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The social program for 2019 kicked off with the successful BBQ at Rosebud and culminating the chairlift ride to Arthur’s Seat – read report on page 3.

This month we head out to Movies, see page 8 for details. In April we cruise the Yarra river see page 8 on how you can participate in this.

In May we have the mid-week coffee and cake days, check out page 9 for details.

Other events we are planning for later in the year are:

- Point Cook Museum
- Living Legends
- Puffing Billy

And of course our Christmas in July and the Christmas party in November. We thank the Social Committee for their great work in putting together this program. We hope to see many of our members at these functions. We always welcome suggestions from members on what other events we can put together. So put your thinking caps on and let us know what you would like to see on the program.
President’s Report

Hi Everyone,
Gee, haven’t we had some hot weather, hope you all kept hydrated but not overloaded! Well, I can’t believe we are in March already, Easter will be upon us next month and we will have those hot cross buns staring us in the face along with those Easter bunnies from Red Tulip, mmmm, must say they are my favourite.
The social committee was planning to go Bare Foot Bowling this month but Alan Thompson who organises it for us is unavailable. We are keeping the event in the West and going to the Movies...Whooppee!!!! We have booked our own cinema at the SUN Theatre. DATA will subsidise this event. See article on Page 8 for booking and more details. Kids of all ages welcome!
Our first event at Rosebud House followed by a Gondola ride on the “Eagle” at Arthur’s Seat, went very well with a good number attending see article page 3.
We still have a date with Mr Bill Shorten’s medical advisor to speak about the Healthy Kidney Program and I will let you know more as I learn more but because an election is on the horizon it might be a little longer than we thought but we will get there!
Please talk to your children, and grandchildren (if they qualify) about the Ron Jones Educational Awards, it can help in many ways, and think about how proud you would be if one of them received an award.
Our website is nearly finished, we had a little viewing of it at our last committee meeting, looks really good. A big thank you to Charlie Ball, for all his liaisons with the creators of it, altogether I think we should be very proud of their work. I am still on my soap box, so please if you have any good ideas for outings, if you can supply us with stories, jokes, or even help packing please do not hesitate to call me or any of the committee members to offer your services! We cannot do this alone and sometimes we need help!
Please volunteer, you would be most welcome, or even just attend the outings, it is nice to see and meet more members, other than the committee!
Cheers
Sue Hatzimichalis
President.

Transplant Games

The next Australian Games are due to be held in September 2020. The next World Transplant Games will be held in 2019 in Newcastle/Gateshead in the United Kingdom, August 17 to August 24th 2019.
One of the main purposes of the Australian Transplant Games is to reinforce the value of organ and tissue donation - basically to thank all those wonderful doctors and nurses for the care they have shown. Also a thank you to all the donors and their families.
Rosebud BBQ

What a beautiful Sunday afternoon, perfect Melbourne weather on 24th March. 36 people, including Maddison 18 months old, came to Rosebud holiday house for a BBQ. If you haven’t been to the house you should make arrangements for a holiday, it’s spacious with a big back yard, perfect for children. We had sausages, salads and some lovely biscuits. It’s not the food but the company that is always great. It was wonderful to see new faces as well as familiar ones of course. 26 people, plus Maddison, soared The Eagle - what a smooth ride. The view from Arthur’s seat of Port Phillip Bay, Dromana and Rosebud was terrific. Come and join us at DATA social events which are generally held on the 4th Sunday of the month. We have fun, we laugh, we gossip (only sometimes), we eat and always have a good time. Hope to see you at our next event in March.
The Social Committee

Welfare and Accommodation Support.

Don’t forget! DATA offers financial assistance to members who face hardship because of their renal condition. Also, our Accommodation Assistance Program can help those who need to pay for commercial accommodation when attending medical appointments. Contact one of the committee members for more information.

Words of wisdom

Be nice to your kids because they would choose your nursing home

The wish bone will never replace your back bone
**DATA Holiday Homes**

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 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.

**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.

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

**Vacancies:**

- From 10 March to 7 April and from 5 May to 31 May

**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

**Yarrawonga**

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

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

**Vacancies:**

- None for March and April. For May - 5th to 12th, 12th to 19th, 19th to 26th, 26th May to 2nd June. For June - 2nd to 9th, 23rd to 30th. None for July.

**Bookings at the Yarrawonga Renal Unit Ph:** 5743 8189

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

Email: fayal_rawson@hotmail.com

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**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
- Contact the hospital to confirm booking dates
- Finally, ring to confirm the booking dates for the house

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Please Remember To Take Your Key!
Ron Jones Educational Awards

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 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 ..............................................................

..............................................................
Service of Remembrance

The Victorian Service of Remembrance will be held on Saturday 25 May 2019 at Collingwood Town Hall. Although Donate Life have moved venue in recent years, the Service is always held in the last weekend in May (traditionally on the Saturday).

