Christmas in July
is coming again to D.A.T.A.!

**WHEN:** Saturday 23\textsuperscript{rd} July 2011

**WHERE:** St Johns Anglican Church Hall
(Across the road from Blackburn House)
14 Queen Street Blackburn

**TIME:** 6:30 pm

**COST:** $25 per person

**BYO:** Drinks & Kris Kringle present
(not more than $5.00)

**RSVP:** Wednesday 16\textsuperscript{th} July 2011

Last year there was a record number of attendees so don’t miss out on a wonderful night! There is lots planned!

There will be: Trivia
Starter games
Live music (so you can get up and dance)
The man in red will show up!

Join in the fun! Send your payment and Return slip back to the Office as soon as possible!

Please reserve our seat…

**RSVP for Christmas in July, by Wednesday 16\textsuperscript{th} July 2011**

Name: __________________________ Phone: __________________________

Number of people: _________

I am paying by: Cheque $………. Money Order $………. 

**Return to:** D.A.T.A., P.O. Box 165, Blackburn 3130
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**A Note From the Editors…**

Hi everyone, hope this edition of ShoeString finds you all well.

It's official! Adrianne and I are flying solo and are excited and honoured to fulfil the position of editors for this wonderful publication. We thank Joan Eastwood for her guidance over the past few months and hope we make her proud.

The July edition of ShoeString has something of interest for everyone (we hope!) including a personal journey story from one of our members which will touch the hearts of our readers.

Frank Simovic, a DATA member from Geelong, brought to our attention the fundraising efforts of Steve Cartin and his Ride for Dialysis.

Faye Rawson provides us with a personal account of her time spent at this year's Thanksgiving and Remembrance Service which reminds us all of the significance of this occasion.

We will have you all cooking up a storm with our delectable reduced potassium diet recipes and not to forget all the updates on our wonderful holiday homes available to all our members. You will be pleased to hear of the proposed upgrades on the Rosebud house.

Hope you enjoy this months edition.

Editors,
June Salt & Adrianne Bethlehem
President’s Report

Unfortunately, for this edition our respected president, Ros Ball, was not well enough to write her bi-monthly report. We hope and pray she has a speedy recovery and will be back on her feet in no time.

2011 Service of Thanksgiving and Remembrance

Saturday, 28th May, saw us making the annual pilgrimage to the Melbourne City Conference Centre for the Service of Thanksgiving and Remembrance. There was a large attendance but it was slightly down from last year.

Donatelife, the Victorian Organ Donation Agency hosted the 2011 Service, which was conducted by Tom Rose, Senior Chaplain at Epworth Hospital, with music provided by the Royal Melbourne Hospital Staff and Volunteer Choir, directed by Emma O’Brien.

The service usually keeps to the same format each year. Commencing with the traditional lighting of candles by representatives of both donors and recipients, the service continued with two donor families sharing their stories – one family donated multiple organs, the other donated corneas and tissue. The medical profession was represented by Professor Gregory Snell, Medical Head of the Lung Transplant Service at the Alfred Hospital, who spoke on the highs and lows of his work as a transplant doctor. This was followed by a heart-lung recipient sharing the story of his transplantation journey and the way the life-giving donation has given him a wonderful new life.

Order of Service booklets, a sprig of rosemary for remembrance and a blank card were placed on each seat. People were invited to write a memory or message of thanks on the card and, at the end of the Service, to place the card in one of the Book of Life folders located around the Auditorium. Attendees were also invited to light a taper for remembrance or thanksgiving.

The Service can be a very emotional experience for many people, evoking memories of their journeys to donation or transplantation.

Afternoon tea was served at the conclusion of the service, providing an occasion to socialise with other attendees and catch up with friends. Each year we, personally, meet up with Margaret and Keith Haggett. My husband, Alan, and Margaret received Kidney transplants at the Austin Hospital at the same time, in 1991—giving them twenty wonderful years of living life to the full.

Thank you to our donor families.

Fay Rawson

RIDe FOR DIALYSIS

Along with the Geelong Touring Cyclists Steven Cartin is cycling on the last Sunday of each Month, in the name of Kidney Health Australia. Funds raised go towards Kidney Health awareness of kidney disease.

Rides leave from Geelong Station at 9.00 am, to a different destination each month.

