Shoe String

Newsletter for the Dialysis and Transplant Association of Victoria Inc.

Holiday in Rosebud

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Editor’s note

It’s time to embrace the digital world

Exciting news for DATA and Members — we are looking into having a much stronger online presence.

We currently have a DATA website which is being revised and completely updated - so stay tuned. We also have a representation on Facebook.

Taking full advantage of any form of digital media, in this case, email, offers a fantastic opportunity for the reader to keep up to date and learn about events as they happen and future events.

The other ways we can benefit from sending out information via email is to let you know any news about our holiday houses, reminders of upcoming social events, news articles, meetings and discussions, our Ron Jones Awards and the outcomes and sharing members stories and photos.

We would love your feedback:

• Do you like the idea of getting information from DATA via email? Please note, we will not be bombarding you with daily emails and there is always the option to say no.

• Would you like to receive our ShoeString newsletter via email? Please note, we will not be stopping our printed newsletter.

• Do you look at our website?

• Do we have your current email address?

Cheers Trudy

Visit our website at www.datavic.org

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

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.

DON’T FORGET YOUR FLU SHOT

DON’T LET IT GO INTO WINTER. GO TO YOUR GP NOW!
Hi everyone,

How was your Easter? Hope you didn’t eat too much chocolate bunnies like me! Never mind, it was very nice. What do they say... ‘a few seconds on the lips and forever on the hips’ or something like that! I’ll make a conscious effort not to look too much at my hips and I won’t notice, right?

My team - Ashton, Grant and myself, learnt an interesting fact about the game...you have to throw the bowl straight so it makes it down to the other end and it doesn’t curve and go into the other teams side making it a ‘dead’ ball that doesn’t count. If it did count, we would have been the champions of the day!!

In May, the Altona group are going out for Lunch at Pier 35 Bar & Grill in Port Melbourne and DATA is subsidising the cost of the Express Lunch Menu meal at $14 per person. Sounds like a great day, so please attend if you can - see details on page 10.

If you think of anything else you would like to do just let us know and we will investigate it and hopefully make it come true.

Save the date for our Christmas in July on Saturday 22 July - always a fun night with food, trivia, prizes and Chrissy treats!

Don’t forget the Ron Jones Educational Awards. The closing date for entries is June 30, 2017. Application form can be found on page 8 in this issue.

And like all good annual events, your DATA Subscription is due July 1 and forms will be with the next issue.

Anyway, as winter closes in on us keep well, get your “Flu Shot” (if you haven’t already) and stay well!

Until next time

Sue Hatzimichalis
0412 469738

We’ve had a very busy social calendar lately and you can read all about them in the pages to come.

We had a beautiful ‘warm’ day at the Caribbean Market and Gardens in March. DATA paid for entry and a ride, so some went on the train, some on the chair lift, others played mini golf. I went on the train around the gardens and found it very difficult to eat my ice cone as the train rattled and shook around the park but other than that, it was a fun ride.

DATA’s next outing was barefoot bowls at the Altona Bowling Club in late March, where we all learnt the art of lawn bowling. Those who attended all agreed it was a fantastic event.

Very easy for those who don’t play Ten Pin Bowling ‘as they don’t tend to throw the ball down an alley at a speed of 100kh (only joking) to knock over the pins!’ With lawn bowls, you had to be gentle but not too gentle at the same time to get the ball down the other end as close as you can to the ‘Jack’.
DATA’s Rosebud Holiday House is a modern 3 bedroom house which sleeps five people. It has air conditioning and colour TV’s in the living and dialysis rooms. The outdoor area with BBQ and furniture, is perfect for dining and entertaining. Rosebud beach is only a 10 minute walk away and there are art galleries, cinemas, the RSL and fabulous restaurants all close by.

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 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.

Rosebud is a lovely family oriented holiday destination providing safe swimming beaches along its continuous stretch of sandy bay coastline, with the focal point being Rosebud Pier which extends about 300 metres into the water and now with the new Rosebud Foreshore Playground, the kids will love it, the parents will love it too. Most of the area between the coastal route of Point Nepean Road and the beach consists of community facilities, parkland and camping areas within sections of bushland. Rosebud has plenty of sporting activities for visitors, including several golf courses, lawn bowls, fishing and tennis. Rosebud is also home to several large sports reserves.

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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.
Visit to Baxter Warehouse

Those of us on dialysis know there is a large network of people keeping us alive. In early March, I had an opportunity to meet a group of people in that network that most of us give little thought to. Staff at the Austin Health Home Therapies Unit had been invited to a tour of the Baxter facility in Brunswick to meet warehouse staff involved in the supply of dialysis consumables. I was one of 2 home dialysis patients who had also been invited to talk about our condition and experience of being on home dialysis.

