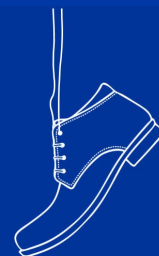


ShoeString



Newsletter of the Dialysis & Transplant Association of Victoria Inc.

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January 2023



Dialysis and Transplant
Association of Victoria Inc.

Registration No A0012114V

ABN 40 628 284 998



HAPPY NEW YEAR

TO ALL.

**WE HOPE YOU ENJOY A STRESS FREE
AND PROSPEROUS 2023**

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FIRST OUTING FOR 2023

When : 26th February 2023

BBQ at Rosebud Holiday House

Where: 17 Rosemore Road, Rosebud, 3939

Time: 12 noon (Melways 158 G12)



DATA will provide BBQ Sausages, Salads,

Tea, Coffee, other drinks .

BYO Plates & Cutlery & drinks

RSVP by 17th Feb 23 to 03 9894 0377

or email: info@datavic.org

*Come for a chat, a relaxing time and
enjoy everyone's company*

Remember This One ?

Rosebud BBQ Feb 2021



President's Report

I hope you all had a good Christmas, and coped with those very hot, hot days. Welcome to 2023. What are we looking forward to this year? I am looking forward to feeling a lot better now the Covid is fading. We should not be too complacent but I think we have learnt how to stay well and keep away from crowds, wear a mask if you can.

DATA is ready for a busy year with a long list of Social Events listed on Page 11. We have already welcomed several new members this year. We hope they will join us on the social outings too.

I draw your attention to World Kidney Day on opposite page. Yvonne has been working very hard over January to prepare for it. We know it is not until 9th March

but we do not have another issue of ShoeString before that date.

The Holiday homes have been used well over the Dec -Jan period. It takes some time to organise a holiday at the right time so talk to Amanda and book in early and I am sure you won't be disappointed.

We are very pleased to see our very first two nursing Graduates who have been successful in winning the "Sue Hatzimichalis Post Graduate Renal Nursing Scholarship" for 2023 (see page 8 & 9).

On 20 January, 2023, Vicki, Gwen, Angela, & Joan met together at Forest Hill to complete a 3 hour training session for Publisher with Nicole from MS Planet. Thanks to



Angela for organising it, it was very good according to the participants . As a result of this we now have a more realistic Editorial team. They are Joan, Gwen & Angela with Vicki available as the 'go to' person if they cannot work something out.

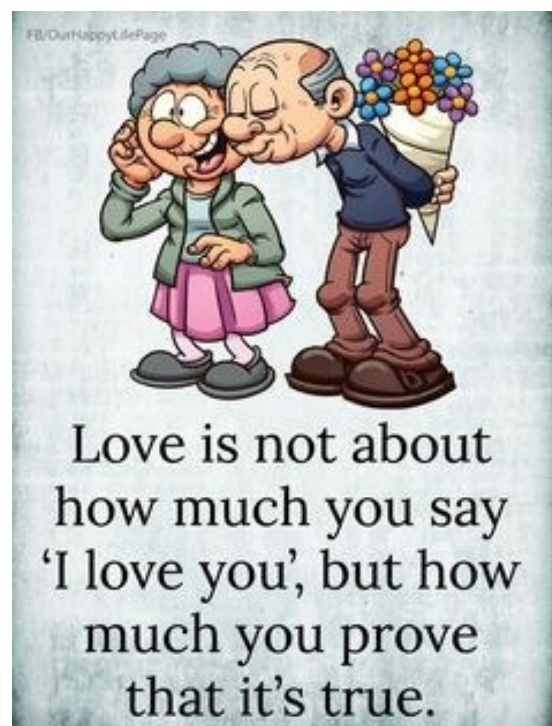
That's it for this issue

take care and Happy 2023 ,

from Brendan

HAPPY VALENTINES DAY

DATA wishes all members a happy and fun filled day!





NEWS FROM FILTER YOUR FUTURE

Yvonne writes : Just wanted to let you know there will be a **Zoom Event on World Kidney Day on 9th March 2023** with details to be provided closer to the date on the **DATA Website**. Also on the **PKD Website**

I will be representing three groups: the Dialysis and Transplant Association of Victoria, Inc. (D.A.T.A. <https://datavic.org>), the Polycystic Kidney Disease Australia Foundation (PKDA <https://pkdaustralia.org>) and Filter Your Future (FYF <https://www.filteryourfuture.com.au>).

