NOTICE OF ANNUAL GENERAL MEETING 2011

Notice is hereby given of the 37th Annual General Meeting of the Dialysis and Transplant Association of Victoria Inc. to be held at Café Vanilli, 89 Railway Road Blackburn (Near the Blackburn Post Office) on SUNDAY 23rd OCTOBER 2011 2PM

GUEST SPEAKER:
Karen Manly, Renal Dietician from the Austin Hospital.

Please find RSVP on page 3. You must return this by October 14

DATA Christmas Party 2011 at Melbourne Zoo page.11
A Note From the Editors…

Hello to all our readers and a special welcome to all new DATA members!

We are very excited to present this edition with a touch of colour and hope you enjoy it as much as we have enjoyed putting it together.

Some great stories come to us from Geoff and Jan Fletcher as well as Twanny Farrugia, who will shortly be celebrating his kidney’s 40th anniversary. Such an amazing milestone! Please keep the stories coming.

We look forward to seeing you all at the AGM.

June & Adrianne, 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 upside-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
Congratulations must go to Alan Rawson and Margaret Tagget on reaching their twentieth birthday for their kidney transplant. What a great day for them, and to celebrate at our Christmas in July party! Alan has not always been well over the last 12 months and it is good to see him well and fighting fit again and his kidney remained stable.

This year our Christmas in July threw up some special challenges, as, with only four days to go, the booked venue became unavailable to us. Our secretary, Sue, took all in hand and found an alternative venue, and managed to notify all those who had booked to go. More about the party elsewhere in this ShoeString.

I must also congratulate the Transplant Sports Association’s (originally an off shoot of DATA) cricket team on winning the Ashes back. The David Hookes Memorial Shield was played in Britain in June and July. You may remember that David Hookes was a test cricket player who died in unfortunate circumstances and his family generously donated his organs. His wife Robyn attended the game. To read more visit: www.ecb.co.uk/development/transplant-ashes,314855,EN.html.

My husband, Charlie and I headed north for two weeks (to Broken Hill and surrounds) and found the dialysis machine in our caravan went really well, and so we are planning another trip in the Spring to NSW. You can read about our trip in a magazine called GO CAMPING, which is available at newsagents and also mentions DATA.

Winter came and so the caravan was put away. Hasn’t it been a cold winter this year? I am certainly looking forward to spring.

I would like to personally ask you all to come to the AGM. This is YOUR organisation, and it is important we get a good number of members at the AGM. Hope to meet many of you there!

Ros Ball, President.

PROPOSED AGENDA

for the 37TH
ANNUAL GENERAL MEETING OF D.A.T.A.
SUNDAY OCTOBER 23rd 2011 at 2.00 pm
to be held at CAFÉ VANILLI 89 Railway Rd Blackburn

*Welcome and Apologies
*Acceptance of Previous Minutes October 24th 2010
*Any Business Arising
*Reports: Presidents Report
  Treasurer’s Report
  Holiday Homes
  Blackburn House
  Social Welfare
  ShoeString
*Election of the DATA Committee 2011-2012
*Appointment of Auditor
*Appointment of Solicitor
*General Business
*Presentation of Ron Jones Educational Awards
*Drawing of Special Effort
*Guest Speaker: Karen Manly – Renal Dietician
  Austin Hospital
*Afternoon Tea

AGM RSVP

VERY IMPORTANT TO SEND THIS BACK!
For catering purposes please return the slip below
Please cross out whichever is not applicable and return to:
PO Box 165, Blackburn 3130 by 14th October 2010

Yes I will / No I will not be attending the AGM on 23th October 2011
Name: .................................................. Phone: .......................
Number of Adults attending: .............................................
**Holiday Homes**

**Rosebud:**
A modern 3 bedroom house which sleeps five people. Rosebud beach is only a minutes walk away.

Rosebud holiday home is equipped with dialysis machines with RO water filtration. Please bring your own dialysis supplies. CAPD bag warmers, change tables and IV poles are supplied.

Crockery, cutlery and bedding is supplied but please bring your own linen.

Some of the local attractions include:
Safe bayside beaches for families, peninsular hot springs, winery and gourmet tours, large community market once a month, golf, lawn bowling, putt-putt golf, library, elderly citizens’ club, RSL, art galleries and cinemas, walks and excellent restaurants.

Rosebud is currently undergoing renovations to make it more accessible to wheelchairs and prams.

*Contact:* Kaitlyn Steavenson: (03) 9785 3036 *(after midday)*

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**Yarrawonga:**
A 3 bedroom holiday house only a few metres from Lake Mulwala on the River Murray. It is a less than 3 hour drive from central Melbourne. The house is fully furnished and sleeps seven people.