Ride dates for rest of year:
July 31st
October 30th

August 28th
November 27th

September 25th
December 25th

To make a donation or get more information and updates go to:
Holiday Homes

Rosebud:
A modern 3 bedroom house which sleeps five people. Rosebud beach is only a minutes walk away.
Rosebud 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.
Rosebud is soon to be under construction to make it more disability friendly with plans for a access ramp.
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.
Contact:
Kaitlyn Steavenson: (03) 9785 3036 (after midday)

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. Colour TV in living and the 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.
Contact:
Alan Rawson, 22 Tarwin Drive Croydon 3136,
Phone: (03) 9723 3019, E-mail: fayal_rawson@hotmail.com

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 - the house is vacant from July 31 until September 4 and then from 11 to 18 September.
Holiday Homes

Blackburn:

At the moment Blackburn is a very comfortable two storey house, set on a large block of land with some lovely big shade trees. As it stands it is has three bedrooms upstairs (two twin bedrooms and a family suite) 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, 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, 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 V.P.T.A.S. (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 8836, 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 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.
"Receiving a chronic condition diagnosis such as kidney disease is like being on an emotional roller-coaster ride that never seems to stop."

“No-one told me it would be like this.”

“Everyone seems to be worrying about my husband/wife/partner, but hey, what about me. I’m affected by this disease, too.”

These are just some comments from the carers of people who have been diagnosed with kidney disease. And what they suggest is that the carers are also deeply affected by the problem. However, nowadays carers don’t have to go it alone.

Share and extend the health-care load.

As well as friends and family, there are also many organisations that can help carers deal with the burden of caring for a loved one with kidney disease or any other chronic condition. There are local council services such as Meals on Wheels, Home Help, in-home respite and personal care.

♦ The Carers Association in your State can help with respite (such as Personal Care Day Centre support), transport, case management, and overall care and liaison with different services that are available.

♦ The Aged Care Assessment Team (ACAT) offers community packages including individual assessments to meet your care needs.

♦ For ethnic groups, your community multicultural centre can provide support for different nationalities.

♦ Centrelink can provide financial assistance in regard to the carers’ payment (which replaces an existing Centrelink Benefit Assets test), carers’ allowance, concession cards, sickness benefits and disability payments.

♦ Further financial assistance can also be obtained through the Salvation Army and St Vincent De Paul.

♦ The Office of Public Advocate offers legal assistance with wills, power of attorney and guardianship.

♦ Contact Kidney Health Australia (www.kidneyhealth.org.au or call 1800 682 531/TTY 1800 005 881) or other not-for-profit chronic disease specific organisations (look in the Yellow Pages under your disease specific area for further contact information).

For more information and support contact:

Carers Victoria
(03) 9650 9966
www.carersvic.org.au

In February 2005, Ian’s kidneys suddenly failed. We had no real warning. Sure, he wasn’t himself, but, as we’ve since discovered, Ian will work through terrible pain and just soldier on. On a Saturday morning he collapsed with his body in full cramp. Five days later, after doctors, specialists and blood tests, Ian was in the Alfred hospital having his first dialysis session via a permacath. After many scans they found an infantile kidney in his groin which had never worked and his other one had succumbed to nephritis.

The cause? Was it environmental, as Ian grew up in an area deep in the country where the spreading of DDT was prevalent and many people died of cancer? Was it genetic—his great-uncle was sent home during WWI with kidney issues? Was his good kidney damaged because of the graffiti remover he used when he was a cleaner that used to make him sick? Or was it the glandular fever he had as a young soldier—he never quite felt himself after that.

The doctor’s prognosis was it was simply bad luck.

For two and a half years, Ian was on peritoneal dialysis. Every night for ten hours he had to plug himself into a machine on his side of the bed. The machine alarm sounded often—he would lie on the leads or the leads would just play up—so our sleep was always disturbed. In our little house we had to put aside a room to store all the equipment and every day he walked around with two litres of dialysis fluid in his stomach. One day, while out fishing with my brother-in-law and nephews, he got so sea-sick and vomited so much he tore the bottom of his peritoneal cavity and ended up with the two litres of the fluid leaking into his body. When he got an infection and ended up at the Alfred again it was decided PD just wasn’t working any more and it was time to go on to haemodialysis.

We were luckier than most as there is a great satellite dialysis unit here in Rosebud. So, after a settling-in period of dialysing at the Alfred or Caulfield or Frankston, they were able to get him into Rosebud. He would go there three times a week for five hours at a time but still managed to work full-time—by starting a little earlier on non-dialysis days he was able to keep his job and his wage did not suffer.

