

Donate Life

Service of Remembrance



Saturday 26 May 2012

2pm (doors open at 1.15pm)

RMIT, Storey Hall Auditorium, Building 16

336 Swanston Street Melbourne



A day of unity and reflection for donor families and friends

Invite page 9



DATA is now on Facebook!

page. 3

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A Note From the Editors...

Hello everyone, we hope this edition of ShoeString finds you all well. This May's issue highlights an important event held each year in the Month of May, and that day is the Donate Life Service of Remembrance. This special day helps bring people who have been touched by organ donation together and acknowledge and show thanks to all organ donors and their families. I personally would like to thank my mother Roseann Campbell, who donated one of her kidneys to my brother David on March the 6th 1990, love you mum x.

Fitting to this month's events, on page 8 you will find a wonderful, courageous story, written and submitted, by DATA members Wendy and David Laing. We hope page 10 of thankful quotes inspires and uplifts you all and don't worry we will have our Recipe Corner back next issue.

We would like to welcome Eleanor Allan as our newly appointed Treasurer and wish her well. Thanks to all who attended our annual member's BBQ, photos and highlights of the day page 11, and don't forget we have our famous Christmas in July just around the corner, we would love to see you there. Reminder, there is only a few weeks left to apply for the Ron Jones Education Award, conditions and application pages 6-7, closing date 31st May.

We hope you enjoy this issue of ShoeString. Thanks to all who contributed and remember we love to hear your stories, so please email or contact either Adrienne or myself. 'Til next issue.

June & Adrienne, Editors

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

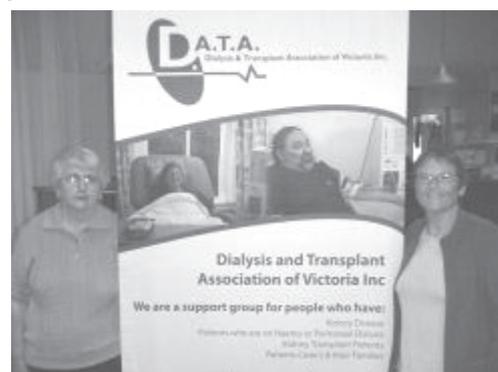
Because of the unusual weather my husband and I have delayed our trip to the Blue Mountains in NSW, until spring. The weather remains unusual for the year, cold over Easter, and when the children have returned to school the weather has shown its autumn best.

After the sad passing of our treasurer, Lloyd Samuel, it was difficult to find a replacement for someone who had offered DATA so much over the years. We were fortunate that Eleanor Allan offered to take on this role for us. Eleanor was on the committee last year, but resigned at the end of the financial year. We welcome Eleanor back to the committee and I believe that we have a very hard-working and dedicated person for the job.

We say goodbye and a big thank-you to John Hulskamp (our previous bookkeeper) for all the work he has done for us. I believe that John was first a committee member and then our treasurer, before becoming our bookkeeper and knows us well. John will stay involved as he runs our webpage.

I attended a health forum in Mildura on the 6th March to represent DATA and join up some new members. It was a great day.

Ros Ball



DATA President, Ros Ball, with Betty a'Beckett

Committee News



Data would like to congratulate Eleanor Allan on volunteering for the role of Treasurer. Eleanor will be filling the position previously held by Lloyd Samuel and admits she has some big shoes to fill.

Eleanor and her husband Michael have been members of DATA for over thirty years or more, and have fond memories of attending the annual DATA Christmas parties held at Ron Jones homestead so many years ago.

After Michael, Eleanor's husband was diagnosed with renal failure he underwent two years of dialysis before receiving his first kidney transplant which lasted for five and a half years. Michael's second transplant did not occur until eleven and a half years later in the year 2000 and is still going strong.

Although a little reluctant in taking on the huge responsibility of treasurer, Eleanor hopes to be successful in her new role and do her best for DATA and its members.

Eleanor and Michael would like to pass on their gratitude to the donor family, and are indebted always.

DATA NOW ON FACEBOOK

DATA - Dialysis & Transplant Association

We have now set up a group on Facebook for DATA!

You should be able to find us if you put "DATA" or "Dialysis Transplant" into the search. You will need to be a member of Facebook first before you can access the site though and become a member of the group. Or you can add us at: www.facebook.com/groups/113757995397037/

Please call me if you have trouble joining the group.

Kaitlyn Steavenson

Holiday Homes

Rent Increase

Due to the rising costs there will be a rent rise at both houses from the start of February 2012.