We arrived at 10:00 am and were greeted by Lisa who gave us some background into the Baxter facility and explained how the tour would be conducted. We then made our way into the warehouse to meet Scott and the warehouse staff. Sally, who is on PD, spoke to the gathering and then it was my turn. We each explained the circumstances that led to our renal failure and both of us were able to share anecdotes about the Baxter drivers who delivered our stock. We both praised the drivers who were always helpful and friendly.

Scott gave us an overview of how the warehouse operated. He explained that the items for each day’s delivery were gathered in bulk from the extensive array of shelves and stacked in a sorting area. From there, each patient’s items were selected and loaded onto separate pallets for dispatch. Whilst the routine is very manual, it is designed to minimise errors and ensure each patient gets the correct items in their delivery. Stock is dispatched from the warehouse to home dialysis patients and renal units across Victoria. PD patients get a delivery each month and HD patients get a delivery every 2 months.

Baxter are very active in recycling. There are large bins throughout the warehouse for collecting waste cardboard and various items of plastic packaging. A program has been set up to retrieve cardboard boxes and some plastic items from home PD patients. Patients who wish to participate in the scheme are supplied with small bins for various waste plastics such as the outer bags of their dialysis fluids. The filled bins are collected by the Baxter drivers during their delivery runs. The drivers also pick up empty cardboard boxes.

Before leaving the facility, we had a quick tour of the pharmacy that is located on the same site. It was unlike any other pharmacy I had seen. With people in pressure controlled laboratories and clad in disposable coveralls, safety glasses and face masks, it was like a scene from a forensic TV series.

The visit was a great opportunity for me to get insight into another aspect of my renal care and I thank Baxter and the Austin HTU for inviting me.

Ros Ball

DonateLife VIC Service of Remembrance

Sunday 28th May
2.30 - doors open 1.30
140 Hoddle St
Abbottsford

The DonateLife Services of Remembrance are held in recognition of all those who have been part of the organ and tissue donation and transplant journey. See more at: www.donatelife.gov.au/news-events
I attended the Home Dialysers United conference recently, and while I was there, I learned that a lot of people are not aware of the early signs of pending BP drop and what to do if they occur. I would like to address some of the issues around blood pressure on home haemodialysis (HD).

Here is some basic physiology about fluid shifts:

Our bodies contain a lot of water. Most of it, however, is in the interstitial (between the cells) and cellular (inside the cells) spaces. Only about 8-10% of our body water is actually in our blood vessels.

The blood vessels are enclosed in a semi-permeable membrane. This membrane is where the transfer of water and waste products from the cells and interstitial region into the blood vessels takes place.

There is a delay in the time it takes to remove water from the blood and the time it takes for the water to shift into the blood vessels.

When you are removing even small amounts of water during haemodialysis, there may be a point where your body needs to "catch up". The first signs of this can be:

- Yawning
- Visual disturbances
- Feeling tired
- Being just a little short of breath

The reason for these symptoms is quite simple: if your blood does not contain enough water to flow easily, it is no longer transporting oxygen from your lungs to the tissues in a timely manner, including your brain.

So, when you are dialysing away and find yourself yawning, or feeling vaguely tired, you might pause your UF for a few minutes. This may prevent you from having to give yourself saline boluses (which is counterproductive to needing to take fluid off). It definitely may prevent you from having your blood pressure drop and having an emergent problem develop. As you know, most of you finish UF before your dialysis is finished, so pausing your UF for a few minutes (10 min) should not make a difference in how long you are dialysing.

If you ALWAYS have hypotension during dialysis, you might, also, just pause your UF about halfway through your treatment to allow your body to return to homeostasis. (Of course, always let your nephrologist know of anything you are doing during dialysis.)

Please note: feeling light headed/dizzy is also a symptom.

This blog post is courtesy of the ‘Home Dialysis Central’ an American website and written by Gale Schulke, RN, CDN.

SAVE THE DATE
Greyhounds Entertainment
Saturday 22 July at 6.00pm.
It includes a 3 course Christmas dinner, trivia & raffle.
$20.00 per person.
What does phosphate do?

Phosphate and calcium helps give bones much of their strength. Extra phosphate in the blood is removed via the kidneys, and this process can fail when kidneys do not work.

The parathyroid gland helps control the balance of the phosphate and calcium in your blood, by the production of the parathyroid hormone. With renal disease the parathyroid gland can produce more parathyroid hormone than the body requires, and if this continues surgery is required to remove a large amount of the parathyroid gland which is in the neck.

High phosphate in the blood can lead to itching, Red Eyes, Bone Pain, Bone Fractures, and Soft Tissue Damage.

Phosphate and calcium influence each other in the blood. High phosphate “pulls” calcium from the bones, resulting in the bones becoming weak and breaking. The calcium will leak into the blood and can be deposited into the heart and blood vessels. This is called calcification, and can lead to having heart disease.

To help control phosphate, medication called phosphate binders may be prescribed, stopping the phosphate from getting into your blood. These phosphate binders MUST BE TAKEN WITH MEALS. This means the phosphate binders will “soak up” the phosphate from the food that is eaten, and be removed through the normal bowel movement each day. Regular blood tests will make sure your medications are correct.

