VISIT TO THE ROSE GARDEN

MORNINGTON BOTANICAL ROSE GARDEN
CIVIC RESERVE          DUNNS ROAD          MORNINGTON

Sunday 13th APRIL 2014  2.30pm

RSVP 3rd April 2014  see form below.

DATA Members gold coin admission

Others $5.00 per person.

DIALYSIS & TRANSPLANT ASSOCIATION VIC INC.

Reply slip for MORNINGTON ROSE GARDEN  13 APRIL 2014

Name ..........................................................                   Phone ..........................................................

Yes I/we would like to come to Rose garden

Number of adults ......................                   Number of children ......................

Return this slip to PO Box 165 Blackburn 3130 by 3rd April 2014
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REST IN PEACE BERNIE KEELEY
Bernie passed away January 2014.
Bernie was a hard working early member of DATA, joining in 1979 serving in all positions, President, Secretary, Treasurer. Looked after both houses, anything that had to be done Bernie did.
He was a member of the committee that was responsible for the purchase of our three homes. Rosebud first then Yarrawonga, and later on Blackburn. The reason was that the Committee wanted somewhere that all our members, especially Haemodialysis members, could have a holiday. Look what we have now, Rosebud by the sea, and Yarrawonga in the country. I worked with Bernie setting up Blackburn so that country members had a place to stay at a reasonable cost, when they came to Melbourne after a transplant, a medical appointment, or a holiday in Melbourne.
Bernie had his transplant for over 30 years. After Bernie’s first wife, June, passed away he met and married Ann and they moved to Mandurah in WA. Bernie was made a LM in 1987.
I am sure that the many friends he had in DATA will be sad that we have lost a valuable member of our organization. Alan Rawson

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

What a few weeks since the beginning of the year! In Melbourne we have nearly boiled alive with over 40 degree days; nearly burned alive with very serious bush fires all around Victoria (and other states around the country). To cap it off, yesterday, we were almost washed away. If it was not so serious you would think it was a joke! This has been a very trying period for many of our members and our thoughts and best wishes go out to those effected.

While on holiday recently at Labrador on the Gold Coast, my wife and I went to a show at the Twin Towns Resort and I noticed Bobby Rydell was one of the upcoming acts. Those of you who are of a “certain age” will remember Bobby, the American pop star (I am talking something like 100 years ago - well almost). For him to be travelling the world and doing concerts at age 72 is pretty amazing, but to be doing that having had a kidney and liver transplant at age 70 is quite unbelievable. Just think about it! (Thomas Jefferson Hospital in Philadelphia is the place to go!) You can read about Bobby’s transplant at Bobbyrydell.com. I believe he visited the Austin Hospital whilst in Melbourne. Did anyone by chance meet him?

Our members get together and BBQ scheduled for 9th February was cancelled at the last minute, not only because of a total fire ban on the weekend of the event, but also in the interests of the welfare of attendees as temperatures were in the high 30’s and low 40’s. Thankfully common sense prevailed. The event is rescheduled for Sunday 16th March. I hope you can make it.

If you are interested in what was happening in the world of DATA over the past seven years, have a look at our website. Some interesting reminiscences and photos.

In conclusion, stay safe, cool and drink appropriate liquids and quantities. If you are on the sick list, I hope things improve and that you are back on deck ASAP.

Michael Allan

STOP AND SMELL THE ROSES Details of Mornington Rose Garden.

Following our Chairperson’s comments last month about a few new outings being planned for DATA, I am happy to announce the first of these is planned for Sunday April 13th next. As Michael said we have become a bit predictable and yes, numbers have dropped off. So we hope to provide a few new items over the year. If you have any bright ideas let us know and we will incorporate them.

The Mornington Rose Garden is situated in Dunn’s Road Mornington

There is ample car parking. When we arrive at 2.30 we will have a short 20 minute talk by one of the volunteers. (Room for 60 people) After a cup of tea or coffee we can then wander around the Rose garden at our leisure.

There is a cost involved. Members of DATA will pay small gold coin, and other guest pay $5.00 per person. Payable at the door to DATA representative. DATA will subsidize the cost for members.

It is unfortunate that we wont have a Shoe String out before that date, so we need to advertise in this one. It does seem a long way off, but I am looking forward to it.

Look it up on the web—put it in your search engine! Mornington Rose Garden.

Joan
Rosebud:

We have replaced the antennae at the Rosebud house so the picture on the TV is much better.

We have had quite a few cancellations at the house so please always ring to see what is available.

Next available dates are
March 23rd to 30th, May 18th to 25th
May 25th to June 1st
All of June is available

Dont forget, if you need to dialyse at the Rosebud Renal Unit, please ring the hospital first and then ring me (Amanda) to book the house.

The Rosebud renal unit phone number is 5986 0776

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

Yarrawonga:

Next vacancies
March 30 to 6 April, 20 to 27 April, 1st to 8th June,
August 3rd to 10th, August 10 to 17, August 17 to 24th,
School Holiday 27 July 3rd August 2014

We do get cancellations so please ring me
I have had people book in who are not members. And so far have not registered to join.