Unfortunately, Ian did have some issues; he overloaded on fluids twice, not really understanding just how little his fluid restriction of 500mls a day really was! The first time he overloaded he was lucky enough to actually be at the dialysis unit when, all of sudden, he couldn’t breathe. The fluid had gone into his lungs and he was effectively drowning. The nurse saved his life by talking to the renal specialist on the phone who kept telling her to just take more and more fluid off—the whole hospital came running and they had to rush him by ambulance to Frankston Hospital where he went into Intensive Care for a couple of days. The second time he overloaded he was at home and he suddenly couldn’t lie down. I insisted he go to Emergency. By the time he walked through the doors his breathing was crackling and he was turning purple again. He ended up going to the Alfred by ambulance and stayed a few days.

Ian also got a condition called Disequilibrium Syndrome, where he would be very sick when he got off dialysis—migraines, blood pressure over 200, vomiting—and this went on for almost six weeks. We never thought he’d feel well again. This diagnosis was missed because Disequilibrium Syndrome is usually only experienced by people new to dialysis, whereas Ian was only new to that kind of dialysis. A diligent nurse at Rosebud took Ian’s charts home in her spare time because she knew it wasn’t right and he was experiencing something more than anxiety. She charted his urea and noticed the highs and lows. With this information they dialysed him differently on the machine—he would
be on 'Profile One', which meant most of the fluid was taken off at the start of the session and it would taper off towards the end. Things started settling down immediately and Ian settled into the next two years on haemodialysis.

On Saturday, 10th October 2009, the phone-call came. For almost five years Ian had carried his phone around with him—refusing to turn it off in meetings, carrying it around at work—and the very morning he forgot it, the call came: they finally had a kidney for him! I was lucky enough to take the call at home, and I broke the news to him when he came home from Bunnings.

The operation went smoothly, but then the kidney slept...and slept...and slept. The Alfred decided to give him a biopsy to find out if everything was going well and it wasn’t rejecting. The results were that the kidney was asleep and we just had to be patient.

In the meantime, Ian continued to dialyse for the next week. After 9 days in hospital and with a still sleeping kidney, they sent him home with instructions to come back the next morning to dialyse—but: if anything happened (like a wee!) do not let him be dialysed or the kidney would sleep again.

At midnight Ian gets up out of bed and I say, 'where are you going?'

'I think I need to wee,' he says.

And, he did—and for every hour after that!

At the Alfred we told the dialysis unit that we think the kidney has woken up with a vengeance and not to dialyse him, but to give him blood tests first to determine that. The nurse looked at me like I was a know-it-all. (I’m sure I’m not the only partner who has experienced this! I remember coping the same look from an emergency doctor at the Frankston Hospital when I was trying to get him to understand that Ian doesn’t wee, so why are you giving him lasex for a fluid overload!) I said to the nurse as patiently as I could, 'I have not made this up, this is what he’s been instructed to do – please give him the blood tests and don’t dialyse him until you get them back or you can make the kidney go back to sleep,' which is exactly what I was told to say.

Without a word she gave him some blood tests and an hour later walked up to us, said (without fanfare) that he won’t be dialysing any more and they wanted to see us in Renal. Well, we were happy anyway! Other than that particular nurse, we are more than pleased with Ian’s treatment at the Alfred; the staff have all been wonderful.

Over the next six months Ian was fantastic—his creatine went quickly down to 130 then ended up hovering around 100—a fantastic result. But in May he started to feel unwell again and, after speaking to his specialist and doctor, we put it down to side-effects from the immuno-suppressants and knew that he would be having less medication soon—the first year was always the hardest.

On Friday, 8th October last year, Ian became short of breath walking up three steps—the next day, he had a couple more episodes, and on Sunday—incidentally the new kidney’s first birthday—we went to a Christening and it happened again. Ian’s sister-in-law is a nurse and recommended we go to Casualty because something wasn’t right, so we drove straight to the Rosebud Emergency Department.

At first they thought he was dehydrated and gave him three units of saline and were about to send him home when his temperature shot up. They knew they were looking for an infection and for the next two days looked for its source. Then, on Tuesday, they gave him an ECG in the morning and sent him...
straight to the Alfred. He rang me and told me it was a leaky heart valve and he had to have a straight-forward operation which they do all the time.

They took him by ambulance to the Alfred. I met up with them in Emergency and the ambos told me that he had a good ride up and slept most of the way. Ian hugged me, looked at me and said, 'I'm in the right place now'. He then became breathless and clutched at his chest. I was pushed aside and stood there rooted to the spot as they raced him out the back; that was the last time I saw him awake for three days.