Yarrawonga is equipped with dialysis machines with RO water filtration. Please bring your own dialysis supplies. CAPD bag warmers, change tables and IV poles are supplied.

Yarrawonga has air conditioning and colour TVs in the living and dialysis rooms. CD and tape decks, microwave ovens, outdoor furniture and barbecues are available.

Crockery, cutlery and bedding is supplied but please bring your own linen.

Rutherglen wine region is just around the corner. Some of the other local attractions include:
Boat cruises, boat hire only 2 minutes from the house, golf and tennis, museums, galleries, the district Services Club.

To our members going on holidays at the Rosebud or Yarrawonga houses don’t forget to send your forms back early so we can send you a key, if we do not get your acceptance form we cannot send you a key.

We are not responsible for your dialysis, it is up to you to ring and arrange with the hospital times available for you to dialyse. If you are on Haemo ring the hospital renal unit 5743 8189, see what weeks they have available, and then ring me. Facilities are available at both houses for members who are on PD.

*Contact:* Alan Rawson, 22 Tarwin Drive Croydon 3136, Phone: (03) 9723 3019, E-mail: fayal_rawson@hotmail.com

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**Vacancies:**

**Rosebud** - there are no vacancies for the near future at the moment but give Kaitlyn a call and she can take your details just in case there is a cancellation.

**Yarrawonga** - all of December is available for bookings, from the 4th until 1st January. Bookings are also open for 2012.
Holiday Homes

Blackburn:
Blackburn is a very comfortable two storey house, set on a large block of land with some lovely big shade trees. Upstairs has three bedrooms along with a lounge room, bathroom, and toilet. Downstairs has a bedroom, equipped with a double-sized sofa bed, shower room, toilet, kitchen, laundry and a small lounge room. Both lounge rooms are very comfortable with lounge seating, television and DVD player.

Blackburn is a house for country patients to enjoy a holiday in the Melbourne area or accommodation for patients who are in Melbourne for medical treatment.

Ideal for patients and their carers who are lucky enough to have received a transplant, the house is only 3 minutes walk to the Blackburn railway station.

Blackburn has no dialysis machines.

Crockery, cutlery and bedding is supplied but please bring your own linen.

Cost per room is $35 per night and $20 per extra person. $140 per week, and $160 during the School holidays.

It is self catering so bring your own food, including tea, coffee and sugar.

Blackburn House is an easy walk to the train station and many bus routes stop at the station. Only 30 minutes east of Melbourne along the Maroondah Highway.

Melbourne is well known for its sporting events, culture, arts and its many cafes and restaurants. A little further east are the Dandenong Ranges, Puffing Billy and Healesville Sanctuary.

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.

Also remember that when visiting hospital or clinics payment for travel and accommodation can also be arranged to be paid by VPTAS (Victorian Patient Transport Assistance Scheme). See your social worker for information.

Come and enjoy a stay at Blackburn and explore Melbourne.

Phone for bookings:

Contact:
Sue Hatzimichalis: Phone (03) 9378 9222, Mobile: 0412 469738 or DATA Office: (03) 9894 0377.

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.

EXPRESSION OF INTEREST...

We have been receiving several emails asking us for ShoeString to be sent as an electronic copy via email to our members. We are curious to see if it is just a few people or more widespread.

If we can get more than twenty members to express an interest in receiving ShoeString in this manner a new mailing list may be set up allowing for those who want it, to receive an electronic copy and the rest to remain with the paper copy.

If you are one of those wanting to save trees and receive an electronic copy of our newsletter, please email the editors at: editor.shoestring@gmail.com.

DATA NEEDS YOUR HELP

Every two months, DATA’s newsletter is folded and packed ready for posting by volunteer members. This is done at 14 Queen St., Blackburn on a Saturday or Sunday afternoon. The process takes around two to three hours and is followed by afternoon tea.

As some of our long time volunteers are no longer able to help, we are looking for new volunteers to add to our contact list. When required, volunteers are contacted to see who is available to help. The packing normally requires eight people.

If you are able to help out, please leave your details at the DATA office (Ph. 9894 0377).

We look forward to hearing from you.
Despite a last minute change to venue, DATA’s annual Christmas in July was a great success.

The night began with a game to welcome everyone. This was followed by an entrée of homemade soup, provided by committee members, Joan and Angela.

Fun was had by all with the challenging trivia sheets handed out between courses with Table 5 taking out first prize.

A catered roast dinner was completed by traditional Christmas pudding and custard (hold the brandy!).

Live music played throughout the night and set a lively tone of entertainment.