Remember you **must be a member of DATA** before you can holiday at our holiday homes

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.

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

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

*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 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, pillows, 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.

Come and enjoy a stay at Blackburn and explore Melbourne.

Phone for bookings: *Contact: Ros. Ball 03 9439 8866 or Alan Rawson 03 9723 3019*

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**RESCHEDULED Members BBQ Blackburn 16 March 2014**

As mentioned previously February BBQ cancelled due to bad weather.

Rescheduled for Sunday March.16th

Date: 16 March 2014  
Time: 12noon

Venue: 14 Queen Street Blackburn

What to bring  Chairs, table, drinks, 
Sausages, salads, tea & coffee  cordial are provided

Cut here

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**DATA** BBQ 16 March 2014

Yes we will be coming

No. of adults ..................  
No. Of children ......................

Name  ..................................  
Phone number  ..........................

Post to PO Box 165 BLACKBURN 3130 by 10th March
My Story – Living with Renal Failure

Tamara Gutsche

My story began almost 15 years ago. I was living in a small country town in SA with my husband and I was pregnant with our first child. At 28 weeks gestation, I went for my standard monthly check-up at the local GP and was told I had pre-eclampsia and that I would be flown to Adelaide via Air Ambulance and our baby would be delivered that night. Our lives were instantly turned upside down and my only concern was for the health and safety of our unborn child.

When my ambulance arrived at the Women's & Children's Hospital the staff were directed to take me straight to the delivery suite. At this point panic set in and I could only hope that my husband could complete his 2 hour drive to the hospital in time for our baby to arrive.

Thankfully, test results settled and rest in hospital prolonged delivery for a very long but important 6 weeks until Lachlan was born Xmas day 1999. Although he was born 6 weeks premature he was healthy and happy and it was only another couple of weeks before we could finally take him home to country SA and begin our new life as a family. Unfortunately my results did not clear and I was referred to a Nephrologist for further testing. An ultrasound confirmed that one of my kidneys was almost non-existent and a biopsy of my “good” kidney revealed a great deal of scar tissue and deteriorating function.

At this time I was told not to attempt further pregnancies and that I will require dialysis and / or a renal transplant in the future. My condition was treated with medications and regular checkups.

In 2001 we moved to Victoria so my husband Adrian could start his career as a Fire-fighter. In 2004 I discovered that I was pregnant with our second child and with very close monitoring and bed rest, Tyler was born in May 2005 (4 weeks premature).

It wasn’t too long after the birth of Tyler that my deteriorating kidney function began to personally affect me. I began to feel extremely tired & lethargic and nauseas on a daily basis. This illness got increasingly worse until the decision was made to begin dialysis in June 2010. Meanwhile, my mother and husband began the workup for kidney donation. My mother was ruled out as a suitable donor but my husband Adrian was looking at being suitable for donation.

I started on Peritoneal Dialysis CAPD at home and after 5 months I received an overnight machine APD. This made dialysis a lot easier for me to manage around my busy life as a mother of two and a part time student nurse.

In April 2011 I was admitted to my local hospital with peritonitis. I failed to respond to the antibiotics and the severity of my condition was increasing so I was air-lifted to the Royal Melbourne Hospital. My PD catheter was removed and a permacath was inserted into my neck and upper chest so I could begin immediate Haemodialysis.

This was a real low point in my life. I was extremely ill. I no longer had the option of dialysing at home. I had to give up my nursing studies and was then told that my local hospital had no spare haemo chairs and I would have to travel approx 80km to the next closest dialysis centre. So 3 times per week, every Tuesday, Thursday & Saturday I would make the 7 hour round trip. (this includes travel time and dialysis time) I could no longer watch Lochie play his Hockey matches on Saturday mornings. I couldn’t get my boys off to school on these mornings because I had to leave home by 7.30am. Adrian had to take time off work

(Continued on page 7)
on occasions and when I was home I spent most of my time resting because haemodialysis made me anaemic and unwell.

But then my life changed for the better. My husband was accepted as a suitable donor and transplant surgery was scheduled. So we both said goodbye to the children, then aged 11 and 6 and left them in the capable hands of their grandparents and we spent 6 weeks living away from them in Melbourne. The transplant was a great success. Adrian had a few minor complications, but I felt fantastic from the moment I woke up from the anaesthetic. I was up and out of bed the very next morning and day by day I became more mobile, less sore and my kidney function continued to improve.

It is now 2½ years since the transplant and my renal function is very good. I have far more energy and no nausea. I did have some not so nice side-effects from the high doses of anti-rejection medications in the earlier days post-transplant, but it is a small price to pay for freedom from dialysis and a quality life with my family.

