MEMBERS BBQ at Blackburn 10th February 2013
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From The Editors:

The new editorial group are Joan Eastwood, Sue Hatzimichalis, Ros Ball, Fay Rawson. We hope we can be productive and informative. It is up to you, the members, to supply us with interesting stories. Our email is still the same editor.shoestring@gmail.com

Page 3  Presidents Report, BBQ  10 Feb 2013

Social Committee reports that we had a great BBQ on Feb 10th. Apart from the chitter-chatter that went on we passed around a questionnaire to get an idea of what the MEMBERS of data would be interested in. We had forty people there so it was a varied group. It was clear that we like to get together and share stories, give support, and talk about different techniques of managing kidney failure. All the same we do not want to be always talking about our illness so we do like some fun times as well. To this end we will run a theatre night or two, also run a coffee & cake gathering at a shopping centre, and of course our old favourites Xmas in July and Christmas Outing/Party. Most of these will be pay as you go, but we will try to get the best price.

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In the September 2012 issue of Shoe String was a page dedicated to recipes. Unfortunately all recipes on that page are high in potassium and fluid, and as such ARE NOT suitable for those of us on a renal diet. We apologize, that these recipes were included in the September issue of ShoeString.
President’s Report

From The President

Well, doesn’t seem so long ago that I was sitting at my computer doing this for the January 2012 edition, how time flies when you’re having fun!

Not much has happened except that settlement for the Blackburn House has gone through and now starts the hard work (see article in the home reports) We need help from you,

We have included a survey for some feedback or suggestions about what we could. Can you spare a few minutes to fill in the survey and send it back to us that would be really appreciated and help us out with a truly important decision. Your feedback is important to us and it will go a long way in making the right decision for the Association. Please make it a priority to send the survey back to us so we can start our search in looking for the right property.

Our BBQ was a great fun hot day, and everyone enjoyed themselves. We had a fantastic day, there was around 40 members who attended, there is an article and photos so please look at these and hopefully you can see how much fun it was.

Sue Hatsimichalis

The BBQ 10 February 2013:

We thought it would be our last BBQ so it was a bit special – It was great to see the children there I hope it wasn’t too boring for them. I had a smile to myself – as I worried about getting the ball games out for them, they calmly produced their ipad and other electronic devices and started to play on them. We never heard a peep out of them, (and we thought TV was the best babysitter of all).

Everyone brought something and it adds such variety to the meal, thanks to Alex for the home grown vegetables – tomatoes for the salad, zucchini and egg plant, cucumber. Thanks of course to the committee members who were issued their orders about what to bring – Angela always keeps track of that. Thanks too, to Hayley for helping to fetch and carry. The guys who did the BBQ: Charlie and Peter. The guy who got there first and had it all set up – (well almost) – Paul and Phil. Everyone lent a hand so it was just like a family BBQ - DATA Family BBQ.

We will all miss the pleasant surroundings at 14 Queen Street.
Holiday Homes

**Rosebud:**

**Vacancies:** The House is free from the 14th April, May is free and a few weeks left in June.

We do get cancellations so please call to check.

We have purchased a new outdoor setting, a lamp and a rug to make the house more comfortable. We have had great feedback so far.

Don’t forget - Haemo patients to check availability at Rosebud hospital before booking the house.

If you are having dialysis at the house, please double bag the waste before putting it in the bin. Also for any sharps, take an empty bottle to put them in and dispose of them in your sharps container once home.

To make it fair for everyone, during school holidays we only book the house for one week at a time so everyone gets a chance to use it.

*Amanda Pratt  Rosebud House Secretary  phone 9589-4894*

**Yarrawonga:** 2013

Next vacancies: 2nd to 9th June, 9th to 16th June, 16th to 23rd June, 23rd to 30th June.

We do get cancellations so please ring me.

We would like to see more of you enjoying a holiday at Yarrawonga or down at the beach at Rosebud. Phone Amanda for Rosebud or myself for Yarrawonga, to see what is available. We have a Gambro AK95 at both houses and Monash will bring a Fresenius dialysis machine to either house for you.

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 Rawson  22 Tarwin Drive Croydon 3136  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.
Blackburn

Blackburn House.

News to Date—Settlement date was 13th February 2013, and we now have a more than healthy bank balance. The Committee and Sub Committee have worked exceedingly hard to get the best outcome and our thanks go to all who helped. Special thanks to Brendan and Eleanor. Now the hard work begins to try to discern what type of property we should purchase.

See enclosed survey (on coloured paper) - please take the time to jot down your suggestions. Please post back to PO Box 165 Blackburn Vic 3150

What happens NOW???

I consulted an expert to help us answer some of these questions

Q What happens now?
A Nothing much. We are renting the property for next six months. at least.

