to kill it's power by allowing the truth of things to be told.

Sun Theatre Yarraville

The Movie, 'Mary Poppins Returns' was fantastic. It was full of truisms and heart wrenching pathos as the old characters of the first Mary Poppins strutted their stuff. Sixteen of us went to see it with DATA at the Sun Theatre, Yarraville. We had the theatre all to ourselves so the choice of where we sat was great. The chairs were very comfortable so feet up & relax. The afternoon tea was great, plenty of yummy cakes with good company & plenty of chatter.





Patient and Carer Forum

On Sunday 14th April, some DATA committee and members attended the 2019 ISN (International Society of Nephrology) WCN (World Congress of Nephrology) Patient and Carer Forum. (see photo)

The forum consisted of: Exercise in ESKD, Symptom and Self-Management, Dialysis related Fatigue, Consumer Involvement in Kidney Disease Research, The Carers Perspective and a Panel Discussion.

Dialysis can be debilitating and exhausting, with fatigue being the number one symptom. It's hard to get motivated when one is fatigued, but

exercise is the best treatment. Exercise can also improve fitness, and walking can improve the quality of life and depression. We should never be too hard on ourselves - all movement counts. Despite being fatigued pushing through this problem and exercising will help.

Rob Smith is a radio host and a fisherman in the Northern Territory. He has been on haemodialysis for quite a number of years. He has taken his dialysis machine and dialysed in a tent. You can see him on You Tube - "Tales From The Tinny - Host goes fishing". Rob was a guest at Fresenius Medical Care Booth. His appearance clashed

with the forum, but he would have been great to meet.



Kidney Education in Primary School near you?



Thanks to generous sponsorship by D.A.T.A. members, the Healthy Kidneys Education Project run by FILTER YOUR FUTURE is now accepting bookings to visit primary schools throughout Melbourne in terms 2 & 3.

If you have family members/grandchildren/friends attending a Melbourne primary school and would like the FREE program to be brought to that school, please contact Yvonne: yvonne@filteryourfuture.com.au. Yvonne will be happy to arrange a school visit on request.

You can view the program in action at: www.filteryourfuture.com.au

Feedback from A Member

Just a quick note to say congratulations on the latest edition of shoestring- it has so many interesting articles and things that are coming up in which members can take part. The new style and set up makes it very appealing. I can't remember when my late husband and I joined DATA but I have always found it interesting and wish I could be able to do more and participate in some of the events you organise, but

living in the country and having a busy life doesn't always allow the time for me to do so. I have been pleased that I have been able to help fold and prepare the Shoestring newsletters for posting on a couple of occasions, the latest being this one just out.

I have forwarded this copy to my sister who has a grandson, (early 30's!), on dialysis, and whom I don't think are members therefore don't receive this.

Hopefully they will read it and find the information of benefit to them and perhaps become members. Looking at all the outings you have coming up, I would like to think that I may be able to take part in something in the future. Congratulations again on the new format.

Regards,
Enid Kay.

Ed: We have had positive feedback from a number of readers about the new format of ShoeString including this from Enid Kay. Thank you Enid and everyone else for your kind words.



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.

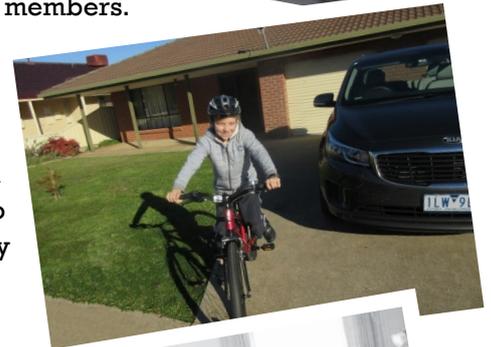
Both houses can facilitate haemodialysis machines. For those members on home dialysis, please contact the House Secretary to discuss if your hospital technician can supply and install a dialysis machine in the house for your holiday.

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. Please don't forget to clean the BBQ's No one wants to be faced with cleaning the Barbie before enjoying their meal.

No pets allowed with Guide dogs being the exception.



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 From 23th June 30th June. 28th July to 31st July, All August and 1st September to 15th September.

Cost is \$ 180 per week. Extra guest is \$ 20 per night.

Bookings at the Rosebud Hospital Renal Unit must be done online email to: holidayatrosebud@phcn.vic.gov.au

For HOUSE bookings please ring
Rosebud House Secretary
Amanda Pratt Ph: 9589 4894

Yarrowonga

A word about keys : Please return keys in **padded Post Pac bag** to House Secretary. Keys are often lost because they are returned in ordinary envelope which get caught in the sorting machines at the Post Office. All we receive is a torn envelope.