New rates are \$180.00 per week between December 1 until Easter. The off-peak rate will be \$160.00 per week from Easter to the end of November. Extra guests are still \$20.00 per night each.

If you have already received a form for 2012 with \$160.00 stated as the rent this is what you will be charged for your holiday.



Blackburn:

Blackburn House is not being used as much now for country patients, it seems that the patients we used to get when they were being trained for home dialysis or had a transplant are staying at the hospital's accommodation, which is nearer to the hospital.

The building next door is going ahead in leaps and bounds and there has not been too much inconvenience with trucks or parking etc. however, the noise has been a bit loud.

On the whole Blackburn has been quieter than the other houses. People from the country should feel free to come down and have a holiday in Melbourne.

The prices have recently changed to \$50.00 per night and \$20 per extra person, the Family room is \$65.00 per night or if you want to stay a full week in a normal room, it will be \$180 (this price is the same as the other Holiday homes weekly price) or \$250 a week for the family room. VPTAS (Victorian Patient Transport Assistance Scheme) will still pay \$35 a night, if you are down here for hospital visits so you will only be out of pocket \$15 for your stay if it is hospital related.

Blackburn House Secretary

Sue Hatzimichalis

Ph. 9378 9222, Mob. 0412 469738

Yarrawonga:

We currently have vacancies for the whole of June, July 15 to 29, all of August, first and third week of September (2 to 9 and 16 to 23) as well as the second week of school holidays at the end of September and early October (30 September to 7 October). We do get cancellations too, so please ring me

Don't forget you Haemo Patients to ring the Yarrawonga Renal Unit (Phone: 57438189) to find out what is available and then ring me to book that time into the house; Haemo Patients get first preference at the house.

We would like to see more CAPD patients using the houses. Everything is up there: a microwave, bag warmer, etc. and your bags can be delivered to the house when required.



Yarrawonga House Secretary

Alan Rawson, 22 Tarwin Drive Croydon 3136,

Ph. 9723 3019, E-mail: fayal_rawson@hotmail.com

Holiday Homes

Rosebud:

Bookings for Rosebud have remained constant and there is a week available for rent at Rosebud from 13 - 20th May. Then we are fully booked out until August. We do get cancellations from time to time - so please ring me if you would like to go on standby for a cancellation.

There has been a lot of positive feedback on the renovations that were undertaken at the home last year, and it's good to know that members are happy with the work that was carried out. We replaced some items to modernise the home, and unfortunately the new vase that we purchased for the home has gone missing. It might have got broken and replaced - but if something like this does happen, please let us know so we can replace it ourselves.

To help keep rent low, we do not employ a cleaner or a routine maintenance person (in any of the houses), we therefore rely on people who stay at the house to clean the home before they leave and ensure it is left in a clean condition ready for the next person who has booked the home. It would be appreciated if members can replace light bulbs and clock batteries when necessary.

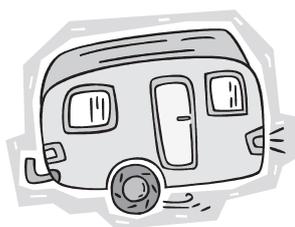
Please call me if there is any mishaps or problems with the house as notes left at the house can be misplaced and the information is unlikely to be passed on.

Rosebud Holiday Home Secretary

Kaitlyn Steavenson

Ph. 9785 3036, Mob. 0403 561 624

Please ring after midday.



Need a Holiday?

Is anyone interested in having a holiday in country Victoria? I am currently negotiating with a dialysis unit to help some of our dialysis members, and their families to have a week's holiday. If this is of interest to you please let me know, more numbers are need to make this happen, so please let me know, unless I get more response I will have to cancel these plans..

Ros Ball, 9439 8866

Reciprocal Health Care Agreement

At last the Government has come to an agreement for those on dialysis to be able to receive public renal dialysis services when travelling to certain countries. This does depend on the country and dialysis unit having available capacity. Some countries participating include Belgium, Norway, Italy and England. For a full list of countries and eligibility, view the webpage. All the information can be found at: health.vic.gov.au/hospitalcirculars/circ11/circ2211.htm

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.

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 a financial Member of DATA with renal failure or a child of a parent who has or did have renal failure.
5. Applicants who have completed years 7 to 11 may apply for an Award by the end of May of the following year for presentation in August 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.**

<u>Close of Applications:</u>	end of May
<u>Applications to Judges:</u>	last week of June.
<u>Results from Judges:</u>	second week in September
<u>Advising Award Winners:</u>	3 weeks before the AGM
<u>Presentation of Awards:</u>	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 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.