The next hour was just a sea of faces. They told me that Ian was seriously ill, he was on life-support in an induced-coma and he had a 40 percent chance of not surviving the night. I suppose I needed something to focus on, but all I could think of was 'what if he did not make it through the night? He wasn't baptised.' The Alfred asked if there was anything they could do for me and, when I told them I wanted him baptised, they swung straight into action.

That night, Ian was baptised in the Alfred ICU by an Anglican Irish Priest on a work visa—the Bishop had been contacted and had said Ian could be baptised, but would have to be baptised as a child, therefore, he would need Godparents to answer for him. By this time one of my brothers, Mark, had driven up from Tootgarook and my cousin, Michelle, had come in from Chirnside Park. That night, I became Ian’s Godmother and Mark his Godfather.

Everyone went home and I tried to sleep on the floor of the ICU. Ian’s operation was in the morning and if he died during the night I didn’t want him to be amongst strangers.

Ian had Endocarditis, bacteria had got into his heart and eaten two valves, which had to be replaced by mechanical valves. They told me his kidney would fail because they had to take him off all the immuno-suppressants to fight the infection, but someone was looking after him and the kidney just burbled away.

The next morning, Ian had a ten-hour operation to face because they knew they had to replace two heart valves—the mitral and the aortic valve—and they were very sure they had to replace the aorta (which is what the overnight wait had been about: they’d found a perfect match in Queensland and it had to be flown down). However, the operation turned into five hours because the aorta was fine and they didn’t have to do a graft.

After three days in a coma, Ian was woken on the Friday (they had tried during the night, but he had become distressed, so they wanted to wait until I came in). When he woke this time, he was much calmer and even tried to smile through his mask. His ten-day ICU stay turned into five when they moved him to Cardiac. His stay on Cardiac was supposed to be at least another week; this turned into four days. Ian was then in Renal for eight days, where they told him he would have to stay for eight more weeks as his antibiotic regime was very unusual.

What a daunting prospect in front of us! I could not bear to think of him up there on his own so I would go up to visit him every day. Rosebud refused to take him but, another miracle, the Alfred pushed and in a week got him into a bed closer to home, at Rosebud. We then settled into, what we thought, would be a couple of months in hospital—we hoped he would be out in time for Christmas. A week later another miracle happened! After being refused by Hospital In The Home, the head doctor at Rosebud insisted Ian would heal better at home and they sent him home to daily nurse visits.

After six weeks on home antibiotics, a further six weeks gaining back his strength (and 30 kilos!) and the okay of five doctors and professors, Ian went back to work in January this year and he has not looked back since. His creatine is around 100 when he is working and 70 when he’s not, the immuno-suppressants have been lessened and, consequently, the steroid-induced Diabetes, which necessitated him to take insulin twice a day, is reversing. He is now on one tablet a day with sugars hovering around five—soon we hope he will not be Diabetic at all...and we pray every day that he will now have good health.

Keryn Rivett

If you have a story to tell and you’re not sure where to begin our editors would be more than happy to hear your story.

Contact us.

Write to: The Editor, ShoeString,
P.O. Box 165
Blackburn 3130
Email: editor.shoestring@gmail.com
STUFFED ZUCCHINI
Serves 4

Ingredients
2 medium zucchini  
1 tbsp cooking oil  
½ small onion, minced  
1 egg, lightly beaten  
¼ cup dry bread crumbs  
¼ cup grated parmesan cheese  
1 tbsp finely chopped parsley  
Pepper to taste

Method
Preheat oven to 180°C. Slice zucchini in half lengthwise, scoop out and save pulp, leaving a shell. Boil shells for 2 minutes, remove and drain. Chop zucchini pulp. In frypan, heat oil over a medium heat and sauté onion and chopped zucchini pulp until tender, remove from heat and combine with egg, breadcrumbs and parsley, season to taste. Fill shells, place in greased baking dish, top with cheese and bake for 15 – 20 minutes until golden brown.

SPICY LAMB MINT KEBABS
Serves 4

Ingredients
500g lamb mince  
1 small onion, finely chopped  
50g fresh breadcrumbs  
1 tbsp ground cumin  
2 tbsp fresh coriander, chopped  
150g natural yoghurt  
5 cm piece cucumber, finely diced  
2 tbsp fresh mint, chopped  
Pepper

Method
Combine lamb, onion, breadcrumbs, cumin and coriander in a bowl. Using lightly floured hands, separate the mixture into 24 portions and roll into balls. Chill in fridge for 30 min. Heat grill to moderate. Thread three balls onto each skewer (if you are using bamboo skewers, soak in water for an hour prior, to prevent burning.) Cook under preheated grill for 20 min, turning occasionally. Combine yoghurt, cucumber and mint in a bowl and serve with kebabs. Serve with white rice, pita bread or couscous.