Q Where will our Office be after that?
A Yet to be decided

Q What will happen to all our office equipment? Computers, filing cabinets?
A We do hope to have alternative accommodation- a room, a unit or a house that will be our office, but its yet to be decided

Q Where will we stay when we come to town for hospital visits overnight?
A We still have the Blackburn house for a minimum of six months after that DATA will either purchase another property or assist in arranging accommodation

Q Will we still get Shoe String?
A Yes there will be no interruption to Shoe String.

Q How will we contact DATA?
A Phone number is unchanged 9894 0377
Email: info@datavic.org
Mail Address PO Box 165 Blackburn Vic. 3130

It is with sadness that we report that CESARE MALANDRA, father of Rob and Melinda, and Pia passed away unexpectedly.

Cesare was one of our newer members and attended the February BBQ with his son and daughter and daughter in law and grandchildren at Blackburn.

Josh and Christian are pictured on page 11 of this SS.

Cesare will be sadly missed.
AUSTRALIAN Test cricketer Rob Quiney will be among the headline players lining up in an organ donation awareness cricket match in Bendigo.

Rob Quiney
Eaglehawk’s Canterbury Park will host the 30-over-a-side match on Sunday, February 24, between the Australian Transplant Club and DonateLife Everyday Heroes team.

The game will kick off DonateLife Week in Victoria and is being played to help raise awareness for organ and tissue donation.

Quiney, who earlier in the summer played two Tests for Australia against South Africa, will be part of the Everyday Heroes team and will open the batting.

Joining Quiney in the Everyday Heroes team will be Prime Minister Julia Gillard’s partner Tim Mathieson and his son Kane, young Victorian all-rounder Alex Keath and former Australian Test bowler and now Cricket Victoria chief executive Tony Dodemaide.

The Everyday Heroes team will also include Northern Victoria Region MLC Damian Drum, Bendigo boxer Justin Whitehead and 3BO radio personality Bryan Coghlan, with the side to be captained by Bendigo’s Steve Hollingsworth, who is a co-organiser of the game.

“This game is kicking off DonateLife Week in Victoria and is the marquee event of the week, so we’re very excited to have it here in Bendigo,” Hollingsworth said yesterday.

“All the players taking part in the game are giving their time for a worthy cause, which is fantastic.

“We’ve also got a number of local sponsors to help out, which has been fantastic, and we’re looking forward to a great day of cricket and to help raise the awareness of organ and tissue donation.”

The two teams will play for the Robyn Hookes Shield.

Robyn Hookes is the widow of former Australian cricketer and Victorian coach David Hookes, who had his organs donated after his death in 2004.

Since then Robyn has been a driving force for organ donation, and two years ago toured England with the Australian Transplant Cricket Club, of which Hollingsworth was a member.

The game will start at 10am, with free entry. As well as the cricket, the day will also include children’s entertainment.

Geoff Adcock
Go Saints
Have a Laugh

Penguins

Did you ever wonder why there are no dead penguins on the ice in Antarctica. Where do they go? Wonder no more!

It is a known fact that the penguin is a very ritualistic bird which lives an extremely ordered and complex life. The penguin is very committed to its family and will mate for life, as well as maintaining a form of compassionate contact with its offspring throughout its life.

If a penguin is found dead on the ice surface, other members of the family and social circle have been known to dig holes in the ice, using their vestigial wings and beaks, until the hole is deep enough for the dead bird to be rolled into and buried.

The male penguins then gather in a circle around the fresh grave and sing:

"Freeze a jolly good fellow"
"Freeze a jolly good fellow."

This is the story of YAM sent to us by kennygrove@live.com.au with love from Kenny & his Mum, Joan Grove.

Well, a Girl Potato and Boy Potato had eyes for each other, and finally they got married, and had a little sweet potato, which they called 'Yam'

Of course, they wanted the best for Yam.

When it was time, they told her about the facts of life. They warned her about going out and getting half-baked, so she wouldn't get accidentally mashed, and get a bad name for herself like 'Hot Potato'.

Yam said not to worry, no Spud would get her into the sack and make a rotten potato out of her!

But on the other hand she wouldn't stay home and become a Couch Potato either.

She would eat properly so as not to be skinny like her Shoestring Cousins.

When she went off to Europe, Mr. And Mrs. Potato told Yam to watch out for those hard-boiled guys from Ireland and the greasy guys from France called the French Fries, and when she went out West, she must watch out for the Indians so she wouldn't get scalloped.

They sent Yam to Idaho P.U. (that's Potato University).

So that when she graduated she'd really be "in the Chips".

But in spite of all they did for her, one-day Yam came home and announced she was going to marry Richie Benaud.

"Richie Benaud!", they cried.

They were very upset and told Yam "You can't possibly marry Richie Benaud because he's just ....

* ...

... just a COMMONTATER!"
Rules of Ron Jones Educational Awards

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 forms 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.**

    - **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.

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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About 3 years ago those of us on dialysis and DATA members were asked to participate in a research project with the aid of using emails or blogs for communication purposes.

