PICNIC AT BLACKBURN LAKE
93 CENTRAL ROAD  BLACKBURN
SUNDAY 20 MARCH 2016
12NOON TILL 3PM
In the Court Yard
You are all invited to meet the new members
and the Committee
See page 6 for details

Half the Family Photo taken in our new office. at Forest Hill. Our street address is :
DATA, Level 1,Office 5 ,
79 Mahoneys Road, Forest Hill, 3131

Thanks to Darren Hennessey for all the animal photos from Healseville
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Editors Report

There was NO ISSUE OF SS in January due to busy time.

Gee have we been busy!

We have been packing up and planning and ringing back and forth. Ros and Charlie, doing the planning Jan and Geoff packing the house up, Eleanor trolling through years of financials and Michael doing the shredding. Such a lot to organise phones and removalist, new office furniture, will it fit in the space? PO boxes to sort out.

So thanks to all who have assisted in any way to this move.

We decided not to try and do Shoe String in January this year. We hope next year will be normal with Shoe String at January.

The plan is to move to our new premises during last two weeks of February.

The Post Office box will remain the same for the time being. PO BOX 165 Blackburn 3130

The new address is

Dialysis & Transplant Association Inc Level 1, Office 5 79 Mahoneys Road Forest Hill 3131

And the phone is the same (already there) . 03 9894 0377

Hopefully by the time you get this the email will be up and running but you can use the Shoe String email if you need to contact us at any time.

editor.shoestring@gmail.com

We were saddened to hear of the death of John Hulskamp on 29th January 2016.

The work he did for DATA and the hours he spent working on financial matters is invaluable. DATA is indeed fortunate to have people with the expertise and knowledge, willing to assist with various tasks. See page 7

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.
Since being elected President at the October AGM, I have been on a steep learning curve. To assist me, experienced, hardworking Committee Members were available with genuine helpful advice and information. This enabled me to get a better understanding of both the structure and history of D.A.T.A’s past operating procedures. I thank all Committee Members for their advice, co-operation and continuing efforts in all our undertakings.

When it became obvious that our days at Blackburn were numbered, the search for new accommodation became more and more urgent. After attending some unsuccessful inspections, I decided to see if I could help. Fortunately among my contacts is Philip Daw, a Whitehorse City Councillor and Mayor. After a cup of coffee and introduction to Julie Lyons – Social Planning Officer, our prospects became brighter. A visit by D.A.T.A. members to the Forest Hill Resource Centre (See page 2 – November Shoe String) ultimately resulted in our new headquarters at 79 Mahoneys Road, Forest Hill. The offer for D.A.T.A. to occupy our new office facilities was made by The Whitehorse Community Resource Centre Tenant Management Group on 26th October 2015, was accepted and a lease signed.

The Sub-Committees are busy in the various relocation tasks. The excellent ‘DATA Office Relocation Plan’, prepared by Charlie Ball is very helpful and I acknowledge our appreciation and thanks to Charlie.

While the Forest Hill accommodation details were being attended to, a Sub-Committee was set up to find some office help. After the November Committee meeting, Brendan Lowry, Angela Lindsey and I had a preliminary meeting with a lady to discuss and ascertain her qualifications and suitability to assist committee members with office tasks. This was reported at the December meeting and a final interview was agreed to take place on Sunday January 17. As Angela was present at the preliminary meeting, she agreed to act as chair person at the final interview with Joan Eastwood and Ros Ball assisting. The report and recommendations will be presented to the February meeting for final decision by the General Committee.

To ensure that, if the person interviewed was found to be suitable and approved by the General Committee, a contract of engagement had to be prepared. This had to be done before the interview. We are very fortunate to have Ms. Kathy Adams, a solicitor with Aughtersons in Ringwood prepare a very comprehensive Contractor Agreement. The discussions and preparation of this contract took many hours of detailed work. DATA is very appreciative of Kathy’s generous efforts and support.

