Service of Thanksgiving and Remembrance
2:00pm Saturday 26th May 2018
Collingwood Town Hall
Afternoon tea is served after the service.
Easy to get to by train or good parking nearby.
Editor’s note

Welcome to another issue of Shoestring. There are a number of interesting articles. The 1000th Kidney transplant performed at Austin Health. The TravelDialysisReview.com is new website designed for patients on haemodialysis to rate dialysis units they attend while travelling or when they are on holiday.

There is a follow up article on Sensipar on page 7 which illustrates what Sensipar is used for. Sensipar featured in an article in the last Shoestring and is being taken off the PBS.

We would like thank the Social committee for their excellent work in organising all the great events for our members.

PLEASE NOTE correction to date and day of Service of Remembrance.

“Service will be held on Saturday May 26th, 2018.”

Fairfield Park Boathouse & Tea Gardens.

Come and join the DATA members for an afternoon tea at The Fairfield Park Boathouse & Tea Gardens on Wednesday 23rd May at 2.30pm. Fairfield Boathouse is only 7 kilometres from the CBD and is surrounded by Yarra Bend Park. The food is simple, fresh and seasonal. It was established in 1908 by John St. Clair as a picnic, camping and refreshment room area. In 1923 it was raised by 12 feet to help minimise flood damage. In 2010 a riverside deck and terrace was added.

Address: Fairfield Park Drive (turn off Heidelberg Rd, it is well signposted) Fairfield VIC 3078

Parking: Limited free 4 hour and disabled parking is available at the top of Fairfield Park Drive, off Heidelberg Rd. There is also parking on Heidelberg Rd. with no restrictions after 9.30am

RSVP by phoning the DATA office on 9894 0377 by Friday 19th May.
President’s Report

Hi All

Hope everyone is rugging up, as I sit here writing this report the wind is very blowy and sounds like it is trying to come in the front door for a visit!

Anyway I would just like to say ‘thank you’ to all of the committee and members who sent their best wishes to us as a family on the loss our beloved Nick and Dad, the kids and I am doing ok, we have pulled ourselves up by our “Shoe Strings” and getting on with it. As you all will know there will be sad times to come but with the support we have around us we will be fine.

We start this year (and can you believe it is May - should I remind everyone we will be at Christmas before we know it) with some very good social events.

They are held on the last Sunday of the month unless we have to move them if we cannot arrange it on that Sunday. Last month we went on a “Ferry trip to Port Arlington” which was absolutely fantastic. In March we went to the “Sand Sculptures at Frankston”, this month we are going to the “Fairfield Boathouse for Coffee and Cake”. Data will kick in a bit on the financial side, you just have to be 100% sure you can come and please let the office know before the cut-off date as many of these outings need numbers confirmed.

We have decided not to have the trivia at the Christmas in July this year and we are just going to the Moreland Hotel in Brunswick, hope to see you there.

Our new website is coming along very nicely but is a slow process, and I thank everyone involved in that especially Charlie.

Our membership is failing and the best way to get the message out is by word of mouth, so if you are sitting in the waiting room of a clinic start up conversations, people won’t mind, they may welcome it, and just tell them about us. We can send you some forms to give out, just ring the office and we will send you some. If you have any other ideas that can help lift the membership please let me know, only too happy to try anything (well, within limits lol).

We have a little competition going, we need your happy snaps from Rosebud or Yarrawonga houses and when you send them in you will go into a draw for a $50 voucher (more information on page 4).

I am pleased to let you all know that the schools program is going ahead this year and we are currently negotiating a contract with “Filter Your Future” and we do have a start date of next term. We are pleased that we are going into 10 schools.

I think that is enough from me for this SS other than to remind you to ring the office and leave your name and phone number if you want to go on one of our outings.

Keep well and warm, Sue

Austin Health’s 1000th Kidney Transplant

Clinical lead of renal transplantation, Dr John Whitlam says it is an exciting milestone that is a reflection of many things, most importantly, the extreme generosity of all living and deceased donors and their families.

"From the donor side, there is the donor family, donor doctors and nurses, DonateLife coordinators and retrieval team. From the recipient side there's the recipient family, recipient nurses and doctors, Victorian Transplant and Immunogenetics Service scientists, transplant surgeons, kidney pathologists and the full recipient allied health team. It is a testament to the health service that transplantation is possible," Dr Whitlam says.