The theme this year for WKD is "Kidney Health For All - Preparing for the unexpected, supporting the vulnerable!" <https://www.worldkidneyday.org/2023-campaign/2023-wkd-theme/>

The purpose of this panel is to provide an overview of how bushfires, floods, the COVID-19 pandemic and other natural disasters can impact the kidney community, particularly those needing dialysis or transplantation. We are interested in education related to emergency plans and practical advice to prepare for disasters for those who undergo dialysis at a hospital, satellite unit or at home. Also, any implications for transplant recipients and donors.

Kidney Health for All – Preparing for the unexpected, supporting the vulnerable!

Kidney patients represent more than 850 million people worldwide and are particularly affected by disastrous events as their ability to access proper diagnostic services, treatments, and care may be hindered.

Preparing for unforeseen events is key for kidney patients. Policymakers need to implement integrated health strategies that prioritize prevention, early detection, and management of #NCDs.

In times of emergency, healthcare services need to provide chronic disease patients with equitable and appropriate access to care.

World Kidney Day calls for governments to include emergency preparedness plans in managing, detecting, and preventing kidney disease.

Patients should plan for emergencies by preparing an emergency kit that includes food, water, medical supplies and medical records.

For the young at heart rather than the technophobes

Details on <https://www.worldkidneyday.org>
Participate in #ShowYourKidneys, World Kidney Day's very own hashtag challenge

Take a picture of yourself

First, place your fists where your kidneys are.

Reminder: They are located just below the rib cage, at each side at the back. This may vary if you are transplanted or born with only one kidney.

Tip: Use a solid colour shirt that makes your fists pop on the photo.

Add a photo frame (4 available explaining key roles of your kidneys)

Share the photo on your social media with the hashtag #ShowYourKidneys

Tag a few friends in the caption and ask them to take part in the challenge

KIDNEY HEALTH FOR ALL

PREPARING FOR THE UNEXPECTED, SUPPORTING THE VULNERABLE!



#worldkidneyday #kidneyhealthforall
www.worldkidneyday.org

World Kidney Day is a joint  ISN  PKF-WKA Initiative



DATA Holiday Homes

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

Both houses can facilitate haemodialysis machines. 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.

We are sure you will appreciate that members on haemodialysis find it very difficult to holiday, so we often prioritise them over PD and transplant members. But there are always vacancies so please don't hesitate to ring and check.

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.

Happy New Year!

As I type this report, both houses are busy with members enjoying the beautiful weather we are having at the moment.

We have made a few improvements to the Yarrowonga house, one being a new mattress for the bed in the dialysis room.

I must thank Maureen and Ken Cook for installing our new front door and staining it for us (see photo below). They also provided a beautiful new toaster, thank you very much.

Beautiful time of year for both houses, so give me a call or leave a message and I will get back to you.

best wishes, Amanda

Rosebud

Vacancies

March 12th onwards

Costs \$200 per week.

Extra guest is \$ 20 per night.

For HOUSE bookings please ring
Rosebud House Secretary

Amanda Pratt

Ph: 9589 4894

Mr Cook admires Yarrowonga Door freshly painted



Yarrowonga

Vacancies

Feb 19th till Feb 26th

Feb 26th till 5th March

March 12th onwards

Cost is only \$200 per week for you and your immediate family.

Call as we do get vacancies.

Bookings at the Yarrowonga Renal Unit Ph:
5743 8189

For HOUSE bookings please ring
Yarrowonga House Secretary

Amanda Pratt Ph: 989 4894

◆ What did the computer say to the programmer at lunchtime?

Can I have a byte?

◆ Why did the computer sneeze?

Because it had a virus

◆ What is the computer's favourite dance?

Disk-o



**Please Remember
To Take Your Key!**



**Dialysis and Transplant
Association of Victoria Inc.**

**Celebrate 50 years of DATA
28th May 2023**

The **Home Dialysis Association**, now known as **DATA** was formed from a group of dialysis patients and friends at Austin Hospital in May 1973.

