OUR DATA FLAG
Joan, John and Ros proudly flank the DATA flag, above. July’s issue of Shoe String mentioned that DATA was given the original flag made for the first service, at the 25th Service of Remembrance held in May this year.

For our records, it would be lovely to know who designed and made this flag. So if you know anyone who was involved or if they recognise this flag, please send us an email at info@datavic.org or call the office 9894 0377. We’d love to hear from you and give our flag a history.

IMPORTANT MEETINGS - OCTOBER 23

SPECIAL GENERAL MEETING - 1.30pm
- Members to vote on new rules

ANNUAL GENERAL MEETING - after SGM
- Summary of 2016 including the Holiday Houses, President’s and Financial reports
- Election of the 2017 Committee
- Special Guest Speaker - John Agar
- Draw the Special Effort Raffle
- Afternoon tea

SAVE THE DATE

OUR CHRISTMAS IN JULY WRAP UP!
See pages 2 & 11 for the full story and members photos.
We had a great turn up at the Christmas in July event with 41 happy party goers enjoying a delicious 3 course dinner (soup, roast turkey with trimmings and plum pudding) at the Greyhounds Entertainment Centre.

Having had to battle a wet and windy trip to get there, we took our seats and our President John Podolak opened the night with a warm welcome and Joan Eastwood kept us all on schedule.

The room soon filled with the buzz of lively chatter with people catching up and new people being introduced. Thanks to Bev’s organizational skills, raffle tickets were selling fast, lollie bags were handed out and the Christmas Kris Kringle gifts were collected for Mr Claus (aka Ken) to hand out later in the evening.

The fantastic trivia quiz hosted by our Trivia Master, Ken Donnelly, was a hard fought competition with 3 people scoring 20 out of 35 but Gwenda Hollingsworth outwitted the rest with an impressive 21 and was crowned the winner picking up a lovely hamper gift. Ken also donated a DVD to the Members who traveled the furthest to attend, so Traralgon couple, Alan & Eileen Stanyer, took home the prize.

This type of event can look effortless however behind the scenes a dedicated team of Data Members worked tirelessly. A big thank you to Angela, Vicki, Joan, Bev, Elaine, Ken and Darren.

See more happy snaps on page 11.

Trudy Robson

As we process the subs at this time of year we often find out little bits of news about our members like who has had a transplant, (congartulations) who has moved house and those who have started dialysis etc. We can’t respond to you ALL - BUT IT’S GOOD to hear from you, so keep them coming in.

Special thanks to those who included a donation to DATA. These donations are very much appreciated.

Visit our website at www.datavic.org
As I approach middle age and will celebrate my 80th birthday next year, I become more and more aware that, like winter, (which is not my favourite season) all good and bad things come to an end.

Many current and future projects are under consideration and in progress overseen by various sub committees. For example we can help you when you need to attend a clinic or doctor’s appointment in Melbourne by subsidising your chosen conveniently located accommodation. Although the details are still being finalised, you are welcome to call or email our office with your request.

I attended the successful Christmas in July at the Greyhounds Entertainment Centre. On behalf of all the members who were in the fortunate situation to attend, I extend our thanks and appreciation to the hard working social sub committee comprising Angela, Vicki, Bev, Elaine, Darren, Ken and many other helpers.

During July, I made a number of telephone calls to members and learned about the diversity and complexity of interesting life’s situations. These conversations made me very aware of the importance and value of friendship and a sense of belonging to a community.

Without support, loneliness and depression is a real danger and a simple phone call, even from a stranger, who is prepared to listen sympathetically, can encourage and brighten and lift another. An excellent way of enhancing your own life and make new friends is to visit and inspect our new premises at Forest Hill. Members are welcome to attend, meet committee members and become familiar with what occurs during our committee meetings which are held on the second Sunday at 2.00pm every month.

An example of such a visit was our welcome to Jonathan Jurrens to our July meeting.

Because our meetings, at times, can become robust and exciting, some members were concerned that Jonathan may have been discouraged. However, I was surprised and impressed when I received a call from him after the meeting and he told me that he would like to participate and become a more active member. This encouraged me to discuss with the committee if welcoming visitors to our meeting may be worth trying in the future.