There is adequate parking and it is easy to get to via the train, stopping at Collingwood station.

Travelling

Here is a list of things to consider.

- Letting your dialysis nurse know you wish to travel is necessary and they can help you plan your trip away. Remember the more time you have for planning the easier it will be. The nurses will also see that your recent dialysis notes are sent to the unit of your destination.
- Contact the dialysis unit you wish to dialyse at. You may need to contact several units before you find a unit with a spare chair. Kidney Health Australia has a website of dialysis units throughout Australia.
- REMEMBER to confirm your booking at the unit before you go.
- If necessary, let your insurance provider know.
- If you book flights, ask for a low-salt meal.
- Ensure you have the correct medications and enough while you are away.
- Pack medications and relevant medical records in your carry-on luggage.

Peritoneal dialysis and home haemodialysis

- Talk to the home dialysis nursing staff about your travel plans.
- Talk to your nurse about how to pack your supplies or ship them in advance. (If requiring large quality of supply, Baxter will help.)
- If flying ask your airline for a low-salt meal.
- Ensure you have the correct medications and enough while you are away.
- Pack medications and relevant medical records in your carry-on luggage.
- Write down the contact details of the dialysis unit at your destination just in case you need help or forget any essential supplies.

Please note that more arrangements are necessary if travelling overseas. Check with your nurses. Kidney Health Australia has travel information on their website. If you want a holiday overseas, remember there is Dialysis Abroad and Dialysis Escape Line. There is more information on holidays further on in this issue of ShoeString.

Welfare and Accommodation Support.

Don’t forget! DATA offers financial assistance to members who face hardship because of their renal condition. Also, our Accommodation Assistance Program can help those who need to pay for commercial accommodation when attending medical appointments. Contact one of the committee members for more information.
**Transition from Peritoneal (PD) to Haemodialysis (HD)**

*Article by Charles Catania*

Had been on PD for eight and a half years, until my kidney function dropped to 7%. The renal specialist at Box Hill Hospital advised that I consider going on to haemodialysis. He suggested I start once a week on HD. And continue with the PD in the evenings.

I started one day a week on HD in May 2018. By August I needed to change to 3 times. I was unable to have this treatment at 5 Arnold Street on the days I wanted however Peter James in East Burwood were able to accommodate me.

My Tenckhoff has not yet been removed but is due for removal early March 2019 at Box Hill Hospital, seven months since I stopped PD permanently. This delay was caused because I had a mild heart attack in September which subsequently led to a triple by-pass in October. After 7 weeks in the Alfred Hospital and another week at the Box Hill Rehab I was discharged and am now on the way to being fit and healthy again.

Since I have been on haemodialysis I enjoy reasonably good health. For the eight and half years I was on PD overnight, my days were free whereas with hemodialysis 3 of my days are taken up with this very necessary treatment.

While haemodialysis can also be done at home, my wife and I are wooses when it come to needling.

I was fortunate to stay on PD as long as I did. In most cases PD is good for about 4 or 5 years, after which the transition is to haemodialysis.

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**New Committee Member**

*My name is Margaret Hagedorn*, I am now on DATA Committee for the first time though I have been member of DATA since 1983.

I have always enjoyed DATA social outings, meeting others with similar problems. I have been packing Shoe String for about twenty years and love reading the magazine I loved Blackburn and the social days we had there.

My husband, Gerd, commenced dialysis in 1986 at a centre near the Royal Melbourne Hospital (RMH) as the hospitals did not have satellite centres then. After dialysing for 12 months, we commenced the six-week home dialysis course. We started on the Drake Willock machine at home, we did this for four years then a donation became available on the register. We carried a beeper and rushed into RMH. Unfortunately this first attempt did not work - because of Gerd’s immune system was too strong for the kidney to be able to function.

After eighteen months another welcome donation. The RMH team were ready with plasma exchange, taking his antibodies out three times per week for three weeks. At last, Gerd’s system welcomed the kidney from a wonderful family on the register. Gerd had good function for about twelve years. Then, as fibrosis and end stage renal failure set in he returned to dialysis, but he was grateful, as he was stronger now. He was now on a COBE computer machine and with EPO injections kept so well. Later other health issues took over and in 2008 Gerd passed away. We were so grateful that he lived for twenty-five bonus years under the supervision of Professor Becker.