1st meeting 3th May 1973

The 1st general meeting of renal patients was held at the Austin Hospital. The suggestion was to form an Association. An Interim Committee was elected, consisting of Dr. Miach, Mr. Sutherland, Mrs. Tait, Mr. Thomas & Mr. Millen

2nd meeting 1st July 1973

Recommendations proposed by the committee.

- 1 That the Association be called "Dialysis Patients Association".
2. That the office bearers be, President, Vice President, Secretary and Treasurer and 5 committee members.
- 3 That the meeting place should be at Austin Hospital.
4. That a sub-committee be appointed to prepare a draft constitution.
5. That each meeting should have a guest speaker.
6. That membership fees should be:

PATIENT (NON PENSIONER)	\$2.00 p.a.
PENSIONER PATIENT	50c p.a.
FRIENDS & RELATIVES	\$1.00 p.a.



Dialysis machine in the 1970's

That was the beginning of DATA. It has come along way since 1973. Initially lots of people attended the meetings. There was a guest speaker at each meeting. The constitution was adopted. Dialysis patients from other hospitals joined the Association.

On Sunday 28th May 2023, DATA will celebrate 50 years. A presentation on the history of DATA will be held at 79 Mahoneys Rd. Forest Hill. There will be a guest speaker. Come and join the party. Find out how dialysis has changed in 50 years. There are sure to be surprises. Afternoon tea will be provided.

Angela Lindsey



Ron Jones Educational Awards



These awards offer a fantastic opportunity for students between school years 6 to 11, to shine.

Applications for the Ron Jones Educational Awards, are now open, so fill out your Application form below for a chance to win fabulous prize money.

Assessment is based on the Applicant's school reports together with essay on the topic of 'My Chosen Career'.

There are two levels of Awards to be won. One Award is based on excellence and scholastic ability plus three Awards for encouragement.

The Ron Jones Educational Awards honour the memory of a founder and long time dedicated worker for DATA, Mr Ronald N Jones, AOM.

- • • • • Applications must include a handwritten essay of 300 words entitled 'MY CHOSEN CAREER'.
- • • • • Please include the Applicant's previous year's school reports.
- • • • • Applications must be received no later than **30 June 2023**. Winners will receive

Please fill in this form using Block Letters and forward it to:

The Secretary, DATA Vic Inc, PO Box 159, FOREST HILL Vic 3131

SURNAME GIVEN NAMES

ADDRESS

POST CODE DATE OF BIRTH

HOME PHONE MOBILE

PARENTS / MEMBERS PARTICULARS

(IF APPLICANT MEMBER IS UNDER 18 OR A CHILD OF A MEMBER)

SURNAME GIVEN NAMES

ADDRESS

POST CODE PHONE MOBILE

SIGNATURE OF STUDENT

SIGNATURE OF PARENT

Financial Member of D.A.T.A. YES NO

MY ESSAY ON "MY CHOSEN CAREER" AND SCHOOL REPORTS FOR THE LAST YEAR ARE ENCLOSED.

YES NO

SCHOOL PARTICULARS:

PRESENT YEAR OF STUDIES

SUBJECTS STUDIED

.....



Family Update from Mark Wolfenden

We're delighted to be able to provide an update from the father of two of our kidney kids plus some great news on a bio artificial kidney that the family supports.

Sadly, after two and a half years our eldest son, Sebastian (Seb) lost his transplanted kidney in February of this year. It was very challenging for him, but he's now settled into life on haemodialysis at home extremely well. It did take a few months to learn how to do home haemodialysis, yet thanks to the supervision of his 'second family' of renal nurses who went above and beyond to care for him, he apparently broke all records getting up to speed with the machine and setting it up at home. Seb has adapted well to sleeping with the needles in his fistula, and because it's every other night, and over a longer duration (8 hours), he feels better and more energetic. He has part time work in a post production studio, where they add SFX into films and TV shows. It is a field he loves and has significant future potential, and he got his driver's licence this year too! We're very proud of our Seb, who continues to smile and embrace life fully.