I have a habit of acquiring and sticking on my office wall positive extracts from various sources I come across – I’m told that I may have to build a separate room because I’m running out of wall space. So to make some room on my office wall and as a conclusion of this report, I’m transferring the following by some unknown author to Shoe String so you may put it on your wall if you wish.

**VALUES OF FRIENDSHIP**

New dimensions can be enjoyed, comfort zones can be challenged and fear can be conquered through the loving inspirations of friends, with whom you are connected in the web of life.

The intangible threads keep you anchored and enhance the sense of belonging.

A friend is someone who reflects back to you what you have given out.

A true friend is like a flower of the same variety which shines their brightest blooms when you bloom and you shine when the friend shines.
DATA Holiday Houses

The Rosebud & Yarrawonga holiday homes are for the use of DATA Members and their immediate family, with a Member present on all holidays booked.

Both houses are equipped with a RO machine. For those members on home dialysis, please contact the House Secretary to discuss if your hospital technician can supply and install a dialysis machine in the house for your holiday.

Please note, as transplant and PD patients have more freedom and options to travel, priority is given to those Members on haemodialysis as this is often the only way they can get a holiday.

Friends and extended family are welcome to join the DATA Member and they must pay $20 per person per night.

Please note, you are responsible for the cleaning of the houses when you leave which does include bathroom and toilet, so we expect the houses to be left neat and tidy for the next holiday makers and please do not leave any food.

No pets allowed with Guide dogs being the exception.

Rosebud

VACANCIES

• Aug 28 till Sept 4
• School holidays - Sept 25 to Oct 2
• All of October is free
• Nov 6 to Nov 13
• Nov 20 to Nov 27
• Nov 27 to Dec 4
• Dec 4 to Dec 11
• Dec 18 to Dec 25
• Jan 1 to Jan 8, 2017

Since the last Shoe String, we have had hand rails put in both showers and are in the process of putting a television on the wall in the dialysis room.

Yarrawonga

VACANCIES

• Dec 11 to Dec 17

But I do get vacancies so give me a ring.

If you have booked a fair way ahead, you must ring or email me to confirm your booking within 3 months of going on your holiday.

Do not leave it until you are about to go to Yarrawonga.

Bookings at the Rosebud Hospital Renal Unit must be done online email to: holidayatrosebud@phcn.vic.gov.au

For HOUSE bookings please ring

Rosebud House Secretary
Amanda Pratt  Ph: 9589 4894

DO NOT FORGET

If you need to dialyse at either the Rosebud or Yarrawonga Renal Units, please do the following:

• Contact the hospital to check the availability of booking a chair

• Check the vacancy dates of the Holiday House

• Then ring to book the Holiday House

• Finally, contact the hospital again to confirmation your dates and book in
Have you had a holiday at the Rosebud or Yarrawonga holiday house and taken some photos?

We would love to see some new photos of the holiday houses to show other members how great they are and if there are people in the shots, even better!! Please send your photos either by post and we can return them to you or by email - see back cover for details.

Getting Well with Humour

If your doctor ever tells you to lighten up, do not be offended. Such a prescription may sound ridiculous, but research shows that laughter and a positive attitude can be healing. There's nothing funny about kidney disease, but people are living happy, productive lives today because they learned to lighten up when things were not going as planned.

Illness can be a stressful event. Hospitalization, separation from family, invasive procedures, complex technology, or unfamiliar caregivers can all create feelings of anxiety, loneliness, discomfort, anger, panic, and depression. These emotions are known to produce physiological changes that are harmful to the body, which the use of humour and laughter can ease.

Laughter is a pleasurable experience. It momentarily banishes feelings of anger and fear. It gives us a feeling of power and control. We feel carefree, lighthearted, and hopeful during moments of laughter.

The Cheapest Medicine

Most people agree that humour is a stress reliever, similar to other positive emotions. Laugh and you feel better. Laughter helps the body to provide its own type of medication. Laughter stimulates the immune system, offsetting the unwanted effects of stress.

Many believe that humour leads to health and longevity, and is necessary for human survival. Yet, scientific research in the area of health-related humour has been sparse. One reason is that until the last two decades, we did not have the scientific technology to study the biochemical and physiological effects of humour has been one factor.