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

How We Beat the Silent Killer

On 26th October, 2011, Dave was given the chance for a dialysis-free life, when Wendy donated a kidney. Just over four months later, both are fit and well, and enjoying a normal life!

By Wendy & Dave Laing

Dave: I have known for 25 years that I had IGA Nephritis (genetic kidney disease). Over the years, my kidney function and health gradually deteriorated. Finally, with my kidney function at 12% - 14%, I was offered a most wonderful lifeline.

Wendy: We've been married for over 27 years.

Knowing that Dave's nearest relatives in UK, (his siblings) were not available, I put up my hand to be assessed as a potential kidney donor. We both used to be blood donors, and I knew that I was a universal blood group, O Rh Neg, and Dave O Rh Pos.

Dave: Six months of testing for both of us started, with everything going smoothly until, in early June, doctors found a benign Meningioma, which was affecting Wendy's balance. This became a priority.

Wendy: What a shock! But on the plus side, I was glad that they had found it, and it was curable. However, this meant a 4 month delay in the donation procedure, as the Kidney team, and my neurological team wanted my body to recover from the major surgery first!

Dave: Finally, early October, we were offered dates

for the donation procedures. We chose the first date offered, 26th October 2011.

Wendy: After a few weeks of final tests and consultations, the final all clear and ready to go was given. On the morning of the 25th, we drove our Labradoodle, Kynda to her holiday camp (dog kennels), and in the afternoon we were driven to the Melbourne Private Hospital.

Dave: Wendy and I had decided to name all our kidneys! Her left one was to be donated and we called him Tom, thus leaving her with Jerry.

Wendy: Dave's diseased kidney's, we appropriately named Frank and Stein. For the rest of our lives, we can now refer to them by name!

Dave: I had a single room, and Wendy had a double room three doors away. As I was the second cab of the rank the next afternoon, I was able to enjoy my dinner that night and a very early light breakfast on the big day.

Wendy: I was taken to the operating theatre in the morning, knowing that around 3 hours later, Dave would be in the adjacent theatre being prepared for Tom.



Dave: When I was taken into the second theatre around 1.30 pm, I knew that Tom was already bathed, and dressed, ready for his new home inside me.

Wendy: Dave and I were up and walking around the ward together, the next morning with our drips and catheter bags in tow! It was good to be able to spend most of the days in Dave's room, where we could chat, watch TV, and go for walks around the ward.

Dave: A week later, we were on our way home!

Wendy: Friends and neighbours appeared out of thin air with baskets of food and helped us settle in. The doorbell rang again, and one very happy dog trotted in for a cuddle! We were so pleased to be home.

Dave: Initially after daily visits to the early morning renal clinic at the Royal Melbourne Hospital, my visits became less frequent over the next few weeks. I feel so well, and began to realise that I had slowed down so much prior to receiving Tom. I realised how lucky I've been, having a live donor transplant, after seeing, and meeting so many others, who have been on dialysis for years, waiting for a suitable cadaver donor.

Wendy: I can only agree with Dave, that after seeing and meeting people, who are in a much more difficult

situation, that we were so lucky. I often wonder how many other people are out there with undiagnosed kidney disease. It's called the Silent Killer, as there are basically no symptoms until the kidneys are seriously affected. My personal hope is that somehow, there could be a funded, blood testing program for everyone. It can be detected with a simple blood test! I encourage more people to donate their organs, particularly live kidney donors! Wouldn't this save, not only money spent on dialysis, and treatment, but potential lifestyle change for many families.

Dave: I thank all the dedicated team at the Royal Melbourne Hospital Renal Unit., and the Melbourne Private Hospital.

Wendy: My thanks also go to everyone that have taken care of us, and who continue to monitor our progress.

Dave: At this time, Tom is operating so well, I feel like a new man. Frank and Stein are still with me, but now retired!

Wendy: Jerry is also going well, and we are both fighting fit. Dave and I often mention their names in conversation, as we don't want them to be the silent ones, forgotten for all the good work they do!

Donate Life Service of Remembrance



please join us..

at the DonateLife Service of Remembrance
to be held at RMIT, Storey Hall Auditorium, Building 16
336 Swanston Street Melbourne on Saturday 26 May 2012
commencing at 2pm (doors open at 1.15pm).