Vacancies From 1st June to 29th June. From 8th July to 31st July. From 1st August to 24th August. All September

Cost is only \$180 per week for you and your immediate family. Call as I do get vacancies.

Bookings at the Yarrowonga Renal Unit Ph: 5743 8189

For HOUSE bookings please ring
Yarrowonga House Secretary
Alan Rawson Ph: 9723 3019

Email: fayal_rawson@hotmail.com



**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**
- **Contact the hospital again to confirm your dates and book in**
- **Finally, ring to book the Holiday House**



Ron Jones Educational Awards



These awards offer a fantastic opportunity for students between years 6 to 11, to shine.

Applications for the Ron Jones Educational Awards, are now open, so fill out your Application form below for a chance to win fabulous prize money.

Assessment is based on the Applicant's school reports together with essay on the topic of 'My Chosen Career'.

There are two levels of Awards to be won. One Award is based on excellence and scholastic ability plus three Awards for encouragement.

The Ron Jones Educational Awards honour the memory of a founder and long time dedicated worker for DATA, Mr Ronald N Jones, AOM.

- Applications must include a handwritten essay of 300 words entitled 'MY CHOSEN CAREER'.
- Please include the Applicant's previous year's school reports.
- Applications must be received no later than the **30 June 2019**. Winners will receive awards at the AGM in October 2019.

Please fill in this form using Block Letters and forward it to:
The Secretary, DATA Vic Inc, PO Box 159, FOREST HILL Vic 3131

SURNAME GIVEN NAMES

ADDRESS

POST CODE DATE OF BIRTH

HOME PHONE MOBILE

PARENTS / MEMBERS PARTICULARS
(IF APPLICANT MEMBER IS UNDER 18 OR A CHILD OF A MEMBER)

SURNAME GIVEN NAMES

ADDRESS

POST CODE PHONE MOBILE

SIGNATURE OF STUDENT

SIGNATURE OF PARENT

Financial Member of D.A.T.A. YES NO

MY ESSAY ON "MY CHOSEN CAREER" AND SCHOOL REPORTS FOR THE LAST YEAR ARE ENCLOSED.

YES NO

SCHOOL PARTICULARS:

PRESENT YEAR OF STUDIES

SUBJECTS STUDIED

.....

.....

.....



Itch

With thanks to Greg Collete for allowing us to copy this article from his blog **The Big D and Me**.

Treatment

The big one is to completely avoid scratching the affected areas. But when it gets crazy itchy, the question is how?

Creams

Anti-itch creams like Antroquoril (a moderately strong rub-on corticosteroid) helps stop the itch. It doesn't treat the cause (what does?), but less scratching helps the spots calm down and maybe fade into the background (maybe).

My skin specialist prescribed it for me, and it's working.

Phototherapy

If the Antroquoril cream doesn't make the grade in the longer term, he suggested I line up for the Phototherapy. There are two types:

1. UVB phototherapy is irradiation with shortwave ultraviolet radiation. To treat the whole body, the patient, undressed, stands in a specially designed cabinet containing fluorescent light tubes.
2. Psoralen Ultraviolet Light A is a combination treatment, where Psoralen (a light-sensitive drug) in cream form

is rubbed on the skin to make it temporarily sensitive to UVA (long wave ultraviolet radiation). The skin is then exposed to UVA. The lamps stay on for increasing lengths of time, starting with about one minute and extending for up to half an hour.

It's been a couple of weeks since I started the cream and I use it twice a day. There is much less itch (though I need a quick scratch every now and then).

Maybe, if things continue to improve, I'll be able to retire my trusty back scratcher- or at least hang it out of site.

Service of Remembrance & Thanksgiving

The Service of Remembrance honours all organ and tissue donors and their families in Victoria. This Service is a ceremony of reflection and remembrance, and is open to anyone that has been touched by organ and tissue donation.

The Service will be held at the **Collingwood Town Hall on Saturday 25th May 2019, at 2pm**. Easily accessible by public transport, an annual event and a 'must do' for all donors and recipients, at least once, always a very moving service.

Check out the website: www.donatelife.gov.au/events/events/vic



From the Archives - Shoestring July 1978

NEWS FROM ENGLAND.

The following is an extract from the Daily Express, London and will be of interest to all members.

THE GIFT OF LIFE OLYMPICS.

The world's first "Kidney Olympics" are to be staged in Britain this summer. Men, women and children who have successfully undergone kidney transplant operations are being invited to compete.

The idea is to drive home the message that successful transplants enable patients to lead normal and energetic lives.

Already the Health Department is showing keen interest and has

promised support together with many organisations.