But the major obstacle to researching the effects of humour is that the main focus within the healthcare system is on disease, illness, and the serious nature of health care.

In reality, humour has always been a form of communication between patients and healthcare professionals. I can say without hesitation that I always liked being taken care of by someone who had a sense of humour. In this age of high technology, scientific miracles, and medical breakthroughs, it just might be something as simple as laughter that turns out to be the best medicine. We must think of laughter as an exercise and make sure we get in a good laugh every day.

Deep in the human psyche, people know that if they don't lighten up when things get tough, they're going to tighten up and snap. Next time you have on a hospital gown, why not parade around and tell everyone it's a new design created by "Seymour Butts?"

Lighten Up and Laugh!

Following are some tips to help you lighten up and laugh:

• Learn to play.
• Join with some children and help them do a puzzle, color, or play hide-and-seek.
• Have a party.
• Invite a few friends over for an evening of laughing and fun.
• Take a mini-vacation.
• Sometimes getting away can help to lighten our attitude.
• Watch a funny movie.
• Check out the comedy section at your local video store.
• Photo fun. Find a photo booth, sit down, pull the curtain, and take four funny face pictures. Carry them in your wallet to look at when you need to laugh at yourself.
• Read comic strips. Find your favorite comic and make a habit of reading it.
• Learn a joke. Get a joke book or go to www.jokes.com and learn a new one each week. Share it with the dialysis staff and fellow patients.
• Play games like Cranium, Pictionary, or Charades to challenge your brain and lighten your mood.

By Terri Melvin
Renal Support Network
http://www.rsnhope.org/programs/kidneytimes-library/article-index/getting-well-with-humour/
Dr. William Fissell’s Artificial Kidney

Vanderbilt University Medical Center nephrologist and Associate Professor of Medicine Dr. William H. Fissell IV, is making major progress on a first-of-its kind device to free kidney patients from dialysis. He is building an implantable artificial kidney with microchip filters and living kidney cells that will be powered by a patient’s own heart.

Fissell says the goal is to make it small enough, roughly the size of a soda can, to be implanted inside a patient’s body.

Nanotechnology

The key to the device is a microchip. “It’s called silicon nanotechnology. It uses the same processes that were developed by the microelectronics industry for computers,” said Fissell.

The chips are affordable, precise and make ideal filters. Fissell and his team are designing each pore in the filter one by one based on what they want that pore to do. Each device will hold roughly fifteen microchips layered on top of each other.

But the microchips have another essential role beyond filtering. “They’re also the scaffold in which living kidney cells will rest,” said Fissell.

Living kidney cells

Fissell and his team use live kidney cells that will grow on and around the microchip filters. The goal is for these cells to mimic the natural actions of the kidney.

“We can leverage Mother Nature’s 60 million years of research and development and use kidney cells that fortunately for us grow well in the lab dish, and grow them into a bioreactor of living cells that will be the only ‘Santa Claus’ membrane in the world: the only membrane that will know which chemicals have been naughty and which have been nice. Then they can reabsorb the nutrients your body needs and discard the wastes your body desperately wants to get rid of,” said Fissell.

Thanks to
Vanderbuilt University Research News
Would you like to participate in research exploring the design of a yoga program for haemodialysis patients?

Researchers at Western Sydney University are conducting a survey about activities for the promotion of health and wellbeing. Participation involves completion of a 20-minute survey online or by post. If you would like to participate, the survey and detailed study information can be found at: www.surveymonkey.com/r/GVH92QN or by contacting (02) 4620 3695 to request a survey pack.

Kylie Barr

You can be a part of ‘A survey to explore the views of haemodialysis patients towards the design of a yoga program for fatigue’

The project was led by Deirdre Fetherstonhaugh, with contribution from CPC education team, including Mark Boughey, Karen Quinn, Lyndsay Cassidy and Margaret Ross. The slides presentations are now available for view on the CPC website. The workshops included the following:

- An overview of supportive care
- Screening & Assessment in Chronic Kidney Disease
- Symptom Management
- Family Meetings and Multidisciplinary Team Meetings
- Psychosocial and social support
- End of Life Care and Bereavement

With Thanks to VRCN (Victorian Renal Health Clinical Network – Part of the State Government Department of Health) for this information

In our thoughts

20.05.1938 - 24.12.2015

Ray was born in Ouyen in the Mallee and had a life time history of health problems but managed to maintain a busy and successful working life.