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**Kidney Disease is not choosy!**

In last month’s edition we reproduced an article about Jack Thompson ..... This month we refer you to an article about another celebrity, Sarah Hyland, US actor and star of TV sitcom Modern Family. For those with internet access read an interview with Sarah where she talks about her two kidney transplants and how she copes with living with kidney disease. [https://www.self.com/story/sarah-hyland](https://www.self.com/story/sarah-hyland)

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**Kidney Health week is between 8th– 14th April 2019**

DATA would welcome your suggestions on how we can participate in this Health week.
Melbourne River Cruise

Come and join the DATA family for a great day out on a Melbourne River Cruise for a return trip from the city (Federation Square) to Williamstown. The trip takes 50 - 60 minutes each way. Best way to get to Federation Square is by public transport (tram to Federation Square or train to Flinders Street) although there is parking available at Federation Square.

Things to see and do at Williamstown, which is an old maritime seaport. - Visit HMAS Castlemaine a WW2 mine destroyer (docked at Gem Pier).

Cost is $8 adults and $4 children 4 - 16 years.

- have a picnic in the park
- let the children play in the playground
- admire the stunning waterfront bay views of our beautiful city
- have fish and chips for lunch. If people are interested to have lunch at Custom House Hotel, 161 Nelson Place, Williamstown please let DATA know so a booking can be made.

When: Sunday 28th April 2019
Where: Meet at 10am at Federation Wharf (Vault 10, Princess Walk, Federation Square) for the 10.30am trip to Williamstown.

For the return trip we meet at Gem Pier at 3.00pm for a 3.30pm departure time.

Cost: $15 for DATA members, carers and children 4 - 14 years. $20 for non members.

RSVP: Monday 15th April 2019, to DATA office on 9894 0377 or email to info@datavic.org

Come to the Movies

Hurry book tickets now as the theatre only hold 42.

Coffee Tea & Cake will be served after the movie in the private room next to the Cinema!

Movie Time: 2pm
Date: Sunday 24th March 2019
Where: Sun Theatre, Ballarat St Yarraville 3013

Cost $12.00 Data Members & Careers & Children
$15.00 Non Data Members

BOOK NOW! Call the office on 03 9894 0387 and leave a message.
Studley Park Boathouse and Bundoora Homestead

Come and join us for coffee and cake at: Studley Boathouse, 1 Boathouse Road Kew on Tuesday 14th May 2019 at 2.00pm and/or Bundoora Homestead, 7 Prospect Hill Drive, Bundoora on Friday 24th May 2019 at 2.00pm

RSVP to DATA office on 9894 0377 or email to info@datavic.org by 9th May 2019
Everyone welcome

Dialysis Unit - Hobart

The dialysis service in Hobart is able to provide haemodialysis to people from other Units who are visiting Hobart or Southern Tasmania, including those from interstate on holiday. This service is only available to 1 person at a time. One (1) chair is reserved on a Monday, Wednesday and Friday at 3.00pm at Nephrology South, Newtown. Given the limited availability, bookings are essential, so please contact the Unit prior to arranging your travel.

For holiday bookings and general enquiries please contact (03) 61661440 (Nephrology South)
Email: renalunit.hobart@ths.tas.gov.au

Jokes Corner

**Doctors’ Law** - If you don't feel well, make an appointment to go to the doctor, by the time you get there you'll feel better... But don't make an appointment, and you'll stay sick. This has been proven over and over with taking children to the paediatrician

**Supermarket Law** - As soon as you get in the smallest line, the cashier will have to call for help

A Renal Nurse asked the Dialysis patient's daughter and grandson what they got him for Christmas. The daughter said gleefully, "We got him a new car!" The grandson added, "I wish I had Chronic Kidney Disease..."

Dialysis patients were chatting at Dialysis. One asked the other, "When you die and your friends and family are looking at you in the casket, what do you hope they will say about you?" He quipped, "I would like them to say, 'He's moving!'"
World Congress Nephrology Patient & Carer Forum

There will be a ‘Patient and Carer Forum’ at the International Society of Nephrology (ISN) World Congress of Nephrology 2019 on Sunday April 14th in Melbourne, Australia. This session is intended for patients, carers and family members, and the program has been co-designed with members of the BEAT-CKD Consumer Advisory Board. The session aims to provide updates on current research in kidney disease and practical information on topics prioritised by patients and their families. You are invited to attend either in person in Melbourne, or via live-stream from around the world. Both modes of attendance are free, however registration is essential.

Patient and Carer Forum

Hear research updates and practical information from people with kidney disease, carers, researchers and health professionals

Attend in-person in Melbourne or join via live-stream!

Registration essential

DATE: Sunday April 14th 2019
TIME: 2:30 – 5:30pm (VIC time)

VENUE: Melbourne Convention Exhibition Centre
OR join via live-stream on the BEAT-CKD website

COST: Free

Topics include:

- Exercise in ESKD
- Dialysis-related fatigue
- The carer’s perspective
- Consumer engagement in research

REGISTER to attend (in-person or via live-stream) via the BEAT-CKD website: http://beatckd.org/events/
Seattle Sojourn & 7-Day Alaska Glacier Cruise on Celebrity Solstice

Seattle – 7 Night Alaska Glacier Cruise (including Ketchikan, Endicott Arm & Dawes Glacier, Juneau, Skagway, Alaska Inside Passage and Victoria, British Columbia)

Savour the “Emerald City” of Seattle followed by an Alaska Cruise onboard Celebrity Solstice with Dialysis Abroad and your host, Nancy Douglas Irving OAM on a journey you’ll remember for years to come!