On the 6th January, Ros and I paid a visit to the ‘Big Red Kidney Bus’ in the Melbourne Botanical Gardens. It is an impressive and very well set-up system. It supports people who are on Haemo Dialysis to be able to travel. We met Ms. Jo Fairbairn who is the Project Manager of the Big Red Kidney Bus organisation. Jo is a dynamic knowledgeable lady who will be an important source of information to me.

Members of D.A.T.A. - I invite you to offer your participation and assistance as volunteers and join a group of people who care for and help people. Our monthly committee meetings are held 2nd Sunday every month at 2.00PM – you are welcome to join us and inspect our new headquarters. Please call me 24/7 on 0418 344 826.

John Podolak.

FOUND at Rosebud House Amanda says A tiny gold chain with a ‘J’ on it, also bead and charm has been found at Rosebud. If you have lost this item while staying at Rosebud call Amanda on 03 9589 4894 and she will post it back to you.
Holiday Homes

ROSEBUD

Vacancies:

We have had a very busy Christmas / New Year with the house being fully booked till the 15th of May 2016.

If you would like to go on the cancellations list, please give me a call. Reminder that you must be a Member of DATA before you can use the house and your membership must be up to date.

We have replaced the old carpet in the bedrooms with carpet that is very easy to vacuum.

A big thank you to Jan Fletcher who washed all the mattress protectors from the Blackburn house and sent them down to Rosebud.

I would like to thank Wilma Gilchrist for donating new pegs, vacuum bags and a new straw brush while staying at the house.

It is much appreciated.

Unfortunately the reading lamp was broken and not reported so at this stage it has not been replaced.

Accidents do happen, so please ring me and let me know.

Please leave the house neat and tidy and do not leave any food at the house.

Finally, if leaving a message on my answering machine, please speak slowly and clearly leave the number I can call you back on.

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

Yarrawonga House Secretary Alan Rawson,
22 Tarwin Drive Croydon 3136,
Ph. 9723 3019, E-mail: fayal_rawson@hotmail.com
Next vacancies Not until May 2016 plenty after that.

Please ring - we do get cancellations

Reminders: you must be a member of DATA before you can holiday at our holiday homes. No animals are allowed exception to the rule are guide dogs.

If you are on Home Dialysis your hospital will take a machine to the houses , Great to see so many Home Dialysis members using the house over Xmas to dialyse either using the Big Red Bus or Dialysing at the house.

Thanks to the Techs from Monash who worked in with the Tech from St Vincent to enable a member to have a holiday, they do a wonderful job. 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. If you need to dialyse at Yarrawonga Renal Unit, please ring the hospital Renal Unit -57438189- first to see what is available, dates available for booking the holiday chair go very fast. 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.

Please if you find anything that needs fixing let me know or ring Ann Bonser her phone number is on the wall near the phone.. Thanks Alan Rawson

PLEASE REMEMBER: NO SMOKING IN ANY OF THE HOUSES
Goodbye Blackburn House.

After 21 years it’s goodbye, and those of us who visited DATA’s Blackburn house for accommodation, worked in the office, enjoyed social activities inside the house, and in the garden I am sure will miss it.

SO NOW

Our new office is nearly open for business.

Same phone number

All members are invited to come and visit the new office but must let us know so one of the committee members can be there to show you around.

Room 5 …Level 1, 79 Mahoneys Rd.

Forest Hill

Parking is nearby in Mahoney’s Road, beside the building.

From the January 1995 ShoeString Archives.

AT LAST! IT’S ARRIVED!!

“OPEN DAY” AT BLACKBURN

WHEN? SUNDAY, 19th FEBRUARY 1995

TIME? FROM 11 AM to 4 PM

WHERE? D.A.T.A. Headquarters, 14 QUEEN STREET, BLACKBURN VIC 3130

(Melways Map 47, Ref. K9)

Do you have any fond memories of the DATA Blackburn house, please write to us and tell us. We can then print those stories in Shoestring.

Should we buy another property? Ideas. Let us know what you think.
Picnic at Blackburn Lake

Come and join us

Any time after 12.00 noon, 20 March 2016 at Blackburn Lake, 93 Central Road, Blackburn

Use this opportunity to meet most of the committee who are responsible for the running of Dialysis & Transplant Association Inc.