Santa made an appearance, sharing sweets and gifts with guests.

At the end of the night the raffle tickets were drawn with Rosemary and Graeme Jenkins walking away with first prize and Ken and Kim Donnelly coming in second.
**Holiday in Port Douglas**

Geoff and Jan Fletcher escape to the tropics

**Dialysis Escape Line** is a boutique dialysis holiday organisation in South Australia. The organisation owns and stores haemo dialysis machines in Sydney. The machines are transported to various holiday destinations within Australia and to cruise liner ports departing from Australia. To be eligible to go on a dialysis holiday with **Dialysis Escape Line** or **Dialysis Abroad**, you have to undergo some blood tests and swabs to make sure you are not a carrier of a transmittable disease. Once you have completed these tests, and are given the ok, you can then book your holiday.

The machines for our holiday were transported to Port Douglas Sheraton Mirage, and an available suite was transformed into a dialysis unit. A volunteer technician set up the machines ready for us to use.

Included in our holiday to Port Douglas was accommodation, all breakfasts, welcome and farewell dinners and all transfers to and from the airport.

Upon arrival at the resort, we were greeted by Wayne, a committee member of **Dialysis Escape Line**.

At a welcome dinner, we were introduced to our dialysis machine technician Dennis and three nurses, Nicole from Warragul in Victoria, Cheryl from the Gold Coast, and Kylie from Adelaide. I had met Nicole before when I was in home training at the Dandenong Hospital.

There were 12 dialysis patients on this trip; eight dialysed in groups of four on Mondays, Wednesdays and Fridays in the AM and PM and four dialysed Tuesdays, Thursdays, and Saturdays in the AM. The dialysis was very well organised and there was also a renal doctor on call at Cairns hospital if required.

While I dialysed in the morning, Jan walked, swam and relaxed at the Resort.

We went on two tours during our holiday. On the first trip, up to Kuranda, we caught a coach to the train station, the train then took us up to Kuranda in the mountains. After some sightseeing and a wander through the iconic markets, we then caught the Sky Rail (gondola) back down the mountain and a coach back to the resort.

Our second organised tour was to the magnificent Daintree. We were picked up from the resort, along with three others, by a luxury seven seat 4 wheel drive vehicle. On the way, we travelled through Mossman to the Daintree River; crossing a river by ferry, but saw no crocodiles.

At the Daintree, we experienced a boardwalk through the rainforest. Our walk took us to where the forest meets the ocean; we walked along the sand to a viewing platform and enjoyed the sights of the ocean followed by a well earned morning tea.

On our return trip back to Port Douglas, we went to the **Daintree Ice-cream Factory**. We then visited a lookout and had lunch of barramundi and tropical fruits at a restaurant. We stopped at Mossman Gorge where we watched a lot of people swimming before returning to our resort.

Both on the way there and back, we saw a cassowary, lizard, butterflies, many insects and a crocodile on the cruise at the Daintree River.

Last but not least, whilst in Port Douglas, we went to see George the Groper at **On the Inlet Restaurant**. George visits each evening at approximately 5.00pm to feed on fish scraps from the Restaurant.

We had a most enjoyable time at Port Douglas and the **Dialysis Escape Line Organisation** was first class.

Geoff Fletcher
Although it was a balmy warm Friday night at 7.00 pm, October 22, 1971, I was very cold and tired after a full day of dialysing at St Vincent Hospital in Melbourne. Suddenly the telephone rang and I was given news which was to change not only my life but also the lives of all of my family. This telephone call was to inform me there was a kidney for me and I was to rush back to the hospital for final matching. I had been waiting for a transplant for such a long time.

Now, 40 years later, with the same functioning kidney transplant I received back in 1971, I cannot help but reflect on my life and the people who played a pivotal role in getting me so far.

I was born in Malta nearly 6 decades ago, the youngest of 5 children. I was fortunate enough to select excellent parents to be born to who loved me throughout life - warts and all.

I had a happy childhood though no one in the family knew that I was a very sick child. It was always difficult to keep up with my older siblings, constantly having lack of energy, being anemic, frequently suffering from cramps, vomiting after every meal and other feelings of “something being wrong” but no one could tell me what it was. Though being taken to doctors, no one was able to diagnose me until we migrated to Australia in 1965.

In Australia, like in Malta, doctors kept telling my family there was nothing wrong with me and that I was just a slow developer like my siblings were before me. Yet no one could explain the symptoms I had, that my siblings had never suffered from.