I will be forever grateful to my husband for his precious gift. And also to my Renal Specialists, the medical team at Royal Melbourne Hospital and local health professionals. It truly took a team of people to get me through some of the darkest times in my life. Due to requiring a transplant at a young age, it is likely that I will need another transplant in future years, but I’m not going to dwell on this. For now I will show my appreciation by making the most out of the life I now have. Life is a precious gift and now that I have a second chance at it, I don’t intend on wasting a day of it.

I have returned to part time work in Administration and Bookkeeping. When I’m not at work I enjoy spending quality time with my children, husband and extended family and friends.

Tamara Gutsche- Wodonga

What a great story this is and we wish Tamara all the best. Do you have a story?

Send it to us for inclusion in Shoestring.

Kidney Health Celebrates 45th Birthday

As part of it’s 45th anniversary, KHA put on a function that focused on research and saw them bring kidney researchers and potential funders together to showcase what had been achieved over 45 years and highlight what still needs to be done. The whole purpose of the function was to encourage financial investment and partnership in kidney research and the people invited had been hand picked for that purpose.

Wayne McGlone as Chair of the Victorian Consumer Committee was invited to represent the Vic Committee and Bill and Jenny Handke attended representing the National Consumer Council. Grant Monks a young man with kidney disease was invited to speak from the consumer perspective and Professor Warwick Anderson AO, Chief Executive Officer of the NHMRC was the dinner speaker.

Representatives from the Department of Health were invited as were clinicians from the RCHN. (Renal Health Clinical Network, which is run by the Victorian Department of Health)

Like DATA, Kidney Health had a name change, it started out as The Australian Kidney Foundation/

From Anne Wilson  CEO, KHA.
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.**

   | 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 …………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………………


News and Tips

**ICE**

IN CASE OF EMERGENCY

ICE1, After putting ICE 1 into your phone, add the name of the first person and their phone number you want contacted if you are being attended to by emergency services.

ICE2 Here you put the second person’s name and their contact number and so forth.

If you are in an accident the emergency services can find these numbers on your phone and hence contact you nearest and dearest. In other words In Case of Emergency contact this person on this phone number first, second etc.

Remember if you have a password that locks your mobile phone this makes your phone numbers unavailable to other people.

**HELP NEEDED**

Data needs at least eight people on the committee. When committee members are away on holidays, have other commitments to attend to, or are ill, this is often difficult to achieve.

Please if you can join the committee please do so. It’s not all work.

We also need help with back-up to run our houses. Those who run our houses can be ill and need someone to stand in for a short while. These houses are not difficult to run, and we can show you how to do it.

Help to do Shoestring would also be appreciated.

We all know, that more hands make light work. Ring 9894 0377 leave a message and someone will get back to you.

Ros.

**Youtube**

Remember in our last edition of this newsletter, we had a youtube address of an advertisement for organ donors, from the late 1990’s and pre digital.

This time we have an up to date advertisement featuring a parody of Gotye which can be found, also on youtube.

http://www.youtube.com/watch?v=3R-I1olkF-Y#action=share
From the Archives

.........Tank System from Shoestring Number 7, Dated 12th April 1973

“......Many of you may have heard or read about the new kidney machine, that we have developed in this unit.

This new machine is totally replacing the Drake Willock, that many of you already have. Instead of a machine mechanically mixing the concentrate and water; the total amount of concentration required for the dialysis is poured into a tank, and water added at the required temperature. This is mixed with a paddle and then tested with a little portable Electronic Chloride Tester.

The tank is insulated adequately to keep the dialysate at the correct temperature, for the entire dialysis. This means, all the proportioning unit, all the proportioning unit, conductivity metre and flow metre, almost 2/3rds of the machine, is replaced by the tank.....”

This article relates to the “archived” article in the last Shoestring, from No 3 Shoestring.

CITY HOLIDAY FOR COUNTRY DIALYSIS PATIENTS

Home Therapy Unit Centre

Bell St. Preston (near corner of Plenty Road.)

Phone 03 9485 9032

Ask your dialysis nurse to help you organize this.

VERY EXPERIENCED DIALYSIS NURSES STAFF THIS UNIT.

Stay at the DATA house in Blackburn or

there is a Rydges Hotel opposite the Home Therapy Unit.

Public transport close by. Trams on Plenty Road and Trains from Bell station, to go to the city.
**Dates to Remember**

- **Members BBQ RE- RUN** Sunday 16th March 2014
  12 noon 14 Queen Street Blackburn.

- **13th March World Kidney Day**
  Mornington Botanical Rose Garden 13th April, 2.30pm
  ‘Stop and Smell the Roses’
  Civic Reserve Dunns Road Mornington

- **25th-31st May Kidney Health Awareness Week**
  Memorial Service TBA
  Christmas in July TBA

- **26th September-5th October Australian Transplant Games to be held in Melbourne**

**Watch our Web site** www.datavic.org

**Find us on Facebook.** Simply put dialysis and transplant into your search engine and it should come up. Remember you have to be a member of Facebook first.

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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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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.