If you don’t know us, you certainly will by day’s end.

*We traditionally welcome new members at this gathering.*

There are Walking paths, Wetlands and birds, Children’s playground.

*Check it out — Google it — Blackburn Lake Sanctuary*

**How to find us**: In Central Road turn into car park opposite Gwenda Road, Park in car park, Walk past the Blackburn Lake Information Centre and you should see the Courtyard on the left. We are in the Courtyard. Look out for the banner.

I promise it’s not as far as the outing to Healesville. (I’ve got my fingers crossed).

Bring your own picnic food.

Chairs and tables provided, as well as tea, coffee and cordial and cake.

As there is NO Cost a phone call to our office will do. 9894 0377

Hope to see you all there.

<i>..................................................................................................................................................................................</i>

RSVP by March 16th

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Post to DATA P.O. 165 Blackburn 3130, or phone and leave a message 9894 0377

**Have a Laugh**  
A priest was invited to attend a house party. Naturally, he was properly dressed and wearing his Priest’s Collar. A little boy kept staring at him the entire evening. The priest asked the little boy what he was staring at. The boy pointed to the priest’s neck. When the priest finally realised what the boy was pointing at, he asked the boy, “Do you know why I am wearing that?” The boy nodded his head yes, and replied “it kills fleas and ticks for up to three months.
A Holiday report from Betty Carman.

I am 92 years of age and been dialysing about 10 years. Life for me NOW is a tiring drag. To get away for a weeks holiday is indeed a blessing. Over the years I have been to many places but Portland is my favourite. The hospital is so clean. The staff so friendly, the Dialysis Team so wonderful, feel in a different world at Portland. We have just come back (November 2015) from my 6th trip. There we always go to Portland via The Great Ocean Road. The long way, but beautiful scenery. We come home through Camperdown. For your next break try Portland, you won’t be disappointed. From Betty Carman

Editors note

It was lovely to get this letter. Unfortunately it missed the November deadline for Shoestring so is included now, the February Shoestring.

Betty mentions being to many places, so I do hope that includes DATA’s holiday homes. Thank you Betty for this lovely letter.

Vale

Emeritus Professor Priscilla Kincaid-Smith

Although it was June 2015 that Professor Priscilla Kincaid-Smith died, she was a valuable researcher, nephrologist and pathologist based at the Royal Melbourne Hospital.

I believe that Professor Kincaid Smith not only discovered the connection between kidney failure and aspirin use but also the connection between high blood pressure and kidney disease.

Professor Kincaid Smith was appointed to the position of President of the Royal Australian College of Physician, and over many years was appointed to many different medical societies.

In 1975 a Commander of the Order of the British Empire (CBE) was awarded to her and in 1989 Professor Kincaid-Smith received the Companion of the Order of Australia (AC) Professor Kincaid –Smith was a foundation member of Australian Kidney Foundation, now know as Kidney Health Australia, Kidney Health Australia named the Pricilla Kincaid-Smith Kidney Research Foundation after her, and funds for this research are used to research kidney disease.

Ros Ball.

We were saddened to hear of the death of John Hulskamp on 29th January 2016. John gave generously of his time and talents, not only to DATA but to several other philanthropic organisations.

In his time with DATA John was Treasurer, Committee Member and Web site manager, a long time member of DATA .he joined in 1983 served as Treasurer for years 1999 to 2003.

John ‘s wife Tricia was the reason he joined DATA unfortunately she died in the late 1990s but John continued on in his various roles.

John is survived by his daughter Tania and we extend our condolences to her. Joan Eastwood
D.A.T.A Christmas Party at Healesville Sanctuary 2015

The annual D.A.T.A Christmas Party was held on Sunday 29th November. We went to Melbourne Zoo in 2011, Werribee Zoo in 2013 and in 2015 it was the Healesville Sanctuary. Now we have been to all of the three zoos, where to next year? The Robert Eadie Pavillion was a reasonable walk from the front gate. There were plenty of seats for everyone to rest after the walk. The barbecues were just outside the pavilion which was pretty handy. The sausages did smell good. There was cold and hot drinks so everyone was well hydrated.