"The Victorian Kidney Transplant Collaborative (VKTC) permits Victorians from the catchments of Eastern Health, Austin Health, Bendigo Health, Barwon Health and St Vincent's Health to access transplantation. We are very grateful for the goodwill and dedication of all in the VKTC team who care for recipients and living donors before, during and after transplantation," he says.

Austin Health's first kidney transplant was performed in 1974 and Dr Whitlam says despite significant advancements since then, the team continues to work hard to improve transplantation access and outcomes.

"Areas of transplantation research at Austin Health include development of transplant rejection biomarkers (in collaboration with Murdoch Children's Research Institute), acute transplant fluid management (in collaboration with the Anaesthetics Department), participation in national and international multicentre clinical trials and clinical studies of cardiovascular disease in kidney transplantation," Dr Whitlam says.

The milestone 1000th transplant was performed on northern suburbs father-of-one, who says he now has a second chance at life.


Editor’s Note.

This is just one Melbourne hospital performing kidney transplants, there are at least 5 other hospitals in Melbourne performing kidney transplants as well, imagine the overall number. Well done to all those hospitals and thank you.
DATA Holiday Houses

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

VACANCIES
• May onwards
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.

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

VACANCIES
Please Remember To Take Your Key

VACANCIES AVAILABLE FROM AUGUST 2018!

Why not enjoy a holiday in a great part of Australia metres away from Lake Mulwala. Cost is only $180 per week for you and your immediate family. Call as I do get vacancies.

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

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
• Then ring to book the Holiday House
• Finally, contact the hospital again to confirm your dates and book in

Shoe String 4
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’.

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 2018. Winners will receive awards at the AGM in October 2018.

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 .............................................................................................................................
HOME PHONE .............................................................................................................................
MOBILE .........................................................................................................................................

DATE OF BIRTH ........................................................................................................................

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

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

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Husband’s life-changing gift

A WANTIRNA woman says she got her life back when her husband of 45 years donated one of his kidneys to her.

Judy Smith was diagnosed with Lupus 20 years ago, and over the years her kidney function began to decline.

Mrs Smith began dialysis treatment in October 2016.

Then, after a year of tests, it was determined that her husband Phillip was enough of a match to donate one of his kidneys to her.

The pair had surgery at Monash Medical Centre in June last year and the transplant was deemed a success.

“It meant I got my life back, it really did,” Mrs Smith said.

“I don’t know how I can ever thank him for it.

“I’ve gone from being someone who could not walk the length of a shopping centre, and struggling to walk around the supermarket to now having so much more energy.

“The fact I don’t have to go to dialysis three times a week, that is a huge thing.”

The couple, both 67, have been married for 45 years and have two children and five grandchildren.

HCF, Australia’s leading non-profit health fund, is calling on Australians to better understand their risk of kidney disease, after the company’s latest data showed HCF members claimed $57 million in kidney-health related expenses in 2017.

HCF Councillor and Senior Staff Specialist in Nephrology at Westmead Hospital, Dr Richard Phoon, said chronic kidney disease was a major public health issue, responsible for a substantial burden of illness and costing Australia an estimated $4.1 billion annually.

Kidney disease affects 4.1 million Australians, with one in three people at risk of developing chronic kidney disease.

It meant I got my life back, it really did. I don’t know how I can ever thank him for it.

JUDY SMITH

Article from Leader (Knox) Newspaper

Letter to the Editor

A couple of weeks ago I visited the DATA office to hear Steven Wells talk about the therapeutic work that he is involved with as a horticulturalist. His talk with his slide presentation was inspirational. I thought about my own circumstances in which I spend six and a half hours every second day to set up my machine and to dialyse.

I mentioned to Steven that I look out of my window and get pleasure just looking at the sun and the sky. My window faces a fence and my next door neighbour’s home. Not much to look at. So I went to work to improve my situation. Given the limited space, the photo shows what I was able to create. All that is left to do now is to enjoy adding a climber and a few colourful plants. Thank you Steven and DATA.

George Said

Editor’s Note: George has sent a follow up photo which the plant growing. Good on you George
Sensipar—Follow up

This article explains just what Sensipar is used for. Sensipar featured in an article in the last Shoestring and is being taken off the PBS.


Maintaining proper levels of calcium is important to good health when you are on dialysis.

When the calcium level in your blood is low, your parathyroid gland makes parathyroid hormone (PTH), which raises your calcium level, back to normal. The change happens because PTH pulls calcium from your bones. This puts more calcium and phosphorus into your blood. If your PTH is high, you can get weak bones, which break easily.

