Service of Remembrance

&

Thanksgiving

to be held on

Saturday 25th May 2013

at

RMIT. Storey Hall, Building 1,
336 Swanston Street Melbourne

Doors open 1.15 pm   Service 2pm

Held in recognition to all those who make transplants possible.

Sponsored by
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**A Word from our President**

Applications for Ron Jones Educational Awards are due in by 31 May 2013 (see pages 8 & 9).

Nick has been in hospital. He had a heart attack and has had a stent put in. Thankfully he is now feeling much better.

Sorry to hear that Kaitlyn Steavenson has been very ill in Monash Hospital. Latest reports are that she is improving. Keep up the good work Kaitlyn, hope you are home soon.

Michael Allan hasn't been too good either, slowly recovering from his hospitalisation.

Thankyou for your responses to the questionnaire The Committee is working on your comments.

We are currently changing over Treasurers: Eleanor has resigned due to family commitments, and Joan Eastwood has agreed to take up this role for the time being. This just serves to highlight the need for more committee members. Over the next couple of months, two of our Committee Members will be away for extended holidays Angela our minute Secretary and Ros our Secretary.

So come on, put your hand up and join us in Committee meeting. If you think you could help in some small way, please speak to a Committee Member (Phone Nos. on back of Shoe). and don’t forget ‘Many hands make light work’.

Incidentally we are still at Blackburn for those country people needing accommodation.

Ring me on 9378 9222

Sue Hatzimichalis

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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.

*** WHY NOT VISIT OUR WEB SITE  www.datavic.org***
The First Service of Remembrance & Thanksgiving

From the Shoestring Archives

ShoeString March 1991

“The Service of Thanksgiving is unique in the history of D.A.T.A. It will also be a first for Australia… Already much interest has been created in New South Wales and Western Australia; these states want to organise their own …”

Then in May 1991, ShoeString front page, shows a photo of our past patron Mr Brian Naylor with eight year old kidney recipient Kate Leszynski holding lit candles. (The candle exchange ceremony symbolised the passing of life) This was surrounded by abstracts from letters D.A.T.A had received such as:

“I was just so pleased to be present, it was a lovely, lovely service”

“The candle exchange was so moving”

“I hope the donor family was there too”

“We brought friends with us to St. Paul’s – a donor family - they said it really helped.”

“Thank you for the opportunity of showing my appreciation.”

From page 2. “it was tremendous to see so many people at St. Paul’s for the Service. We thought perhaps 400 would come, planned for 500, were overwhelmed to know just over 800 participated; the pews were filled from front to back. It was magnificent to see so many transplantees (heart, liver and kidney), dialysis people, families, friends, staff from all transplant units …”

“...we were pleased to know there were donor families in the Cathedral too but, of course, we have no idea how many.”

Another paragraph states:

“... In answer to many questions – No, we do not plan this to be an annual event. Held too often, we feel it would lose its impact; once in five years would be ideal, or maybe every three.”

My Comment. (Ros Ball)

Over the years I have been to many of these services which are now organised by DonateLife and held annually. The service is very moving and very well attended. The venue for the service is always full, proving it is a very popular event and that it provides a need in the transplant community.

D.A.T.A. now has this first Memorial Service on DVD, and it can be borrowed from us if you so wish. Leave a message on our answering machine, and we will loan you a copy.
Holiday Homes

Rosebud:

Bookings for Rosebud have remained constant. The rates for Winter are now $160 for the week. Weekend rates are $50 per person per night and $20 per person for each extra guest. Here are the weeks that are available:

- June 16 – June 23
- July 6 – July 14
- July 28 – Aug 4

August and September are vacant at this stage.

If you would like to go on a cancellation list please let me know. Forms for your holiday will be sent out one month before. Keys for your holiday will be sent two weeks before.

I am pleased to say that the house has been kept clean for the next people coming in. We appreciate this as it keeps the house clean without having the added cost of hiring a cleaner. Finally, I would like to thank the Psaroudis family for the donation of money to buy a new mattress protector for the main bedroom at Rosebud.

Rosebud Holiday Home Secretary
Amanda Pratt
Phone: (03) 9589 4894, E-mail: alpratt@gotalk.com.au

Yarrawonga:

Next vacancies: May 12-19, May 19–26
June 23 – June 30, July 7-14
July 14–21, July 21–28, July 28–Aug 4

We do get cancellations so please ring me.