He started haemodialysis at home and continued to work around it until his retirement in 2000. He continued on haemodialysis at home using the same shunt for twenty one years and eight months, only requiring dialysis at the hospital occasionally.

Married to Betty for fifty five years, it was only during the last five years that travelling became difficult and his quality of life deteriorated.

He loved his music and enjoyed playing the piano accompanied by his two little dogs Thomas and Ellie who sang beautifully in tune to ‘Scotland the Brave’.

Ray was Treasurer for the Sunraysia Dialysis and Transplant Support Group for many years and his expertise keeping the financial records, was of great value to the group.

He was instrumental in obtaining facts and figures for the need for a dialysis unit in Mildura as people unable to dialyse at home had to relocate, which was upsetting to the family. Dr. Michael Laver moving to Mildura and The Royal Melbourne Hospital providing equipment and support was the saving grace enabling the establishment of the Mildura Dialysis Unit.

Rays fascination for all things mechanical or how they worked made dialysis a challenge which helped his motivation to keep going even when his body was worn out. He finally reached the end of the line when he had a fall breaking his leg in two places and the stress on his heart was too much.

‘The song has ended but the melody lingers on’

Betty a’Beckett

Shoe String 7
The Australian Transplant Games

September 24 - October 1

Australia’s most inspirational sporting event, The Australian Transplant Games is held every two years. The Games provide living proof of the success of transplantation and encourage all Australians to discuss organ and tissue donation with their families.

In 2016 The Australian Transplant Games will be held in Western Sydney, bringing together up to 1,500 people touched by organ and tissue donation from across Australia and overseas. Athletes come from a range of cultural, age and socio-economic demographics – but they all have one goal – to demonstrate the gift of life at the Australian Transplant Games.

Many Transplant recipients use the Games as motivation to a greater end goal, setting various health and fitness targets along the way as they train for The Games. The Australian Transplant Games is also the country’s largest awareness activity for organ and tissue donation. Each year the Games draw a large amount of national, state and local media attention. Transplant Australia boasts an enviable record of influencing public understanding of organ and tissue donation through the staging of the Australian Transplant Games.

The DATA Award

In recognition of outstanding sportmanship, DATA is proud to present a trophy to the best performing Victorian Transplant sportsperson from the Games.

Catch up on the winner of the DATA Award in the next issue of Shoe String.

DATA visits the Big Red Kidney Bus

DATA visited the Royal Botanic Gardens Melbourne in summer. John Podolak the new President of DATA (Dialysis and Transplant Association), and longserving DATA Secretary Ros Ball paid a visit to the Big Red Kidney Bus in the Royal Botanic Gardens Melbourne.

Ros, who is on home haemodialysis, has enjoyed holidays accessing the Big Red Kidney Bus for dialysis and she is a wonderful advocate for this project.

DATA most generously provided sponsorship for a defibrillator on the Big Red Kidney Bus. Thank you DATA.

The Australian Transplant Games were first held over three days in Melbourne in 1988 with 150 recipient competitors competing in Tennis (at the Kooyong courts), Golf, Table Tennis, Lawn Bowls and for children, Quoits.

Thereafter, the Australian Transplant Games have been held every two years in different cities in different states or territories of Australia. The Games now last for an entire week and cover a multitude of sports and recreational activities. Individuals have the opportunity to try out sports they have not participated in before as there are a range of different sports on offer throughout The Games.

Courtesy of
www.australiantransplantgames.com

DATA

Kidney Health Australia
The Specialist
‘What kind of job do you do?’ a lady passenger asks the man travelling in her train compartment.
‘I’m a Naval surgeon,’ he replies.
‘Good grief!’ splutters the lady, ‘How you doctors do specialise these days.’

Doctor’s Diagnosis
Dr Trebble examined Maria and then took her husband to one side saying, ‘I don’t like the look of your wife at all.’

‘Me neither doc,’ said Ross, her husband. ‘But she’s a great cook and is really good with the kids.’

