You are invited to
MEMBER’S BBQ
14 Queen Street Blackburn
At 12 noon till 4pm
29 March 2015
Sausage & salads
tea & coffee provided.
RSVP Pge 3

BYO Other refreshments
BYO sunscreen or woolly jumpers.
When was this picture taken?
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A Note From the Editors…

Another issue of Shoe String doesn’t seem any time since we had the last one! No it isn’t but it will settle down a bit after this. It is awkward to get the January issue out before February! We suffer from Christmas-lag which is similar to jet-lag.

I will be emailing this copy to a few people who have requested it. If you would like email instead of snailmail let me know (email on the back page).

Has anyone enjoyed a holiday on the Big Red Kidney Bus yet? If you have, can you write and tell us how it went. This photo is 12 months ago at the launch of the BRKB in Traralgon which I attended.

We are looking forward to the BBQ on 29th March I may have a surprise for all who attend. I have to organise a few things. So come and join in the fun. Hope to see you there.

Joan

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 party.

*ShoeString* denotes the feeling of life when it is turned up-side-down and that, with Kidney failure, Dialysis & Transplant, you sometimes have to pull yourself up by the shoe strings to get going.

Visit our website at www.datavic.org
President’s Report

I do hope you are all well and remaining out of the heat. The weather is very odd this summer. I have found out it is easy to overdo the fluid intake, as I am on haemodialysis. Those with a transplant remember to keep your fluid intake up.

Charlie and I are making plans for another trip to Western Australia. You may remember we went to the Kimberley 2 years ago, leaving all the office work to Joan, with help from Eleanor, our assistant treasurer. During our absence the busy time occurs, with members updating their membership. DATA does hope to have an office worker employed by this time, but things move slowly at DATA due to our volunteers always being busy with their own lives.

Buying a new house will also be a problem as DATA Committee need to find time out of their own lives to look for a house, have it inspected by the committee, and go from there.

Have you looked at our Facebook page? You can read reports on a 16 year old girl who has “invented” a new dialysis machine that is very much cheaper than the current machines. Read about a 6 day old baby whose organs were donated, and more stories that are put into our Facebook by those with renal disease.

Please remember to respect DATA and our rules. For our holiday houses we use an “HONESTY” system. That means we can keep our costs for rental down. So any extra family members or friends you take on holiday with you please pay the appropriate cost which is just an extra $20 a night per person still making it a cheap holiday. AND if you use the BBQ please clean it for the next residents of the houses. Animals are definitely NOT ALLOWED (except for companion and guide dogs). Remember no one is paid to run these houses. Respect our rules and you - and the people after you - should have a great holiday.

Ros. Ball

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Joke

How do you get down from an elephant?
You don’t get down from an elephant; you get down from a duck!

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Reply Slip   Members BBQ  29th March 2015

Yes I will be attending the BBQ on 29 March 2015 □

No I am unable to attend. □

Name………………………………………………………………………………... Number of Adults...........

Phone .......................... Number of Children........

Please return slip to D.A.T.A, PO Box 165 Blackburn 3130 by 23th March 2015

or ring 98940377 and leave a message, or email: info@datavic.org
**Holiday Homes**

**Rosebud:**  Vacancies— 
May 17th onwards.

I only do the book up to July, so any time before that from the above date is free.

I am pleased to say the house was kept very clean over the Christmas period.

I would like to thank the Purificato family for donating the new clothes horse, which was in need of replacing and also the Gilchrist family for the new toilet accessories. Both are much appreciated.

Reminder that you must be a Member of DATA before booking the house. No animals are allowed, exception to the rule are guide dogs

Remember if you are going to dialyse at the Rosebud hospital, you must ring them first and get a few dates they can fit you in.

and then check with me what is available.

**Rosebud Holiday Home Secretary**
*Amanda Pratt*
Phone: (03) 9589 4894.

**Yarrawonga:**

Next vacancies:  April 12/19, July 12/19 19/26 26/2 August

All of August 2/9, 9/16, 16/23, 23/30, 30 Aug / 6 Sep, 6/13 Sept

We do get cancellations so please ring.

Reminder  See above.

If you have booked a fair way ahead, you must ring or E/mail me to confirm your booking within 3 months of going on your holiday.

Do not forget, if you need to dialyse at Yarrawonga Renal Unit, please ring the hospital first to see what is available, then ring me to book the house, you must then ring the hospital to confirm the dates and book in straight away. Do not leave it until you are about to go to Yarrawonga. If you notice anything that needs fixing please report it.

We have now got Jims Mowing to mow the lawns. But if you are able to mow the lawns it would be appreciated.

We are having trouble with the mailing of forms and the keys, post being very unreliable please send you forms back early so I can post the keys to you in plenty of time

Remember you are responsible for the cleaning of the house which does include bathroom and toilet.