It was nice to hear from members who enjoyed their stay at the house at Yarrawonga. We have had 2 home dialysis members dialysing recently at the house and the feedback we got was terrific. A big thank you to the technicians from Monash and RMH who made their stay so much enjoyable. We would like to see more home dialysis members enjoying a holiday at Yarrawonga and Rosebud. Phone Amanda for Rosebud or myself for Yarrawonga, to see what is available.

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. But please ring the hospital and book in straight away.

Do not leave it until you are about to go to Yarrawonga.

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

Yarrawonga House Secretary
Alan Rawson, 22 Tarwin Drive Croydon 3136, Ph. 9723 3019, E-mail: 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.
I thought you may be interested in my recent experience having gone onto dialysis Mid-November 2012. I am doing PD at home with Fresenius supplying all my equipment and fluids.

After having a Tenckoff catheter installed at the Austin on 3rd October 2012, I was asked to decide what company I would prefer to act as suppliers for machines, fluids, and other equipment. As I was not very well informed as to which organisation did what, and relative pros and cons, I decided to contact Cameron at the Austin Renal Peritoneal Unit. He had actually left and gone to work for Fresenius Medical Care, so I chased him down and went to Melbourne to discuss this with him.

He told me to look at available material and decide which I thought would be best for me. He advised that both Baxters and Fresenius were good organisations and they would look after my needs now that I was going onto PD.

Cameron then came to my home and went through the training needed to do home dialysis. This had its lighter moments. After the training was finished he organised for everything to be delivered to me. Now my home looks like a warehouse, but I had all I needed and to begin. I only did manual PD until the machine arrived. After rearranging my ‘boudoir’ I was able to do overnight PD. This has been trouble free and an absolute boom to how I feel.

I was feeling pretty confident by Christmas so I took some time off work and went to Darwin where my daughter lives. She is very near to Humpty Doo on a small rural property with dogs, chooks, horses, and crocodiles. All I needed for my two week stay was at Eliza’s place when I turned up. Apart from the heat all went well. Eliza is a live wire and had a never ending round of social gatherings to attend. She also had lots of jobs on her property to complete while she had me there. A great deal of fun was the order of the day.

All too soon it was ‘back to the cactus’ and the normal routine here. The only small problem I had was a low grade infection around the site of the Tenckoff catheter due to perspiration while up north, so now at least I know what to do in the future.

I write this to let those on PD know that it is no trouble travelling on PD – so go for it!

Peter McKenna Hepburn springs.

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**Reciprocal Rights.**

The quest to clarify the arrangement for reciprocal rights between the Australian Government and other Governments continue.

DATA can now provide the following information.

Reciprocal Rights, for Medically Necessary Treatment including dialysis is available in these countries: Netherlands, New Zealand, and the United Kingdom. Other countries including: Belgium, Finland, Italy, Malta, Norway, Republic of Ireland, Slovenia and Sweden, may have an initial small charge e.g. Sweden initially charges $50.

You must provide the following:

An Australian Passport or proof of permanent Australian residency, and a current Medicare card.

It is imperative that all dialysis requirements (dialysis units and times) be booked and confirmed prior to travelling, and these units are aware of your wish to use reciprocal rights.

More Information is available at the Kidney Health Website, under the link “for Patients” and dialysis and travel.

Call the Department of Health Service general enquiry Line on 132 290

Call the Travelling with PBS medicine enquiry line on 1800 500 141 (for taking medicine out of Australia)

Read the story of Greg, (on his blog) who used reciprocal rights in England and Sweden.

www.thebiglandme.wordpress.com (the May 2012 section).

I find the blog by adding dialysis if I forget to add wordpress.

Apologise for those who could not access this blog after our last publication, and could only get a dancing page.

Ros Ball
It was only after having a medical check up for the purpose of taking out some life insurance in 1985 that I discovered that I had a problem with my kidneys. I was told that it may gradually worsen, but with medication, I could keep working and keep reasonably healthy.

In 2000, after many years on medications, the blood tests indicated that I would soon be needing dialysis. I prepared myself for haemo dialysis and had a fistula put in my arm, and I planned to dialyse at the hospital.

In 2005, the staff at the Royal Melbourne Hospital Peritoneal Unit advised me that I could do my dialysis at home with Peritoneal Dialysis - fluid bags draining through a tube in my abdomen. Eventually I was given an overnight PD machine which was very helpful, as I had my day free to have an almost normal life.

I was put on the waiting list for a new kidney and after almost five years, at the age of sixty four, I received the phone call of a lifetime. It was 10th February 2010 at 5pm that I received the BEST NEWS EVER - That a donor kidney was available and I was to get to the Royal Melbourne Hospital as soon as possible on the next available flight.