Have a laugh

Hearing Aids
An elderly gentleman had serious hearing problems for a number of years. He went to the doctor and the doctor was able to have him fitted with a set of hearing aids that allowed the gentleman to hear 100%.

The elderly gentleman went back in a month to the doctor and the doctor said, ‘Your hearing is perfect…your family must be really pleased that you can hear again.’

The gentleman replied, ‘Oh, I haven’t told my family yet. I just sit around and listen to the conversations. I’ve changed my will three times!’

Doctor, Doctor,
Can I have second opinion?
Of course, come back tomorrow!

Across
2. twine
5. Holiday house
7. relating to kidneys
9. we had coffee and cake there
10. first name of new editor
11. physician

Down
1. three members of the committee
3. someone caring for patients
4. a garden term for kidney replacement
6. our treasurer
8. first name of person in charge of Rosebud House

The Editorial Committee would like to apologise if we offended you with our choice of jokes.
Our aim is merely to add a bit of light-heartedness in a glum world and we do not intend to offend. We will endeavour to be more selective in the future.
It had all happened so quickly. The first alarm bell rang when Ian went to the local doctor in the small Riverina town of Urana. His blood pressure had been very high, so the doctor made an appointment for Ian to see a Nephrologist, Dr Russell Auwardt in Wodonga.

Dr Auwardt said he would arrange for Ian to have a kidney biopsy at the Royal Melbourne Hospital. When we got home, over a two hour drive, there was a message on our answering machine to contact the hospital. I rang and was told an appointment had been made for Ian to have his biopsy the next day. “Come off it”, I said, “We’re at least four and a half hours from Melbourne and we’re not going anywhere tonight.”

Next day it was a nervous trip down to Melbourne. Things had moved very rapidly and it’s not what you expect from the medical profession if things aren’t serious. So of course our imaginations were running riot and we didn’t have a clue what a nephrologist was. It turned out to be just a fancy name for a kidney specialist.

So by the time we walked into Royal Melbourne Hospital, in the early afternoon; it was with fear and trepidation that we negotiated our way through the rabbit warren of building changes to Ward 6. Here, everything was taken out of our hands as Ian became a patient in the system. I’m not sure when he had his biopsy, that afternoon or the next day, because my memory is very confused, but his records show the 13th September 2002.

Late in the afternoon, we staggered into our room at Elizabeth Towers, fortunately just over the corner from the hospital. Dropping our bags, I put on the kettle. Then relaxing with a cup of tea, my eyes turned to the large envelope they’d given us that I’d put on the bed. What did it say? It wasn’t sealed, so I couldn’t resist having a peep at Ian’s kidney biopsy result. I didn’t understand much of it but my eyes picked out the word “dialysis” - shock, horror and alarm! It was the first time we’d associated the “D” word with Ian. Kidney failure and dialysis were unheard of in either of our families, and the only experience was a few years ago glimpsing a local woman on her home dialysis machine, set up at the Urana Hospital.

Dealing with dialysis was going to be a huge challenge for Ian and I.

That night we slept poorly, not only because of the medical news, but because I always find the city very noisy and light at night. We had a meeting first thing with a social worker attached to the Renal Unit. It turned out she knew quite a bit about our part of the world, especially because of the woman who dialysed at the Urana Hospital until she received a transplant. Like all these meetings you do not take it all in at once, but she did calm our fears a little by explaining that dialysis is not a death sentence, but a treatment that extends and improves your quality of life.

Home we went with much to talk about.

To be continued in the next issue of Shoe String.
Christmas in July
Special General Meeting & Annual General Meeting
Dialysis & Transplant Association of Victoria Inc.
23 October 2016, 1.30 pm
Manchester Unity Hall
8 Main St, Blackburn
Melway Map 47 Ref K10

Christmas Outing 4 December 2016
Still in the planning, but keep this date free.
More details in next Shoe String.

Some web pages of interest
www.nwkidney.org
www.peninsulahealth.org.au/
www.worldkidneyday.org
www.cari.org.au
www.australiandialysisbuddies.org
www.greendialysis.com
www.transplant.australia.org.au
www.homodialysis.org/news-and-research/blog

Our thanks to all who contributed to this edition

Why not spread the word and pass this copy on?
Shoe String 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 any 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 NEXT ISSUE 11 OCTOBER 2016