The raffle was drawn by Nick Hatzimichalis. Joan Eastwood’s name was drawn first – Joan chose the hand made cushion and blanket (her husband would have chosen the wine). Second name drawn was William Lindsey and he chose the hamper. Third name drawn was Dawn Mackrill and she got the bottle of wine. We all had fun rummaging through our raffle tickets, but alas better luck next time. As it’s customary we were all given a bag of lollies. Thanks to Ken and Bev. I don’t know about you, but I really enjoy the lollies.

People went their own separate ways to see what Healesville had to offer. Did you know that Healesville Sanctuary is the best place to see Australian wildlife in their natural habitat? There was plenty to see – kangaroos, emus, platypus, dingoes, birds of prey, reptiles. The “Spirits of the Sky” show featured the raptors, such as the Wedge Tailed Eagle and the beautiful coloured parrots.

It was a warm, sunny Melbourne day. Everyone had fun. It was a very pleasant day out. Angela Lindsey

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**AGM Raffle Tickets**

**Apology we got it wrong.**

2nd prize should have read George Cipolla (not Tripolla)

3rd prize Joss Lopex (not Joss Lopey)

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**HAVE A LAUGH**

An Irishman is stumbling through the woods totally drunk, when he comes upon a preacher baptising people in the river.

He proceeds to walk into the river and subsequently bumps into the preacher ... The preacher turns around and is almost overcome by the smell of alcohol, whereupon he asks the drunk, ‘Are you ready to find Jesus?’

The drunk shouts ‘Yes, oi am.’

The Preacher grabs him and dunks him in the water. He pulls him out and asks the drunk ‘Brother have you found Jesus?’ The drunk answers ‘No oi haven’t found Jesus’

The preacher shocked at the answer, dunks him into the water again for a little longer.

He again pulls him out of the water and asks, ‘Have you found Jesus me brother?’

The drunk again answers ‘No, oi haven’t found Jesus’

By this time the preacher is at his wit’s end and dunks the drunk into the water again, but this time he holds him down for about 30 seconds and when he begins kicking his arms and legs he pulls him out. The preacher again asks, ‘For the love of God, have you found Jesus?’

The drunk wipes his eyes, catches his breath and says to the Preacher

‘ARE YOU SURE THIS IS WHERE HE FELL IN?’
What happens if dialysis and transplantation is not a suitable option for someone with failing kidneys?

Until recently there was no recognised and supported treatment option for people with end stage kidney disease (ESKD) for who dialysis or transplantation is not the patient’s preferred option.

How did we investigate the issue?
In 2012 the VRHCN Leadership Group recognised this as a major issue for Victorians and established a RSC (Renal Supportive Care) Working Group to provide advice, direction and guidance on the issues related to RSC to the Department of Health and Human Services (DHHS).
Extensive consultation with a broad range of clinicians, consumers found that there was no streamlined pathway or model of care for people with ESKD or whom a decision had been made (medical advice, patient preference or a combination of medical advice and patient preference) not to have dialysis or transplantation.

How did we respond to the problem?
It was agreed that a RSC pathway in Victoria was required as it would assist people with ESKD access appropriate supportive care education and services in a timely and equitable way and to help guide and support the state wide approach to this treatment option.
However, we also realised that for any RSC pathway to be implemented, there needed to be some capacity building within health services. In 2014 the DHHS committed $590k for RSC capacity building across the ten major renal services in Victoria to:
- strengthen the relationships between palliative care and renal services
- support a review of educational and information resources for patients and clinicians to support change in the health service culture to recognise RSC as a clinically supported alternative to dialysis and transplantation.

This was further supported through funding to enable renal staff to participate in a Program for Experiencing the Palliative Approach (PEPA) placement to enhance their skills and understanding of palliative care.
We also introduced the concept of routine functional and symptom burden assessment of all renal patients over the age of 65 years using tools such as the Australia Modified Karnofsky Performance Scale and the POS-S Renal.