Active vitamin D can help keep your PTH level down and maintain healthy calcium levels. Active vitamin D is different from regular vitamin D that you buy over the counter. Some patients take oral medications with active vitamin D such as calcitriol, Zemplar or Hectorol.

Another medication that can lower your PTH is Sensipar. Both active vitamin D and Sensipar bind on the parathyroid gland, telling it you don’t need to break down your bones.

Too much calcium isn't good for you either. When your calcium is high, it can be deposited in soft tissue like your heart and blood vessels and clog them up, contributing to heart disease. When calcium increases, your care providers decrease vitamin D supplements, decrease the calcium in the dialysis bath, and change to a phosphorus binder that contains no calcium. If your PTH or calcium levels are high, talk to your doctor, nurse or dietitian about ways to lower them. Always tell your care providers if you are taking any vitamins or nutritional supplements like vitamin D.

Editor’s note – as I understand it Sensipar helps prevent the need for a partial parathyroidectomy. Hence the removal of Sensipar from the PBS is puzzling.

Travel Dialysis

TravelDialysisReview.com is new website designed for patients on haemodialysis to rate dialysis units they attend while travelling or when they are on holiday. Its main aim is to show everyone that the units are safe and reliable and to encourage patients to travel.

The website is run by DATA member Greg Collette who instigated its development as a community collaboration project with Swinburne University.

When you are going to dialysis in a strange unit it is likely you will have many questions about that unit - Is it safe? Are the staff knowledgeable and capable? Will I have to wait long for my sessions, are the chairs comfortable, is there Wi-Fi? Will it be clean and attractive? Any chance of a nice meal? Credit or cash?

Greg believes the best way to find out is to ask someone who has dialysed there. Someone who knows the ins and out of what dialysis patients worry about and expect. This is where the TravelDialysisReview website can play an important role in your travel plans. If you are looking to travel, search for the unit where you would like to dialyse and check it out.

The success of the website depends on a build-up of accurate reviews, so if you have travelled, please register and add your Dialysis Unit ratings.

There are no fees (if you are on dialysis, you’ve already paid enough).

Hopefully, as it grows it will be our travel checkpoint: used by dialysis patients on the move, owned and managed by dialysis patients on the move.
Anticipation of Peritoneal Dialysis

Sixteen years ago, when I was around 35, I experienced strong chest pain. My GP sent me off for a Doppler scan of my kidneys and I was diagnosed with Autosomal Dominant Polycystic Kidney Disease (ADPKD). Usually genetically passed on, neither of my parents have the disease so I’m a “fresh mutation”.

For many years, the diagnosis didn’t impact on my life, other than yearly appointments to a nephrologist to keep an eye on my kidney function. During this time I met my husband who, when I told him of this condition (and a few others) loved me anyway and it has only really been the last couple of years that it has become prominent in our lives.

Sometimes lying awake in the middle of the night, I would dread dialysis and feel a bit of caution around the catheter as I’m a bit clumsy and, with large kidneys, my belly sticks out a little and attracts knocks which are not good.

That aside though, it’s all fine. I’m writing this in the hope that someone else who is going through the scary education phase and who might be feeling sick with worry, understands that dialysis is okay. My husband and I are extremely grateful to “Bob” (my nephew named the cycler) because he keeps me alive and well.

The team at Home Therapies are fantastic. They are truly wonderful people who train you and check up on you – ensuring you feel well supported. Kidney disease is something that I have to get through and, with the support of those around me and this Country’s fantastic health system, I know that I can.

Doctors will give you all the negatives to prepare you for the worst and I think to try to get you to source a kidney from a relative, but live organ donation is not always possible. Try not to feel uncomfortable when people ask about siblings and other family members donating.

The people around you most likely love you, but sometimes people have other commitments and cannot afford any downtime, sometimes there are medical reasons why they can’t donate, sometimes they’re afraid and sometimes they just like their kidneys right where they are.

I’m successfully dialysing myself at home (peritoneal dialysis) and life is wonderful and full of promise. That’s my story. And I’ve never received so many compliments! I think people expect you to look sick, but you don’t.

One word of caution though, don’t put off having the Tenckhoff inserted. It’s difficult to take yourself off for an operation when you’re feeling well, but the need for dialysis can hit you out of nowhere and you need to be ready. Plus, the sooner you’re on dialysis, the sooner you’re on the list.

Good luck to all those who are waiting. I’m proud to be one of you. We’re made of tough stuff.

NICOLE SANSOM

Friend for a reason, Friend for a season, Friend for a lifetime.