The amount needed to stage the Olympics at Southsea Common in August is five thousand pounds.

The man who thought up the idea, hospital consultant Maurice Slapak, co-director of the Wessex renal unit in Portsmouth, said "Something like 32,000 transplants have been carried out throughout the world. But initially we are confining the first games to British and some European countries.

"Later we shall extend the scope so that it becomes truly international". Teams of transplant athletes from 30 renal units in Britain have been invited. Reaction has been very encouraging.

A wide variety of events is planned: sprinting, long distance running, riding, squash, badminton, archery, discus throwing and jumping - high and long.

One event is banned - boxing - because of the danger of kidney punches.

As well as emphasising to people throughout the world the excellent results of the operation, the Games also aim to stress the urgent need for kidney donors.

Adds Mr. Slapak "All we need now is some financial support and a nice sunny day to guarantee success".



Live Your Dream

This article was sent to Shoestring last year by George Said.

Live Your Dream & Growing Up!

The first day of school our professor introduced himself and challenged us to get to know someone we didn't already know. I stood up to look around when a gentle hand touched my shoulder. I turned around to find a wrinkled, little old lady beaming up at me with a smile that lit up her entire being. She said, "Hi handsome. My name is Rose. I'm eighty-seven years old. Can I give you a hug?" I laughed and enthusiastically responded, "Of course you may!" and she gave me a giant squeeze. "Why are you in college at such a young, innocent age?" I asked. She jokingly replied, "I'm here to meet a rich husband, get married, and have a couple of kids..." "No seriously," I asked. I was curious what may have motivated her to be taking on this challenge at her age. "I always dreamed of having a college education and now I'm getting one!" she told me.

After class we walked to the student union building and shared a chocolate milk shake. We became instant friends. Every day for the next three months we would leave class together and talk non-stop. I was always mesmerized listening to this "time machine" as she shared her wisdom and experiences with me. Over the course of the year, Rose became a campus icon and she

easily made friends wherever she went. She loved to dress up and she revelled in the attention bestowed upon her from the other students. She was living it up. At the end of the semester we invited Rose to speak at our football banquet. I'll never forget what she taught us. She was introduced and stepped up to the podium. As she began to deliver her prepared speech, she dropped her three by five cards on the floor. Frustrated and a little embarrassed she leaned into the microphone and simply said, "I'm sorry I'm so jittery. I gave up beer for Lent and this whiskey is killing me! I'll never get my speech back in order so let me just tell you what I know."

As we laughed she cleared her throat and began, "We do not stop playing because we are old; we grow old because we stop playing. There are only four secrets to staying young, being happy and achieving success. You have to laugh and find humour every day. You've got to have a dream. When you lose your dreams, you die. We have so many people walking around who are dead and don't even know it! There is a huge difference between growing older and growing up. If you are nineteen years old and lie in bed for one full year and don't do one productive thing, you will turn twenty years old.

If I am eighty-seven years old and stay in bed for a year and never do anything I will turn eighty-eight. Anybody can grow older. That doesn't take any talent or ability. The idea is to grow up by always finding opportunity in change. Have no regrets. The elderly usually don't have regrets for what we did, but rather for things we did not do. The only people who fear death are those with regrets." She concluded her speech by courageously singing "The Rose." She challenged each of us to study the lyrics and live them out in our daily lives. At year's end Rose finished the college degree she had begun all those years ago. One week after graduation Rose died peacefully in her sleep. Over 2,000 college students attended her funeral in tribute to the wonderful woman who taught by example that it's never too late to be all you can possibly be. These words have been passed along in loving memory of ROSE. REMEMBER, GROWING OLDER IS MANDATORY. GROWING UP IS OPTIONAL. We make a Living by what we get. We make a Life by what we give.

Thanks George for this one—an oldie but a goodie. The Editors

Jokes Corner

There is a man at the door collecting for the old people's home. Shall I give him granny?

"Doctor, my family think I'm mad!"

"Why is that?"

"Because I like sausages."

"Nonsense, I like sausages too."

"You Do? You must come around sometime and see my collection. I have hundreds."



Meet Mr. Bates, our perfect patient. He controls his fluid levels by not drinking and his potassium, cholesterol and phosphates by not eating.



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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 21 JUNE 2019

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

Another issue of SS with interesting articles and events. We hope you enjoy reading them. We hope you have had a great Easter and have not over indulged in chocolates.

We have also received many positive congratulations on our new look SS. We can't put all the letters or emails in but there is a very encouraging one on page 3.

Send us your ideas, stories, or items you would like covered in Shoe String. Maybe you could just say hello.

We look forward to hearing from you

The Editorial Committee email: editor.shoestring@gmail.com