**Yarrawonga Holiday Home Secretary**
Alan Rawson, 22 Tarwin Drive Croydon 3136, Ph. 9723 3019, email:fayal_rawson@hotmail.com

**REMINDER:** YOU ARE NOT ALLOWED TO SMOKE IN ANY OF THE HOUSES.

Please consider the health of other members who use these facilities. Any member who does smoke in the DATA house will be dealt with at the discretion of the DATA committee, which will probably include a ban on using any of the holiday homes.
**Blackburn House/Headquarters**

As you should all know our headquarters and city accommodation has been sold.

*The house is still available for anyone who wishes to stay* for a holiday visit, or who requires accommodation while receiving healthcare. Those who wish to come and stay “one more time” should make it sooner, rather than later.

The cost of staying at the Blackburn house is $50 per room per night per membership and $20 a night for each extra person. If on a visit for medical reasons, accommodation payments may be paid by V.P.T.A.S. (Victorian Patient Assistance Scheme), ask your social worker for the details.

The house is self-catering so bring your own food, including tea, coffee, and sugar. You will also need to bring your own linen: sheets to fit a queen sized bed/single bed, pillowslips, towels, and tea-towels. (you are also responsible for cleaning after yourself, otherwise, an extra charge will apply)

Blackburn House is an easy walk to the train station and many bus routes stop at the station.

Melbourne is a great holiday place so why not come for a holiday and explore this great city and stay at Blackburn. It is not here just for you to go for check-ups or hospital visits; it is here for holidays as well.

We believe the new owner has made development plans which may be presented at the January council meeting. We still have no plans where we will move to, nor when. Whether we will be given short notice to vacate the premises or not is unknown. When DATA knows what is happening we shall inform all our members.

Come and enjoy a stay at Blackburn and explore Melbourne.

Phone for bookings: *Contact: Ros. Ball 03 9439 8866*

Or *Alan Rawson 03 9795 1649*

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**HAVE A LAUGH.**

God may have created man before woman, but there is always a rough draft before the masterpiece.

**WIFE VS. HUSBAND**

A couple drove down a country road for several miles, not saying a word. An earlier discussion had led to an argument and neither of them wanted to concede their position. As they passed a barnyard of mules, goats, and pigs, the husband asked sarcastically, 'Relatives of yours?' 'Yep,' the wife replied, 'in-laws.'

**WORDS**

A husband read an article to his wife about how many words women use a day... 30,000 to a man's 15,000.

The wife replied, 'The reason has to be because we have to repeat everything to men... The husband then turned to his wife and asked, 'What?'

How do you make an Irishman laugh on Mondays?

Tell him a joke on Friday.
ShoeString

You may remember George wrote to us and we included his story in a previous edition of Shoestring, well here is an update. **An Old Boy Learning New Tricks**

It was an eventful day today. I have just come back from the hospital with an extra extension to my body. I have been doing peritoneal dialysis but it slowly became ineffective. I have had two failed fistulas and now I have none. So I gained this extension today; it is called a permcut. It is a thingo that sticks out from my chest and enabled me to have my first haemodialysis.

I know all about peritoneal dialysis. I have to forget all I know and start learning all about haemo. You perhaps know that haemo is totally different. At 82 I will be taught how to set up and use this machine so that I can dialyse at home. I have only one consolation; with this new machine; I will be busy and will have no time for dementia.

Our family has another story teller. Our daughter Helen Said has written a book called "Five Egyptian Pounds - The life of George Said". It took her 12 years to write; it is sometimes serious and at times funny. This book can be obtained by ordering from ebooks  www. Equilibricumbooks.com Or contact Helen via email on FiveEgyptionPounds@gmail.com

*We thank George for his contribution and congratulate his daughter on writing a book about George.*

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**Letters & emails**

**Five Egyptian Pounds**

By Helen Said, the compelling biography of multicultural community leader George Said.

To order a book go to:

- www.equilibricumbooks.com/pounds
- ISBN: 978-0-9924335-7-5
- Amazon for Kindle eBook

For inquiries contact

FiveEgyptionPounds@gmail.com

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To: editor.shoestring@gmail.com

I have been on dialysis for 10years- I dialyse at the Swan Hill unit- the staff there are terrific- it is lovely and clean- we have 7 chairs and operate 6 days a week. From time to time we have holiday patients which we are pleased to have.

We have morning tea, and for those who dialyse in the pm, afternoon tea is provided for them.

I have been on cruises to Port Douglas twice, as well as a lot of other units, but there is none better than the Swan Hill unit, as we are so fortunate to have such great staff and unit.