CAN YOU HELP?? : help with folding and packing Shoe String for mailing

It only takes about 7 people 2-3 hours to get the job done Often held on Saturday or Sunday. You meet some great people, usually people who know all about renal disease.

If we get a good response you will only have to attend once or twice a year!

So come on! fill in the details below and post to PO Box 159 Forest Hill 3131 or send us an email we will reply, or phone 9894 0377. Leave your name we will contact you.

--------------------------------------------------------------------------------------------------------------------------

INTERESTED in helping pack SHOE STRING:

NAME .......................................................... ..........................................................

Best phone contact .................................................. Email ..................................................

Saturday .................. Sunday ................... Weekday ..................................................
Fantastic Trip To Thailand

By Malcolm MacDonald

Continued from the previous issue of Shoestring

The trip to my cousin’s apartment gave me a good cross section of life in Yangon. Donna was lounging by the pool, the 27th floor apartment had a two-story lounge with a chandelier, and our bedroom was fit for a king! There were pagodas and stupas everywhere. The city seemed to be centred around the large one, but many religions were represented here, Islam, Catholicism, Judea, and more. Seventeenth street was an amazing hive of industry and activity: from every variety of bananas, to noodle makers still using machinery that is 100 years old. Most were very welcoming and happy to have their photos taken. We lunched at the historic Rangoon Tea House. You could really grow to love the city.

My stomach was starting to object to the continuous intake of spicy food, so it was time to back off and have just a cup of black tea the next morning before my second dialysis run here. By god, we are lucky!

That night our hosts, discovered a new club, , as a friend was singing there. Atlas was a rooftop dry season bar with incredible views, cocktails and mocktails, and a band. The highlight before leaving was an evening visit to the huge (Golden) Shwedagon Pagoda, which was awash with tourists and worshipers. We gave our tributes and felt blessed. The best part was stumbling upon a huge Bodhi tree. A fearsome looking policeman gently reached up, took one of the leaves and gave it to me for good luck.

We boarded a plane for Mandalay. My romantic image of Mandalay was shattered as we arrived from the freeway into the city: its appearance was nothing like I expected. We were staying a bit away from everything and soon learned that you need the nearest crossroads for drivers to have any idea of where to go. Also, food did not have to be served hot in Mandalay, nor was there hot water in showers! We did not need an alarm, as a pack of dogs woke us up when the early morning train went past.

Sorting dialysis out on the ground with the hospital was a nightmare, and a valuable lesson to make sure that I carry hard copies of everything that was sent. Three of the four hospitals claimed they had not received any paperwork from my clinic! At Yangon, I had requested a copy of their blood certificate result stating that I had no nasties, and this was all Mandalay really wanted but there was confusion on the phone with language barriers.

We asked for a recommendation for a market that turned out to be a shopping complex! We needed lunch, and a local business man showed us to the good restaurants. We wanted to buy a lacquered walking stick to replace one I had lost in Yangon, and stumbled across a local gem trader, Allan, who rang his daughter, and she told him where to go. Allan drove us clean across Mandalay and back to our hostel with a wooden stick. The generosity and the two who helped us there turns out to be typical of these people.

I finished dialysis and went to the Golden Palace, the seat of the last Burmese King before the British drove them out. On the way there, we passed an open air restaurant, so we returned to it. Amazingly, it was exactly what we were after, and only 3 dollars! By now, we were starting to get under Mandalay's skin and becoming enthralled by the narrow streets, overhangs, and endless roadside stalls. We wanted to stop at every one.

On our 3rd day, we booked a tour of the three ancient cities that preceded Mandalay, which turned out to be very long, 11 hours, and an intense day. But we squeezed in a lot. A boat ride took us across the river, then we had an uncomfortable buggy ride to the Teak Temple that we remember as the best part of the day! We crossed the Peace Bridge, climbed up a steep hill to another Pagoda, and were swamped by 1,000s of tourists and locals on the longest wooden trestle bridge in the World.

To be continued in the next issue of Shoestring
DATA members are invited for a river cruise on Sunday 24th June at 1.00pm. The cruise is for 2 hours from Footscray to Avondale Heights.

DATA members enjoyed a ferry ride to Port Arlington (see page 1), now DATA is organising a River Cruise on the Maribyrnong River. DATA committee would love to see those of you who do not come to our functions.

Numbers are limited so booking is essential. Bookings need to be made by Wednesday 30th May - please ring DATA office on 9894 0377 to reserve your place.