Then, at age 15, though looking more like an 8 year old, my brother Joe, who I shared a bedroom with, noticed that I couldn’t stand on one leg to put my trousers on without falling over, so he insisted he accompany my parents on our next GP visit. Again, without any blood or urine tests being done, nor even a simple blood pressure test, the doctor stated I was just a slow developer and all I needed was exercise to build me up. Hearing this news my father, a retired British Army soldier, created a mini obstacle course in our back yard and put me through my paces. Being already physically weak the only thing all this exercise achieved was to make me even sicker.

Of course this didn’t work so back to the doctors we went.

Since my brother and parents wouldn’t take no for an answer, the GP, being at a loss in what to do next, decided to refer me to a heart specialist even though there was no evidence of any heart problems.

After a few weeks of extensive testing by the heart specialist, which made me even sicker, he stated that my heart was fine but he could not find my kidneys. He then referred me to a renal specialist. Finally, after a bank of medical tests, I was diagnosed with renal failure or, medically speaking, I had glomerulonephritis. The way the doctors explained it to me was that my kidneys were retaining all the toxins in my body while discharging the nutrients I needed to survive. In other words my body was slowly poisoning me.

One of the reasons my kidneys couldn’t be found by the heart specialist was due to the kidneys being surrounded by a lot of potassium. The doctors decided one of the first procedures was to clear excess potassium from my body. One of the side effects of this process was to cause me to have a seizure and advance into a coma. During this episode my left hip broke (I also suffered from brittle bones) and I woke up in traction with my hip having been replaced and have had 3 such replacements since.

The renal specialists stated I could live for years on diets before I would require dialysis and/or transplantation, which to me, as a teenager, was a relief. Then one day, while doing my Form 4 exams at age 16, I fainted and was rushed to the casualty department at St Vincent Hospital, Melbourne.

In the late 60’s and early 70’s, hemo-dialysis consisted of 6 to 8 hours - three times a week depending on height, weight and overall health condition. Given I was a very small specimen – approximately 19 to 25kg and 1.47m – I used to be completely drained after each dialysis session.

While dialysing, I continued with my Form 5
secondary studies, being tutored by a accommodating teacher. This process continued for 10 months until that fateful evening when I received that most important telephone call.

When I arrived at the hospital there were 4 other potential recipient’s for this available kidney. After more intensive testing it was considered that the graft kidney matched me far better then the other 4 even though 2 of them were ahead of me on the waiting list. The operation itself took approximately 10 hours and the new kidney started to produce urine while I was still on the operating table, which according to the doctors is the best sign that the new kidney will work.

After spending 2 weeks in hospital I was ready to go home.

As mentioned, up to this point in my life (age 18) every time I ate, I would end up vomiting all my food. There were limited foods that I could eat as, prior to and during dialysis, I was on a 50-gram low protein diet which limited food intake. After my transplant I was able to eat anything and everything - I went on an eating binge not only because I was experimenting with new foods I never had before but also all the immune-suppressive medication I was on made me eat a lot. Unlike today, back in the early 70’s transplant patients were placed on high dosage of steroids, which in my case increased my appetite along with my weight, which went up to 70 kg.

In 1985 the rock in my life, my father, died and I realised what an important person this man was in my life. He directly and indirectly taught me how to be a man in so many different ways. The biggest lesson he taught me was that even as a man it was alright to feel different emotions and to be able to cry whether you were happy, sad or in pain. On his death the family decided to agree to his wishes while alive to become a donor. So for our family the circle has been completed. I was a recipient and, in turn, my father became a donor.

Since my transplant I have been diagnosed with osteoporosis, had by-pass surgery (after initial complications requiring a visit to intensive care and a return to temporary dialysis), and have become vision impaired. I am on the same anti-rejection medication given to me at time of transplantation.

In 2009, due to my vision impairment, I was hit by a car, which made me consider applying for, and was successful in obtaining, a guide dog. In June 2010 I was trained with a lovely 2-year-old black Labrador called Valli, whom I call Val for short. This highly intelligent dog not only guides me and keeps me safe when I leave home but has also become my very good friend and companion.

Many people say to me ‘isn’t it sad you had all these health issues’ but to me they have been a blessing in disguise as it has made me the person that I am today. Since my transplant I have a great quality of life which I never experienced in the first 18 years of my life. I live life each day as if it is my last and enjoy every minute of it.

I have been gainfully employed since 1973 – even managing my own business for 15 years. I participated in ballroom dancing for over 30 years with a few years of competition, volunteered in various community groups and enjoy a lovely social life. I feel proud of the volunteering work I have done for Kidney Health Australia and the Dialysis and Transplant Association where I am honoured to have served as both President and Secretary.