Where to from here?
All of Victoria’s renal hubs now either have, or are developing, their RSC capability that includes training and up-skilling staff and enhanced linkages between renal and palliative care services.
Through the capacity building initiatives, renal clinicians are now much more aware of the many benefits that Renal Supportive Care can provide to patients and their families and are more comfortable referring patients to palliative care and having (the difficult) discussions around advance care planning and end-of-life needs.
Further work will be undertaken to embed Renal Supportive Care into routine renal care.

Taken from Victorian Renal Health Clinical Network September 2015Newsletter
A Visit to Seymour

Last year I was invited to visit the NEW Renal Unit in Seymour by Doreen Waite, a member of DATA. This visit finally happened in September, and I was able to tell everyone on haemodialysis about DATA and distribute brochures and membership forms to those people dialysing at the time. I also gave this information out to the staff to enable them to distribute to people not there that day.

This new unit is pristine and all those on haemodialysis had single rooms. WOW It currently dialyses people 3 days a week.

We need YOU our members also to spread the word to fellow renal patients about DATA. I would especially like to thank Doreen for her kind invitation to visit the Unit, and assistance in doing so.  

Ros Ball

PERITONEAL DIALYSIS(PD)

From John Podolak.

It’s likely that all who are reading the DATA Shoe String publication would be very familiar with PD. So I will focus on some of the more interesting procedures which I found useful.

I was very fortunate to have the option of choosing PD instead of haemodialysis because it gave me the freedom to travel and work. The procedures of using manual CAPD bags immediately convinced me that PD was for me, especially when I realised that CAPD stood for CONTINUOUS AMBULATORY PERITONEAL DIALYSIS. Also the additional advantage of being able to use the overnight machine made it easy to decide that PD would best fit my lifestyle that for me meant FREEDOM to live with little disruption.

The method of changing bags, especially when travelling was my next consideration. After the professional hospital PD staff trained me in the procedures of dressing the catheter site; changing bags and the correct use of the overnight machine, I was ready to fly solo.

Like a new driver, that’s when I realised that at this point my learning really started.

It was emphasised during my training sessions that infection was the enemy and that hygiene was of paramount importance. The daily catheter exit site dressing and the bag change procedures must be disciplined and precise. This was relatively easy for me in a dust free clean home environment. But I often had to travel long distances, spending many hours in a motor car. So to provide me with the necessary safe and reliable back-up system when travelling, I organised two ‘travel’ containers, one for dressing the catheter exit site and the other for bag changing (changing on the road when necessary). The containers had all the tools, dressings and medications requirements for a week, but I always packed a couple of day’s extras to allow for unforeseen situations when changing bags in a park etc. in case, for example, if something dropped on the ground. This procedure was easier to do in a motel or other accommodation where clean conditions were available.

At the end of each trip, the boxes were cleaned and the contents carefully replenished so they were ready for the next trip.

See photo opposite
John’s containers. Below left are all the necessary components for a bag change. Some important items being metal hooks and string to hang the bag plus all the other items such as hand wash and sanitizer, catheter caps, sterile wipes etc.

On the right is a fisherman’s container with two drawers with all the requirements for the ‘catheter site’ morning dressing routine. This procedure was done in a motel or other accommodation where sterile conditions were available and was much easier to do.
Dates to Remember

- March 20th  DATA Picnic see details Pge 6
- March 10th  World Kidney Day
  this year’s logo is Kidney Disease and Children
  “act early to prevent it”  More Info http://ifkf.org
- May 22 28th  Kidney Health Week  information packs
  are available from events@kidney.org.au
- To be advised  Transplant Memorial Service
  A Special Service this year

Some web pages of interest:-
- www.worldkidneyday.org/
- www.cari.org.au
- www.australiandialysisbuddies.org
- www.greendialysis.com
- www.transplant.australia.org.au
- And don’t forget our webpage: www.datavic.org

Thanks to Darren Hennessey for all the animal photos
from Healseville

Our thanks to all who contributed to this edition.

Why not spread the word and pass this copy on?
ShoeString  is 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.

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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.

Deadline for the next ShoeString: 24th March 2016