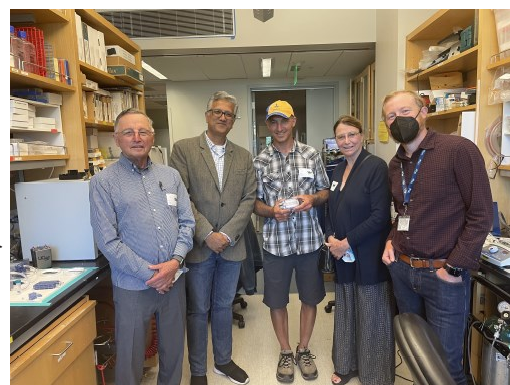
Raph is charging on like a busy home schooled 11 year old – I'm (Mark) his math teacher, and Emily (his mother) language arts -we follow an excellent American curriculum. It means Raph's relatively protected from bugs (his kidney function is now down to about 20% and treatment for rejection is high, meaning his immune system is heavily compromised). We're able to get away in the caravan in term time too, which is pretty cool. We've just returned from the Grampians where he completed a Bear Grylls survival course (don't panic, it was age appropriate – although he would happily fight a bear). He's got tons of social contact with cricket, tennis, sailing and a bunch of great kids in our neighbourhood. Raph is a real delight and doing well.

Kidney Project news. My Uncle Neil, Aunty Louise, and cousin, Eric Paton went to see Dr Shuvo Roy and team at UCSF to view the lab and check out the bio-artificial kidney (photo below- Eric is holding a prototype, Dr Roy is in the grey jacket, Neil & Louise are either side and Bo, one of the UCSF team, is on the far right. Both Neil and Eric have backgrounds in material technology (before retirement Neil was a top scientist with NASA and Rockwell; best known as one of the designers and engineers of the tile for the space shuttle and Eric lectures at the local university in San Luis Obispo on material). In italics below is Neil's summary of the lab visit.

In terms of funding, as a group of family and friends, we've managed to raise almost \$35,000 AUD so far. This is truly incredible, and we are so grateful for everyone's ongoing support. As Neil says in his summary below 'The clinical trial phase is expensive and time consuming.' Nevertheless, Dr Roy remains 100% committed to the project and we remain committed to help him and his team.

From Neil: As you know we visited UCSF yesterday and spent over an hour talking to Dr Roy and his team working on the Kidney Project. Dr Roy was very friendly and open about the project, and was clearly excited about the progress being made. The artificial Kidney they are developing consists of two chambers. A primary chamber with a silicon filter and a secondary chamber containing cultured live kidney cells.

The silicon filter in the primary chamber consists of an array of 10 nanometer pores spaced 400 nanometers apart etched into a thin silicon wafer, using photolithography methods developed by the semiconductor chip industry. In testing the filter works well but the spacing between the pores needs to be reduced to improve the efficiency. Current efforts include improving the packaging and refining the filter design. A prototype of the artificial kidney was tested in a pig about a year ago, and the next step is to run more extensive tests of the improved design in several pigs. According to Dr Roy, clinical trials in humans are at least three years away, but this will require a significant increase in funding levels..



Editors note: Thank you Mark for this interesting story. Keep us posted..

If you are interested in knowing more or donating please contact Mark on email, markdwolfenden@gmail.com



INAUGURAL TERTIARY SCHOLARSHIP RECIPIENT Maryam Rezakhani



My name is Maryam Rezakhani. I am currently employed by Austin Health as a registered nurse in 7 North (renal ward). I started my nursing career as an Austin Health graduate nurse in 2020 and I have been fortunate to have a permanent nursing position in 7 North since November 2021.

It is a tremendous honour to be the recipient of [The Sue Hatzimichalis Postgraduate renal nursing scholarship](#) for 2023 and I am extremely grateful for scholarship panel for providing

me with such an amazing opportunity.