Dr Lanteri comes to Swan Hill every 2 months and Marg Morris from St Vincents comes every alternate 2 months- so as you can see we are extremely fortunate to have them come to Swan Hill.

Gavin Polinelli, Swan Hill.

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If you can answer the question on page 1 (in the oval.

And tell us who is in the photo - you will win a mystery prize at the BBQ. On 29th March 2015.

This is NOT open to any committee member or their spouse!

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We have received an email from Doreen of Seymour about the new dialysis Centre at the hospital.

We are hoping to get a photo or two and will print them next time.

Thanks for these emails it makes us feel like there is someone out there.

There is also have a new PD Unit at Dandenong that I would like to tell you about but I don't have the information or photos yet

If you go to that unit you could take a photo and send it. That would be great.

Thanks Joan
FOR CARERS

Preventing Compassion Fatigue

As a carer of someone with renal disease, it can be a challenge to make time to care for yourself. Routine self-care is essential to maintain compassion satisfaction and prevent compassion fatigue, and even adding a few minutes each day for self-care can be beneficial.

1) Acknowledge your own feelings, meditation (just sitting in a quiet room, by yourself) as a daily practice is mentally and emotionally purifying. Use it as a tool to review your day, let go of any negativity and become more accepting, compassionate and non-judgmental of emotional and behavioural responses to situations. Nurture yourself and tell yourself that you’re doing a great job. Journaling is also helpful for uncovering emotions contained by thoughts and mind clutter.

2) Move your body. Regular physical activity that gets your heart rate up helps you process emotions and move them out of your body.

3) Avoid unhealthy substances and behaviours Alcohol and other drugs as well as excessive habits might become tools for coping with the discomfort of negative emotions. It really doesn’t help, just buries it.

4) Get support this includes facilitator-led peer support, supervision, debriefing, mentoring or counselling from someone outside of the carer environment. In other words, talk about your feelings to someone you trust. You’ll likely find that your peers have similar experiences.

5) Lead an inspiring life outside of the situation by getting involved in clubs, walking groups, sports teams, volunteering, art, spiritual, religious or cultural groups.

If you feel well, both physically and mentally, your caring will remain calm and coping. Preventing compassion fatigue is not only important for you but also for your family.

How do you know if someone is having a stroke? Think F.A.S.T.

1. FACE : check their face, has their mouth dropped?

2. ARMS : Can they lift both arms?

3. SPEACH : Is their speech slurred.
   Do they understand you?

4. TIME : is critical. If you see any of these signs, call 000 immediately.

Think Fast Act Fast.

For more information call 1800 787 653 or visit via the internet strokefoundation.com.au
1. These Awards are to be known as the *Ron Jones Educational Awards*. They are to honour the memory of a founder and long time dedicated worker for DATA, Mr Ronald N Jones AOM.

2. The purpose of these Awards is to encourage scholastic achievement.

3. The Awards will be judged on scholastic ability exclusively assessed by a panel of judges accepted by DATA. No correspondence will be entered into.

4. An applicant must be either a financial member of DATA with chronic renal disease or the child of a financial member of DATA who has or did have chronic renal disease.

5. An applicant must have completed any of years 7 to 11 and may apply for an Award by the end of May of the following year for presentation at the AGM of that year.

6. Assessment will be judged on an Applicant’s previous year’s full school reports together with a 300-word hand written essay on the topic of ‘My Chosen Career’. Failure of an Applicant to submit full years’ reports may, in the discretion of the DATA Committee or the Judges, result in the disqualification of that Applicant.

7. The amount to be expended each year will be $2000.00 and any amount not expended in any one year will not be available for use in subsequent years. Provided there are sufficient Applicants with merit, there will be:
   a) One (1) Award of $800.00 based on demonstrated excellence and scholastic ability.
   b) Three (3) Awards of $400.00 each for encouragement of future academic achievement.

If, in any one year, no Applicant demonstrates a sufficient degree of excellence, the judges may, in their discretion, withhold the Award of $800.00 based on excellence and scholastic ability. However, irrespective of the standard of the Application and provided that there are sufficiently qualified candidates, the judges must award three (3) encouragement Awards.

8. Notice of the Awards will be advertised in at least three subsequent editions of ShoeString starting in the November edition of each year.

9. Applications will be printed in ShoeString and should be forwarded to the DATA Office by the end of May. Late applications will not be accepted.

10. **Schedule of Deadlines for Applications and Judging.**

    | Deadline                          | Date                      |
    |-----------------------------------|---------------------------|
    | Close of Applications             | end of May                |
    | Applications to Judges            | last week of June         |
    | Results from Judges               | second week in September  |
    | Advising Award Winners            | 3 weeks before the AGM    |
    | Presentation of Awards            | at the AGM in October     |

11. An Award winner cannot apply for another Award for another two (2) years.

    An unsuccessful Applicant can apply in subsequent years.