The transplant took place and thanks to the wonderful skill of the surgeons, the operation was a great success. I am very grateful to the surgeons, doctors, and specialists and nursing staff at R.M.H. for their wonderful care and attention. After spending six weeks at a hotel near the hospital, I was able to go home. Then after having some bowel problems and having my anti rejection tablets adjusted, I am now enjoying my life again. I can do some gardening and I play carpets bowls once a week.

I hope my story will provide some encouragement to the readers. I would be glad to talk to anyone who wants to ask me how I felt at the different stages of my treatment. I am eternally grateful to the donor family for my “Gift Of Life”

Antonio Chiovone
Mildura

Two inspiring personal stories. Thank you both, Peter and Antonio. To all Shoestring readers, we love to read your story, so send us yours, so we can help inspire all those with renal disease.
Diet Restrictions for those With Renal Disease.

Over the next few Shoestrings we will include helpful hints to stay on track with your renal diet.

With special thanks to Karen Manley Renal Dietician at Austin Health.

Karen was guest speaker at the DATA 2011 AGM.

Restrictions for those on peritoneal dialysis are not as strict.

Remember to always be guided by your renal dietician.

Fluid Restrictions

Once kidneys fail, people have limited ability to urinate and hence fluid can build up within the body. This can lead to heart strain (heart attack), fluid on the lungs (difficulty breathing), excess fluid in the blood stream (high blood pressure) and pressure on the brain.

All fluids need to be counted, including, but not just drinks, – custards, yogurt, ice cream, jelly, soups, and even the juice from canned fruit. If rice and pasta is eaten in frequent amounts such as daily or every second day this also needs to be included.

- Spread your fluid balance over the day. For myself, I have a drink at each meal and 1 extra if I’ve had no other fluids (such as yogurt) during the day.
- Know the volume of your drinking cup. I use a cup that holds 200mls. At breakfast I use this drink to have my tablets, saving on another drink. Often when I have meals at friends I end up with a large glass, I only drink ½ that glass.
- Try freezing some fluid, and suck this, slowing down your fluid intake.
- Fill a jug with your fluid allowance, and then throughout the day, just drink from that jug.
- Also tip out the equivalent fluid, from the jug to keep track of where you’re at with your restrictions, if not drinking from that jug.
- Find the drink that quenches your thirst best and stick to that. For myself it is tea and water. Sometimes I will have ginger ale.
- Try chewing gum, or mouth wash to keep your mouth fresh and moist. I often eat an apple, cutting it into 4 pieces and eating it throughout the day.
- Whatever you do, don’t have salty foods.
- Have a craving? Yes, I’m sometimes bad, I will have a pizza, high in salt and potassium. I do find I’m thirsty afterwards. I always eat these “bad foods” just prior to dialysing.

Send us your hints that work for you, and not included in the above.

Next Shoestring Issue: We will discuss Salt Intake.

Ros Ball

It was recently announced that a Boston (USA) research facility had managed to advance the development of laboratory produced kidneys. Rat kidneys were washed in a chemical solution to remove the native cells leaving just the scaffold of the kidneys. The scaffold was then coated with new cells. The resulting kidneys worked in the lab and when transplanted into rats. They filtered out and discharged urine although not as efficiently as natural kidneys.

Read more on the New Scientist web site:

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

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.**

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<td>Close of Applications</td>
<td>end of May</td>
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<tr>
<td>Applications to Judges</td>
<td>last week of June</td>
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<tr>
<td>Results from Judges</td>
<td>second week in September</td>
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<tr>
<td>Advising Award Winners</td>
<td>3 weeks before the AGM</td>
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<tr>
<td>Presentation of Awards</td>
<td>at the AGM in October</td>
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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 2013. 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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Letters and emails

Access to parking at Melbourne's Public Hospitals

Dear All

Over the years there have been many reports on the rising cost of parking in Melbourne's public hospitals. These costs are thought to be higher than in many other countries. Unfortunately such costs are likely to be most felt by people with chronic illnesses. Below is a link to a survey to explore how these expenses impact on the people we represent. This survey will remain open until 14th June to give all our members time to advertise the link to the survey across their networks via email and printed newsletters.