Exact measurements should be used for a low-potassium diet. Recipes are based on information from Kidney Health Australia, Back on the Menu: Recipes for a reduced potassium diet, 2nd edition.
Recipe Corner

BAKED RICOTTA AND APPLE CHEESECAKE
Serves 10

Ingredients
200g prepared shortcrust pastry
30g margarine
2 apples, cored, peeled and sliced
Cinnamon

Ricotta Filling
750g ricotta cheese
4 eggs, separated
½ cup honey
1 tbsp finely grated orange rind
3 tbsp orange juice

Method
Pre-heat oven to 190°C. Roll out pastry to 3mm thickness and use to line deep, 23cm spring-form tin. Prick base and sides of pastry with fork, line base with non-stick baking paper and fill with baking beans or uncooked rice. Bake for 10 min then remove rice and paper. Bake for another 5 – 8 mins or until golden brown. Melt margarine in a pan and add apple slices, cooking over medium heat, stirring occasionally until golden. Once cooled, arrange apples evenly over pastry base and sprinkle lightly with cinnamon. Set aside and make the filling.

Filling
Place ricotta cheese, egg yolks, honey, orange rind and orange juice in food processor or blender and process until smooth. In a separate bowl, beat egg whites until stiff peaks form. Fold egg white mixture into ricotta mixture and carefully pour filling over apples. Reduce oven heat to 180°C and bake for 1 ¼ hours or until firm. Cool and refrigerate overnight. Enjoy.

Be prepared for anything—have an emergency meal plan

Be prepared—there may come a time when you can’t dialyse due to an emergency. Follow these tips for short periods of time (five days or less) when you cannot dialyse.

1. Limit meat to 3 to 4 ounces (around 100g) a day. This is about half of the protein you normally eat
2. Avoid all high-potassium fruits and vegetables (avocados, bananas, spinach, kiwi fruit, etc.).
3. Limit fluids to 1 to 2 cups each day.
4. Choose only low-salt foods and do not add salt or salt substitute.
5. Use fats like butter and oils, and sugars for extra calories.

Note: an emergency meal plan is NOT a substitute for dialysis.

Thanks to dietician Katy Wilkens, output, Jan/Feb 2011, Northwest Kidney Centers, Seattle, for this information.
Dates to Remember

July 23rd  
**Christmas in July**
**Time:** 6.30 pm  
**Where:** St John’s Anglican Church Hall  
Opposite 14 Queen St., Blackburn

July 31st  
**Ride for Dialysis**
**Time:** 9.00 am  
**Where:** Geelong Station  
*(see further dates on page 3 of this issue)*

October 23rd  
**Annual General meeting**
**Time:** 2.00 pm  
**Where:** 14 Queen St., Blackburn

December 4th  
**Christmas BBQ**
Details TBC

Bendigo and Regional Support Group
Bendigo Club, Park St., Strathdale

July 18th  
**General Meeting & Dinner**
**Time:** 6.00 pm
Phone: Gwen /Alan: 5444 0892 or Lola: 5442 1258

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 hear your story. 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: 8th August

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

Executive Committee

**President**  
Ros Ball  
(03) 9439 8866

**Vice President**  
Alan Rawson  
(03) 9723 3019

**Past President**  
Sue Hatzimichalis  
(03) 9378 8836

**Treasurer**  
Lloyd Samuel  
(03) 9527 2911

**Secretary**  
Sue Hatzimichalis  
(03) 9378 8836

Holiday Homes Secretaries

**Yarrawonga House**  
Alan Rawson  
(03) 9723 3019

**Rosebud House**  
Kaitlyn Stevenson  
(03) 9785 3036

**Blackburn House**  
Sue Hatzimichalis  
(03) 9378 8836

**ShoeString Editors**  
June Salt  
0404 008 799

Adrianne Betlehem  
0411 326 093

Committee Members

Nick Hatzimichalis  
(03) 9378 8836

Ken Smith  
(03) 5977 3580

Kaitlyn Steavenson  
(03) 9785 3036

Amanda Pratt  
(03) 9589 4894

Brendan Lowry  
(03) 9589 4894

Michael Allan  
(03) 9561 4806

Elenor Allan  
(03) 9561 4806

Joan Eastwood  
(03) 9795 1649

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