12. Awards will be presented to the successful Applicants at the AGM of each year. Parents will be invited to bring the Award winner to the AGM to receive a Certificate of Achievement or a Certificate of Encouragement.

13. The awards will be presented by Mrs. Elvie Jones, a Ron Jones family member (i.e. Mark or Dirk) or the President of DATA.

14. Privacy: No personal information given in an Application will be available to anyone. The only exception to this rule will be that an Applicant’s age, school reports (with the Applicant’s name and School obliterated) and the essay will be available to Members of the Judging Panel. Further, this exception will apply to a Sub-Committee specifically nominated each year by the DATA Committee to process the Award Applications. Those nominated persons will work in accordance with all Privacy Laws applicable in Victoria.

    Applications forwarded to the Judges will have a code of identification known only to the nominated Sub-Committee.

15. **Amendment:** These Rules may be amended by a majority decision at any validly constituted DATA Committee meeting provided that the Members of the Committee have been given at least 7 days notice of the proposed changes.

Rules amended 7 October 2008
APPLICATION FORM FOR THE RON JONES EDUCATIONAL AWARDS.

Applicants are requested to complete this form and forward it to
The Secretary
D.A.T.A. Vic Inc.
P.O. Box 165, Blackburn 3130.

Applications must be received no later than the 31st May 2012. Winners will receive awards at the A.G.M in October

Applications must include a handwritten essay of 300 words entitled “MY CHOSEN CAREER.”
Also include the previous year’s school reports.

Please fill in this form using Block Letters.

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 ……………………………………………………………………………………………………………
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**Fluid Balancing Staying Healthy**

**Signs to Watch For**

**IDEAL WEIGHT**
- Near dry weight
- Normal blood pressure
- Feel good

**FLUID OVERLOAD**
- Headache
- Coughing - Short of breath
- Weight gain
- High blood pressure
- Can’t lie flat
- Difficulty sleeping
- Oedema (swelling)
- Tired

**TOO DRY**
- Headache
- Dizziness - blurred vision
- Weight loss
- Low blood pressure
- Nausea
- Faint feeling
- Tired & weak
- Cramps
- Sweating

**Check Daily:**

1. Weigh yourself and take your blood pressure every morning.

2. Check your eyes, legs and feet for puffiness.

3. Choose your dextrose as needed to take off fluid.
   - 1.5% Weak
   - 2.5% Medium
   - 4.25% Strong

A big thank you to Cameron from Fresenius’s for allowing this poster to be reproduced into Shoestring.
Presentation by Monash Nephrology.

Several members of DATA attended an excellent presentation on 16th September 2014 when we were given a short clinical history from mid-70’s at Prince Henry’s Hospital to the current day at Monash. It was interesting to learn that Monash is one of only 2 sites in Australia to perform Kidney-Pancreas transplants and to hear brief details of staff and their successes.

After that we heard about clinical and laboratory research and trials both underway and future plans including currently into transplant rejection. David J. Nikolic-Paterson, head of Laboratory Research, then introduced us to the department’s goals of greater understanding of kidney injury to end-stage kidney disease and to develop new treatments for both kidney disease and transplant rejection. He outlined stages from basic research to clinical treatment and detailed how Diabetes can attack the Kidney Cell along with the status of the ASK1 (inhibitor drug) and Syk Projects. Tubular Damage project was also discussed before we were shown round the laboratories.

The morning was very interesting but whilst at the time I understood what was being presented, it was of a highly technical and medical nature. There is no way I can pass on the contents! However both Michael (DATA President at the time) and I agreed it was a very professional and interesting presentation. The lack of funding of such on-going research is a major concern. Should you wish to contribute to research such as this, I am sure that Monash and other major units would be only too keen to receive well deserved donations.

Eleanor Allan.
Dates to Remember

- 26th March World Kidney Day
- 29th March Sunday –DATA Members BBQ
- 14 Queen Street Blackburn see page 3 for details
- Thursday 14th May DATA mid week Social Outing
- Mystery outing KEEP THIS DATE FREE
- Next Shoe String packing date 3/05/2015
- Queen Street Blackburn
- July TBA DATA Christmas in July
- 2nd-9th August Donate Life Week.
- Watch our Web site www.datavic.org
- Find us on Facebook—and read the stories posted by people with renal disease and questions and support given to each other.

Our thanks to all who contributed to this edition.

Why not spread the word and pass this copy on?

ShoeString Editors are 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 ideas of issues you would like to see covered, contact us.

Write to: The Editor, ShoeString,
PO Box 165 Blackburn 3130
Email: editor.shoestring@gmail.com

Deadline for the next ShoeString: 10th April 2015