The cruise will be subsidised for DATA members & their carers at $10 a head. For friends & family the cost is $20 a head for adults & $5 for children. BYO food & drinks, as no food is available on board. Wheelchair friendly. See you there.

Ferry Terminal - Bottom of Saltriver Place, Footscray (Melways 42 E5, GPS 2 Saltriver Pl, Footscray)

DATA members are invited to celebrate Christmas in July, on Saturday 28th at The Moreland Hotel, Cnr. Sydney Rd. & Moreland Rd. Brunswick 3056.

DATA always celebrates Christmas in July. A different venue this year and there will be NO quiz.

The dinner will be at 6.00pm, at $25 a head. All welcome. More information in July Shoestring.
A wonderful day on Sunday 25th March 2018. The Sand Sculptures at Frankston about Alladin & The Arabian Nights was a great treat, Alladin certainly had a lot of adventures.

The artists who made the sculptures are very talented. There were 28 DATA members, family and friends. Melbourne weather just held out, it started to rain when we were ready for lunch. We had a lovely lunch at the nearby pub.

It was lovely to see new faces as well as old ones. If you haven’t been to one of DATA’s outings, hope you can come to some others offered this year. It’s great fun, lots of talk, laughter & friendship.

DATA Social Committee

On Sunday 4th March 2018, It was a lovely day at The Altona Bowling Club. Melbourne weather was kind to us. Bob 83 years old, a member of the Altona Bowling Club, showed us how to bowl. The rules were easy to understand but the ball didn't always go in the direction it was meant to. We all had a great time bowling followed by a nice barbecue.

Thank you to Carol & Alan Thompson for organising a great day.

On Sunday 29th April, there were 30 DATA members with family & friends who enjoyed the trip from Docklands to Portarlington. Melbourne weather was just right, not hot and not cold either. People had fish & chips for lunch, walked on the beach, visited a winery or just relaxed. There were some new faces as well as familiar ones. Overall it’s one of those outings that would be nice to repeat sometime on the future. If you haven’t been to a DATA function come next time, you’ll have a good time.
**Dates to remember**

15 & 23 May – Coffee & Cake at Fairfield Boathouse.
24 June – Maribyrnong River Cruise.
28 July – Christmas in July.
26 August – Indoor bowls or ten pin bowling.
September - Royal Botanical Gardens Cranbourne.
21 October—AGM
October – Day Rail & Sail: Steam train to Geelong and return by the Victoria Star Ferry (or vice versa).
November – Christmas Party.

**Some web pages of interest**
- www.homedialysis.org/news-and-research/blog
- www.nwkidney.org
- www.peninsulahealth.org.au/
- www.worldkidneyday.org
- www.cari.org.au
- www.australiandialysisbuddies.org
- www.greendialysis.org
- www.transplant.australia.org.au
- www.bigdandme.wordpress.com

**Our thanks to all who contributed to this edition**

Why not spread the word and pass this copy on?

Shoe String is always looking for stories to publish. If you have a story to tell and you’re not sure where to begin, our Editors would be more than happy to assist you in writing your article. Or if you have any ideas of issues you would like to see covered, contact us.

Write to: The Editor, Shoe String
PO Box 159, Forest Hill 3131
Email: editor.shoestring@gmail.com

Visit us at www.datavic.org

**PO Box 159, Forest Hill 3131**
**Ph: (03) 9894 0377**
**Email: info@datavic.org**
**www.datavic.org**

**Office Bearers**
**President**
Sue Hatzimichalis 0412 469 738

**Vice President**
Peter Collins 0432 052 392

**Secretary**
Charlie Ball (03) 9439 8866

**Treasurer**
Vicky Abbetangelo 0408 103 571

**Holiday Homes Secretaries**
Yarrawonga House
Alan Rawson (03) 9723 3019

Rosebud House
Amanda Pratt 03) 9589 4894

**Shoe String Editorial Committee**
Joan Eastwood 0402 097 331
Ros Ball (03) 9439 8866
Fay Rawson (03) 9723 3019
Simon David 0411 132 236

**Committee Members**
Angela Lindsey  Minute Secretary
Joan Eastwood 0402 097 331
Ros Ball (03) 9439 8866
Ken Smith 0428 138 282
Alan Rawson (03) 9723 3019
Paul Murphy (03) 9779 9386
Darren Hennessey (03) 9878 5483
Elaine Hennessey (03) 9897 3211
Ron Hennessey (03) 9897 3211
Christine Coleston 0402 828 970

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**DEADLINE FOR NEXT ISSUE 25 June 2018**

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