This research was being carried out by PHD candidate Natalya Godbold in the Faculty of Arts and Social Sciences, University of Technology, Sydney. (Human Information Behaviour/Health Communication). Natalya’s husband is a long term renal patient, just having to go back on dialysis after 21 years with a transplant.

Natalya tells us that research is now being presented for assessment and here is an overview.

I studied the processes that people go through while they are coping with kidney failure, and in particular, watched how experienced kidney patients helped new kidney patients. What advice did they give, how did they give it. And I asked myself, what can I learn from that, to help professionals to support new patients coping with kidney failure? I noticed how people looked for and used patterns in their experiences, to develop routines and work out what would be normal for them; I noticed how people needed to work out how to feel as well as how to think; and I noticed how people needed information from others, like about kidney failure and about medications, but they also needed to create their own understandings which were about their lives and their bodies. These understandings were unique, they couldn’t be given to a person by someone else and couldn’t come out of a brochure or a booklet. People needed to create their own understandings, which takes time and involves trial and error. So my three findings are:

1. People make sense by finding patterns and breaking patterns, which requires repetition and time;
2. People make sense by testing ideas against experience, which means sense making is physical and emotional, and it involves living; it is not only a mental activity;
3. People make sense by creating their own customized connections between ideas; the connections are shifting and improvised; this is how people can respond to life’s complexity, and it means that providing access to many examples of ‘how things might proceed’ is as valuable as providing ‘the most accurate’ information possible.

I discussed those findings in terms of implications for clinical practice and for information professionals: how to help people develop understandings in the context of their lives rather than expecting to just ‘give’ people generic information. On my website (http://godbold.name/experiencingdialysis) I summarised my findings slightly differently.

Summary of findings and recommendations

I have found that, as people make sense of kidney failure:

- People need repetition and time to develop understandings, find patterns in experiences and work out what is normal
- People need to make unique links from general information into their specific situations
- Hearing descriptions of other people’s experiences gives a person vocabulary to describe and understand their own experiences
- Understandings must be tested by time and experience, and
- Experience is closely related to authority

Recommendations

- Patients and families need ongoing exposure to ideas, because information is not ‘given’ in a single instant so much as understandings are developed over time.
- Patients and families need information from a range of sources, because repeated ideas from different sources create a sense of consensus and familiarity; also variations in stories gives us a vocabulary with which to make sense.
- Patients and families should be encouraged to network with their peers, because clinicians are not experienced at all aspects of being a patient – particularly, at making the unique, specific links which allow a person to live with chronic illness in their particular situation
- Patients and families could be advised to expect that making sense of renal failure will be ongoing, will take time, will involve constant change, and will involve trial and error. They could also

(Continued on page 11)
be shown how to notice and respond to changes and encouraged to collaborate with clinicians.

- For this, clinicians also need training and some hospitals may need cultural change.

These changes are worth making because helping patients and their companions to make sense of kidney failure contributes to their capacity for adequate compliance, their ability to contribute to clinical safety, and their ongoing happiness.
### Dates to Remember

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<th>Event</th>
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<tr>
<td>Donate Life Week</td>
<td>24th Feb-3rd March</td>
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<td>World Kidney Day</td>
<td>14 March 2013</td>
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<td>Packing Shoe String Blackburn</td>
<td>3rd May</td>
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<td>Kidney Health Week</td>
<td>May 2013</td>
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<td>Service of Thanksgiving</td>
<td>TBA</td>
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<tr>
<td>Packing Shoe String Blackburn</td>
<td>29th June</td>
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<td>Xmas in July (to be confirmed)</td>
<td>27th July</td>
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<td>Christmas event TBA</td>
<td>December 1st</td>
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### Executive Committee

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<tbody>
<tr>
<td>President</td>
<td>Sue Hatzimichalis</td>
<td>(03) 9378 9222</td>
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<tr>
<td>Vice President</td>
<td>Joan Eastwood</td>
<td>(03) 9795 1649</td>
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<tr>
<td>Secretary</td>
<td>Ros Ball</td>
<td>(03) 9439 8866</td>
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<tr>
<td>Treasurer</td>
<td>Eleanor Allan</td>
<td>(03) 9561 4806</td>
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### Holiday Homes Secretaries

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<tr>
<th>House</th>
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<tr>
<td>Yarrawonga House</td>
<td>Alan Rawson</td>
<td>(03) 9723 3019</td>
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<tr>
<td>Rosebud House</td>
<td>Amanda Pratt</td>
<td>(03) 9589 4894</td>
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<tr>
<td>Blackburn House</td>
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### ShoeString Editors

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<td>Fay Rawson</td>
<td>(03) 9723 3019</td>
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### Committee Members

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<tr>
<td>Nick Hatzimichalis</td>
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<td>Ken Smith</td>
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<td>Kaitlyn Steavenson</td>
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*The views expressed in the editorial and the contributed items are those of the authors and are not necessary the opinions of D.A.T.A. Inc.*

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### 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

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### Deadline for the next ShoeString: 16th April 2013