For further information 03 8317 7400

Quotes of Thanks...

Two kinds of gratitude: The sudden kind we feel for what we take; the larger kind we feel for what we give.
—*Edwin Arlington Robinson*

The best way to pay for a lovely moment is to enjoy it.
—*Richard Bach*

We can only be said to be alive in those moments when our hearts are conscious of our treasures.
—*Thornton Wilder*

There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.
—*Albert Einstein*

Gratitude can transform common days into thanksgivings, turn routine jobs into joy, and change ordinary opportunities into blessings.
—*William Arthur Ward*

Real life isn't always going to be perfect or go our way, but the recurring acknowledgement of what is working in our lives can help us not only to survive but surmount our difficulties.—*Sarah Ban Breathnach*

(Some people) have a wonderful capacity to appreciate again and again, freshly and naively, the basic goods of life, with awe, pleasure, wonder, and even ecstasy.
—*A.H. Maslow*

Give thanks for a little and you will find a lot.
—*The Hausa of Nigeria*

Happiness is itself a kind of gratitude.
—*Joseph Wood Krutch*

The moment one gives close attention to anything, even a blade of grass, it becomes a mysterious, awesome, indescribably magnificent world in itself.
—*Henry Miller*

Reflect upon your present blessings, of which every man has plenty; not on your past misfortunes of which all men have some.
—*Charles Dickens*

Feeling grateful or appreciative of someone or something in your life actually attracts more of the things that you appreciate and value into your life.
—*Christiane Northrup*

Whatever our individual troubles and challenges may be, it's important to pause every now and then to appreciate all that we have, on every level. We need to literally "count our blessings," give thanks for them, allow ourselves to enjoy them, and relish the experience of prosperity we already have.
—*Shakti Gawain*

We can only be said to be alive in those moments when our hearts are conscious of our treasures.
—*Thornton Wilder*

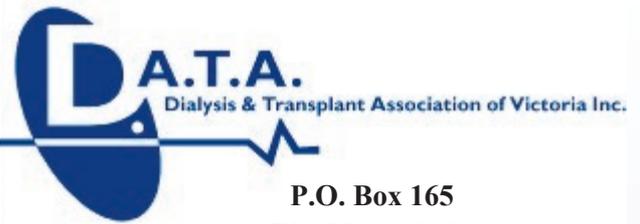
Let us be grateful to people who make us happy; they are the charming gardeners who make our souls blossom.
—*Marcel Proust*

Members BBQ

The member's summer BBQ, held at DATA's Blackburn house, was enjoyed by all who attended. The Blackburn house has beautiful gardens providing a lovely venue for our annual BBQ. Making it especially enjoyable this year were the new tables and chairs provided by DATA (thanks DATA). Old and new members mingled and shared personal experiences whilst dining on the delicious BBQ sausages and salads. Thanks to Ken for the apples from the Farmers market. Members came from near and as far as Traralgon. Thanks to everyone who came and pitched in, it was a fantastic day.



Dates to Remember



**P.O. Box 165
Blackburn 3130
Ph. (03) 9894 0377
Fax. (03) 9894 0266**

Executive Committee

President

Ros Ball (03) 9439 8866

Vice President

Kaitlyn Steavenson (03) 9785 3036

Secretary

Sue Hatzimichalis (03) 9378 9222

Treasurer

Eleanor Allan (03) 9561 4806

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Alan Rawson (03) 9723 3019

Rosebud House

Kaitlyn Stevenson (03) 9785 3036
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Blackburn House

Sue Hatzimichalis (03) 9378 9222

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Adrienne Betlehem 0411 326 093

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Michael Allan (03) 9561 4806

Joan Eastwood (03) 9795 1649

Paul Murphy (03) 9779 9386

Neal Sixtus (03) 5977 8903

The views expressed in the editorial and the contributed items are those of the authors and are not necessarily the opinions of D.A.T.A. Inc.

* * *

May 27 - June 2 Kidney Health Week

June 15 Carers' Night
14 Queen St, Blackburn, 6.30pm
BYO plate of food to share

July 21 Christmas in July
Eley Community Centre

October 14 Working Bee at Rosebud

December 2 DATA Christmas Party
Keep the date free!
Details TBA

* * *

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,
P.O. Box 165 Blackburn 3130
Email: editor.shoestring@gmail.com

Deadline for the next ShoeString: 18th June