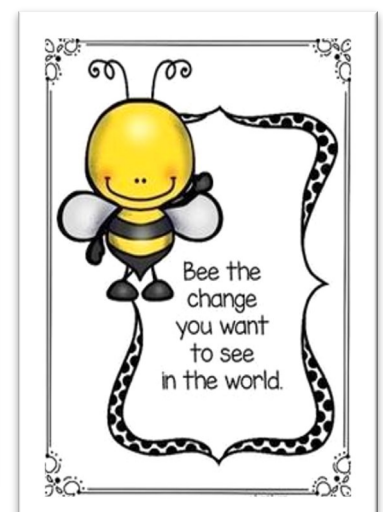
I have a bachelor's degree in engineering and a master's in education and worked in the engineering and education fields for few years before immigrating to Australia. I have always had passion for medical related fields especially nursing. Therefore, changing career to nursing when an opportunity came up was not a hard decision.

I first became interested in renal nursing during my undergraduate degree when I picked up a renal related issue and conducted comprehensive research about renal transplant as a social determinant of health in my home country. My passion for renal nursing has continued to grow immensely while working in 7 North dealing with high acuity renal cases which motivated me to

pursue renal nursing speciality.

Having this valuable scholarship helps me overcome financial burden and enables me to obtain postgraduate education I would not have access to otherwise. This is a fantastic opportunity to gain necessary knowledge and skills to further advance my renal career and play a more active role in providing a holistic patient care and patient education in our ward. I believe having more nurses equipped with postgraduate education is associated with improved patient self-care and overall better health outcomes. This scholarship prepares nurses like me for ever-increasing workplace challenges, The Sue Hatzimichalis prepares me for the future!

Maryam Rezakhani





INAUGURAL TERTIARY SCHOLARSHIP RECIPIENT Kate Gayle

Introducing Kate Gayle – Recipient of the 2023 Sue Hatzimichalis Post-graduate Renal Nursing Scholarship for Grampians Health Dialysis Unit Nurse

I would like to introduce myself to the DATA and members. My name is Kate and I am a Clinical Nurse Specialist in the dialysis unit, I am also the wife of a fellow hospital shift worker and we're raising 2 teenagers. My hobbies include running around after teenagers, cooking, baking and decorating cakes, sewing, keeping healthy and making outdated pop culture references that make teenagers cringe, I particularly enjoy the last. I started my nursing career as a mature aged student, so I have only been working in the dialysis unit for 8 years. I was on the casual bank during my first year of nursing and enjoyed it so much that when permanent hours became available, I jumped at the opportunity. I really enjoy working in the

dialysis unit, the staff are fantastic and so knowledgeable, and you get to build a rapport with your patients that you can't do in most



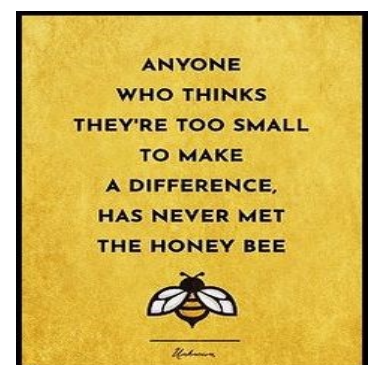
other areas of nursing.

A few years ago, I was involved in the restructure of our unit to introduce nocturnal dialysis and I worked the night shift permanently for the almost 4 years that it was running. Night shift was a great challenge made even more interesting by the addition of a pandemic. However, now our unit has

restructured again, and we have 3-day shifts running, so it's back to the daylight hours for me! Now that my challenge had ended, I wasn't sure what my new one would be, that was until the scholarship opportunity presented itself. This was a light bulb moment for me. I hadn't thought about the education possibilities that were available for renal studies, yet now I have looked, there are so many! I now look forward to starting my new challenge and I want to thank DATA for the generous scholarship that has opened this door and given me a direction that I didn't know I could go in.

I am now enrolled in the University of Tasmania to complete my post graduate certificate in renal studies. I look forward to touching base with you all throughout the course to let you know how I'm going and what I've learned.

Kate Gayle





Q Train Outing December 2022

Well! just getting to Docklands ferry terminal was the hard part, but the rest of the day was easy and very enjoyable.

Ferry ride to Portarlington was wonderful and relaxing, then the bus trip to Queenscliff. which took about twenty minutes.

Q Train was waiting at the station for us as we got off the bus. We had a carriage to ourselves all set up as a restaurant with seating for four at

each table and some tables were just two seats. The meal was served – all six courses, just small serves over several hours, but we didn't notice the time passing.