All of this would not have been possible without some very special people in my life. They include: - my God that I believe and have Faith in; my family, particularly my mother, father and brother Joe; my friends, many of whom have also been my work colleagues along the way; the Medical Profession – Dr John Niall (deceased - my nephrologist who cared for me till he retired), the hundreds of doctors, nurses including the allied health workers and many more who supported me medically and psychologically; my teachers; my field supervisors; my rehabilitation workers; and many, many more who have given freely to support me.

Most importantly, this journey would not be possible without the donor family. Even though I don't know who they are and they don't know me, I'd like to think that I haven't wasted this gift I was given by them in their time of sorrow.

So the journey continues and I would like to finish by sharing my motto in life, which I appropriated from other sources. It is a familiar one used by most worthy scholars, poets and warriors although I make no claim to be one: 'He who dares – wins.' Or to use a Monty Python equivalent: 'Always look on the bright side of life.'
Recipe Corner

In anticipation of the warmer months and days of sunshine, our recipes include suggestions for picnic and gift hampers and two recipes for delicious, healthy lemonade. Enjoy.

WHEN LIFE GIVES YOU LEMONS...

...MAKE LEMONADE

**Ingredients**
- 2 tbsp. fresh-squeezed lemon or lime juice (approx. half a lemon)
- 1 or 2 tbsp. organic maple syrup (the darker the better)
- 1 c. bottled or spring water (do not use tap water)

**Method**
Combine lemon or lime juice, maple syrup and water. Chill and drink.

GIFTS FOR FOODIES

**Bringing gourmet to your hamper...**

The next time that you need to give a gift consider giving a homemade hamper filled with gourmet salt-free goodies. Instead of filling a basket with chocolates and wine, make a healthy hamper yourself.

Making your own hamper allows you to hand-pick items you know the recipient likes, and he or she will be touched you went to the extra effort.

**For the Italian Lover:**
- Low-sodium pesto
- Low-sodium roasted peppers
- Gourmet dried pasta
- Packages of fresh herbs
- Garlic bulbs
- Truffle oil
- Specialty olive oil
- Balsamic vinegar

**For the cheese lover:**
- Brie
- Artisan cream cheese
- Brillat –Savarin cheese
- Chevre goat’s cheese
- Brown rice crackers
- Flatbread crackers
- Baked pita bread
- Dijon mustard
- Horseradish mustard

Buy a basket at a craft store and fill it with the tasty low sodium items above, feeling confident that all the items in your hamper are suitable for a friend on dialysis.

Pick and choose items from these lists for delicious, guilt-free food and make up a picnic hamper to entice your loved ones outdoors, shaking off the Winter blues.
Notice Board

RIDE FOR DIALYSIS

Reminder: next rides, Sept 25, Oct 30. Meet at Geelong Station at 9am. To make a donation or get more information go to: www.everydayhero.com.au/steven_cartin

BIG D AND ME

BigDandMe is a blog, written from DATA member, Greg Collette’s, personal experiences with dialysis. Updated every fortnight, find his blog at: bigdandme.wordpress.com/

Christmas at the Melbourne Zoo

Data would like to invite you to join us at the Melbourne Zoo for a Christmas Party this year on …

Sunday 4th December 2011

11pm to 4pm

We will subsidise $10.00 off the price of the entrance fee

That will make it:
- each Adult: $15.40
- Concessions: $9.90
- Children under 16 are free

So please join us…

We have booked a Pavilion so we have a place to come and rest and enjoy each other’s company.

A picnic lunch will be provided.
Please bring your own chairs, tables and blankets and have a fun day at the Zoo with DATA.

Hope to see you there!

RSVP: 14th November so we can buy your tickets and get them out to you!

Cut Here and send back, along with payment, to: DATA, PO Box 165, Blackburn 3130

Yes! Please book me tickets to join you at the Melbourne Zoo!

Tickets needed: _______ Adults ($15.40) _______ Concession ($9.90) _______ Children (free)

Please find enclosed my Cheque/Money Order for the amount $_________

Please post to:
Name: _____________________________________________ Address: ___________________________________________________________ Post Code: _______
**Dates to Remember**

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**October 23**  
**Annual General Meeting**  
*Time:* 2.00 pm  
*Venue:* Café Vanilli  
89 Railway Rd. Blackburn

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**November 14**  
**World Diabetes Day**

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**December 4**  
**Christmas Party**  
*Time:* 11.00am-4.00pm  
*Venue:* Melbourne Zoo Pavilion

**RSVP by 14th November**

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**TBC**  
**Rosebud Members Renovation BBQ**

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**P.O. Box 165**  
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Fax. (03) 9894 0266

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- **Past President**  
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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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**Deadline for the next ShoeString: 17th October**

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**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