The results will be used to publicise the problems people with chronic illnesses face and to provide the basis for a better understanding of people's needs. We would be grateful for as wide a circulation as possible.

http://www.surveymonkey.com/s/9VFYH9H

Christine Walker
Dr Christine Walker
Chronic Illness Alliance
587 Canterbury Rd Surrey Hills 3127
03 8809 0641
04 02 416 868

Government Announcement

Early in April, The Australian Government announced a new two year pilot of a National Live Organ Donor Leave scheme. This means people who are working and donating a kidney will get a payment (for 6 weeks) via their employer, to help ease financial difficulties while on sick leave. How to apply for this payment is not made clear.

Source : www.donatelife.org

Remember that DATA has a small welfare grant that members can apply for through their hospital social worker.

Bowels OK?

I heard a useful metaphor the other day. When asked by a visiting doctor: “How are your bowel movements?” I hesitated, not sure how to say what I wanted to say. So then he said helpfully: “A good movement is like toothpaste.”

How useful is that? Toothpaste glides out after a reasonable squeeze and keeps its shape outside the tube. What better?

But then, on further reflection I realised that it also covers most other eventualities:

If you leave the cap off the tube, the toothpaste gets a little dry and firmer at the start, and you need a little more energy to get it flowing – a common problem with us perpetually dry BigD-ers

Toothpaste left out of the tube goes rocky if left sitting for a while – a regular outcome (excuse the pun) every time I have an anaesthetic

Mix toothpaste with water and it becomes quite slushy (loose) – some meds will do that too.

Thankfully, the metaphor ends there.


**SPECIAL HIGH INTENSITY TRAINING**

In order to ensure the highest levels of quality work and productivity from employees, it will be our policy to keep all employees well trained through our program of *special high intensity training* (S.H.I.T.) We are trying to give employees more S.H.I.T. than anyone else.

It you feel that you do not receive your share of S.H.I.T. on the job, please see your manager. You will be immediately placed at the top of the S.H.I.T. list, and our managers are especially skilled at seeing that you get all the S.H.I.T. you can handle.

Employees who don’t take their S.H.I.T. will be placed in *DEPARTMENTAL EMPLOYEE EVALUATION PROGRAMS* (D.E.E.P S.H.I.T.). Those who fail to take D.E.E.P S.H.I.T. seriously will have to go to *EMPLOYEE ATTITUDE TRAINING* (E.A.T. S.H.I.T.). Since our managers took S.H.I.T. before they were promoted, they don’t have to do S.H.I.T anymore, and are all full of S.H.I.T. already.

If you are full of S.H.I.T, you may be interested in a job training others. We can add your name to our *BASIC UNDERSTANDING LECTURE LIST* (B.U.L.L.S.H.I.T). Those who are full of B.U.L.L.S.H.I.T. will get the S.H.I.T. jobs, and can apply for promotion to *DIRECTOR OF INTENSITY PROGRAMMING* (D.I.P.S.H.I.T.)

If you have further questions, please direct them to our *Head of Training, Special High Intensity Training*. (H.O.T.S.H.I.T.)

Thank you

**Boss in General**

*Special High Intensity Training*  
(B.I.G.S.H.I.T.)

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**Have a laugh**

A little boy got on the bus, sat next to a man reading a book, and noticed he had his collar on backwards. The little boy asked why he wore his collar that way. The man, who was a priest, said, "I am a Father"

The little boy replied, "My Daddy doesn't wear his collar like that". The priest looked up from his book and answered, "I am the Father of many".

The boy said, "My Dad has 4 boys, 4 girls and two Grandchildren and he doesn't wear his collar that way". The priest, getting impatient, said, "I am the Father of hundreds" and went back to reading his book.

The little boy sat quietly thinking for a while, then leaned over and said, "Maybe you should wear your pants backwards instead of your collar".

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Do you know what would have happened if it had been three wise women instead of three wise men?  
They would have asked directions,  
Arrived on time  
Helped deliver the baby  
Cleaned the stable  
Made a casserole, and,  
Brought practical gifts.

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

Smart is when you believe only half of what you hear.  
Brilliant is when you know which half to believe.  
**********
Dates to Remember

26th May—1st June 2013 Kidney Health Week

Saturday 25th May Service of Thanksgiving
RMIT Storey Hall, 336 Swanston Street Melbourne

29th June 2013 Packing Shoe String
14 Queen St Blackburn

20th July 2013 Xmas in July

December ? Christmas event
This Christmas event may be held on 25th Nov 2013
Watch our Web site www.datavic.org

Our thanks to all who contributed to this edition.

Why not spread the word and pass this copy on?

ShoeString 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: 13th June 2013