I believe we all enjoyed the ride and the food was lovely and the scenery was great. I took some great photos The stop halfway where we got off the train for a stretch and watched the train pass and got a photo or video of it pass-

ing by.

The forty people who enjoyed the outing would like thank Angela Lindsey for her dedication and organising the day out.

Angela has now taken over as Secretary of DATA. There will be new people doing the social events so look out for them in 2023.

Darren Hennessy, Events Team





COMING EVENTS 2023

Welcome everyone to Social Events for 2023.

The new Social Committee has now been formed. Darren Hennessey & Nicole Pearce with the help of Neane Collis & Michelle Thevenet have been working hard, checking out new venues and activities for DATA to attend in 2023. The new Social Committee would like to say a big thank you to Angela Lindsey for all her dedication during the last few years.

2023 Events are now ready

Sunday February 26th 12pm BBQ at Rosebud Holiday House. See page 1 for details.

ALL dates subject to change and will be confirmed closer to the time.

PLEASE NOTE: - Those of us who have seen on Facebook and Web that we were going to Boneo Discovery Park, please note that has now been changed to November.

There will be no events in March as it will be one year since we lost Sue Hatzimichalis.

As there are five Sundays in April we will have 2 events

April 2nd Tour of The Shrine of Remembrance in the city

April 23rd Barefoot Lawn Bowls at Altona

May 28th Celebrating DATA's 50 Anniversary at Forest Hill

June 25th Either or Both, Melbourne Exhibition Building and Melbourne Museum

July 23rd Christmas in July will be held at Brian & Michele's place near Ballarat

August 27 Chocolaterie In Yarra Glen

September 24th RAAF Museum Point Cook

October 18th coffee & Cake (Somewhere)

October 22th DATA AGM

November 2nd Coffee & Cake (Somewhere)

November 26th Boneo Discovery Park

More information about the coming events will be in Shoestring, Facebook & Website.

We are always looking for new ideas .If anyone has been to an interesting venue please let us know and we will check it out and see if we can include it for this year's events or 2024. Email us at info@datavic.org or ring 9894 0377



We Have a Facebook page:

DATA – Dialysis and Transplant Association of Vic Inc please like or follow our page

which links into our website: datavic.org

If anyone can help us with website that would be good. Would like some help. DARREN HENNESSEY

Three sisters age 92, 94 and 96 live in a house 🤗
 together. One night the 96 year old draws a bath, puts her foot in and pauses. She yells down the stairs, "Was I getting in or out of the bath?" The 94 year old yells back, "I don't know, I'll come up and see." She starts up the stairs and pauses, then she yells, "Was I going up the stairs or coming down?" The 92 year old was sitting at the kitchen table having tea listening to her sisters. She shakes her head and says, "I sure hope I never get that forgetful." She knocks on wood for good measure. She then yells, "I'll come up and help both of you as soon as I see who's at the door." ★''*•♪•Pass it on!! Give someone else a reason to smile. ♪ ..*★





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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. Vic. Inc.

DEADLINE FOR NEXT ISSUE 03 March 2023

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 event.

We own and run two holiday homes for use by our members— One is at Yarrawonga, the other at Rosebud.



'ShoeString' denotes the feeling of life when it is turned up-side-down and that, with Kidney failure, Dialysis or Transplant, you sometimes have to pull yourself up by the shoe strings to get going.



From The Editors

CONTACT US ON EMAIL: editor.shoestring@gmail.com

Happy New Year to one and all ,

Wishing you all the best for 2023 AND IF THAT HASN'T WORKED SO FAR Come and join us on our social outings. Or we can also offer you work on Shoe String Committee, learning on the job. What about helping with packing and posting Shoe String, that only happens 6 times a year.

Plenty of vacancies on DATA Committee, or Social outings Committee. You will never be lonely.

We welcome the new committee for Social Events. They are Darren Hennessey, Nicole Pearce, and Neane Collis.

Please give them your full support. If you think you could do better , come and join them .

How are all those new Kidneys going ? I heard about a few last year - drop us a line and tell us all about it ; the good news and the not so good. It's certainly not all 'plain sailing' - is it?

We wish you all a happy, healthy, and enjoyable 2023.

Cheers Joan Eastwood