Visitors to the Emerald City of Seattle will find a fusion of American, Asian and Native American cultures set against a backdrop of Puget Sound and the magnificent Olympic Mountains. Travel in comfort knowing that your dialysis treatment has been taken care of. Highlights include the Elliott Bay Waterfront, Pioneer Square, Pike Place Market, Olympic Sculpture Park and the Seattle Center.

Journey through the wild terrain of Alaska on board Celebrity Solstice and discover the natural wonders that await at the rugged beauty of this pristine frontier unfolds. Get up close and personal with 30-ton whales and massive glaciers or take a flight high above the glaciers. The complex labyrinth of fjords, bays and lush green islands is home to an abundance of wildlife including orca, mountain goats, bald eagles, bears, puffins and sea otters.

The port of Ketchikan is the ideal version of an Alaskan town while Skagway is home to many gold rush era structures. Travel the White Pass and Yukon Route Railroad which runs through the mountains.

31 August 2019
12 days land & cruise only
$9,813.00*
Per person twin share
Single Supplement $7,420.00

TOUR INCLUSIONS
Meet and greet on arrival in Seattle.
Transfers and transport throughout the entire trip.
4 nights accommodation in Seattle.
Portmage of one piece of luggage at the Grand Hyatt Hotel Seattle.
4 x full breakfasts & 1 dinner in Seattle.
Seattle Half Day City Tour with inclusions as per itinerary.
Tips and gratuities for drivers and guides throughout the tour.
7 night Alaska Glacier Cruise on Celebrity Cruises’ Celebrity Solstice in a balcony stateroom.
All meals on cruise.
All cruise taxes and port charges.

Dialysis treatment will be available in Seattle and on the cruise.
Limited to 6 (six) dialysis patients only.

Discover and Cruise Eastern Canada and New England
with Dialysis Abroad • 22 September to 5 October 2019.

Toronto • Niagara Falls • 9 Night Canada & New England Cruise (including Cape Liberty, Boston, Portland, Bar Harbor, Halifax and Saint John)

An intimate metropolis filled with culture, creativity and a unique mosaic of diverse neighbourhoods. Canada’s largest city Toronto is one that celebrates culture, heritage, food and the arts. Take a memorable day trip to the breathtaking Niagara Falls and enjoy the Voyage to the Falls boat tour followed by lunch overlooking the magnificent horseshoe falls. A visit to the region isn’t complete without a trip to the charming town of Niagara-on-the-Lake in the heart of wine country.

Following a short flight to New York, New Jersey, USA, board your 9 day cruise on Royal Caribbean’s “Anthem of the Seas”. The autumn colours of a Royal Caribbean cruise are one of nature’s great spectacles. Your itinerary will include the cities of Boston and Portland, quaint and colourful Bar Harbor and the seaside historic sites of Halifax in Nova Scotia and magical Saint John in New Brunswick.

Discover Eastern Canada & New England with Dialysis Abroad, a registered Dialysis Nurse and your host Michael Pound on this amazing 14 day small group journey and cruise.

22 September – 05 October 2019
14 days land & cruise only
$8,562.00*
Per person twin share
Single Supplement $6,292.00

TOUR INCLUSIONS
Meet and greet on arrival in Toronto.
Transfers and transport throughout the entire trip.
4 nights accommodation in Toronto.
1 full breakfast, 1 lunch, 1 dinner (Toronto & Niagara Falls) internal flight and taxes.
Admission to the Falls boat tour and CN Tower.
Tours as detailed on itinerary.
Parcs fees, Destination Management Fees, city taxes as well as provincial and federal taxes.
9 night cruise on Royal Caribbean’s “Anthem of the Seas” in a balcony stateroom.
All meals on cruise.
All cruise taxes and port charges.
Host and Registered Dialysis Nurse for the duration.

Call 1300 978 466
or email info@dialysisabroad.com.au
for bookings and a detailed itinerary.
The Dialysis and Transplant Association of Victoria Incorporated (D.A.T.A.) is 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.

‘Shoe String’ 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.

Note From The Editors

This is another issue of Shoestring jam packed with information and DATA events for our friends and families. We have also had some positive feedback on the new format of ShoeString. We hope you will enjoy reading this issue too.

We thank Margaret Hagedorn and Charles Catania for their contribution to this issue of ShoeString.

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