Phosphate binders are Caltrate; Cal-Sup; Renagel; Sensipar and Alutabs.

**MOST FOOD CONTAIN PHOSPHATE BUT THESE ARE FOODS HIGH IN PHOSPHATE**

- Dairy products including yogurt, cheese, ice-cream, milk
- Meat, legumes, poultry, fish and eggs
- Wholemeal and cocoa products including bran, wholemeal bread, roasted peanuts, peanut butter
- Cola soft drinks, including diet cola

**LOW PHOSPHATE SNACK IDEAS**

<table>
<thead>
<tr>
<th>Food</th>
<th>Phosphorus (mgs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plain dry biscuits</td>
<td>13mg</td>
</tr>
<tr>
<td>Rice crackers</td>
<td>19mg</td>
</tr>
<tr>
<td>Pretzels x 50g</td>
<td>19mgs</td>
</tr>
<tr>
<td>Plain Sweet Biscuits</td>
<td>4mgs</td>
</tr>
<tr>
<td>Wholemeal bread and jam x 1 slice</td>
<td>33mgs</td>
</tr>
<tr>
<td>Danish pastry, doughnut or croissant</td>
<td>27mgs</td>
</tr>
<tr>
<td>Crumpet with honey</td>
<td>22mgs</td>
</tr>
<tr>
<td>Pear</td>
<td>7mgs</td>
</tr>
<tr>
<td>Apple</td>
<td>5mgs</td>
</tr>
<tr>
<td>Orange</td>
<td>20mgs</td>
</tr>
<tr>
<td>Peach</td>
<td>18mgs</td>
</tr>
<tr>
<td>Mandarin x 2</td>
<td>16mgs</td>
</tr>
</tbody>
</table>

Look for phosphate or phosphoric acid on ingredient lists or as an additive 338-343.

Take your binders after a few mouthfuls of your meal or snack.

**REMEMBER**

Be guided by your renal dietician and ask them for more information if required.

What else can you do? Take some walks or exercise regularly (3-4 times a week) to help keep bones strong by keeping the calcium where it is meant to be...in your bones.
Ron Jones Educational Awards

These awards offer a fantastic opportunity for students between years 7 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 and 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 the 30 June 2017. Winners will be notified by mail and receive awards at the AGM in October 2017.
- Please fill in this form using Block Letters.

RON JONES EDUCATIONAL AWARDS APPLICATION FORM

Please complete this form and forward it to:
The Secretary, D.A.T.A. Vic Inc. PO Box 159, FOREST HILL 3131

STUDENT'S DETAILS

SURNAME 
GIVEN NAMES
ADDRESS
POST CODE
DATE OF BIRTH
HOME PHONE
MOBILE
PRESENT YEAR OF SCHOOL
SUBJECTS STUDIED

PARENTS / MEMBERS DETAILS (if Applicant Member is under 18 or a child of a Member)

Financial Member of DATA?
YES ☐ NO ☐

SURNAME 
GIVEN NAMES
ADDRESS or same as Student ☐
POST CODE
HOME PHONE
MOBILE
SIGNATURE OF STUDENT

SIGNATURE OF PARENT

My essay on “MY CHOSEN CAREER” and last years school reports are enclosed.

YES ☐ NO ☐
Shoestring

The Altona Branch of DATA is having their next get together over lunch at 12.00 pm at Pier 35 Bar & Grill in Port Melbourne.

Saturday 27 May
12.00pm
263 - 329 Lorimer St, Port Melbourne
03 9646 0606

RSVP by Wednesday 24 May
Contact George Said
on 0425 753 936

Ethan eyes the prize

KILMORES Ethan Daws has his sights set on the World Transplant Games in Malaga, Spain commencing in June 2017.

The former gold, silver and bronze medallist at the 2013 Games in Durban is keen to return to the days as he represents his country and also all those who have been the lucky recipients of organ donation.

Ethan’s story is an amazing one. Born 12 weeks premature with an under functioning kidney, he was not expected to see his first birthday without a transplant, but a fighting spirit prevailed, seeing him mark his 14th birthday before his father donated his own kidney to Ethan.

The youngster, never one to shy away from a challenge took up competitive swimming at 16 and has never looked back.

Now 20 and studying Agriculture and Business at Latrobe University, working as a lifeguard, and swimming with the Kilmore Swimming Club in multi class events, Ethan still sets a pace even the most able bodied athlete would struggle to keep up with.

He lives every day to the fullest and sets a great example for all transplant recipients on giving back with his ambassador work for Kidney Health Australia and the Make a Wish Foundation.

No matter what I do for these organisations it never feels like enough compared to what they did for me,” Ethan said.

“The simplest message I can get out there is to get kidney checks regularly and that prevention is always better than dealing with problems later.”

Ethan was recently the grateful recipient of a $500 Local Sporting Champs Grant from Member for McEwen Rob Mitchell who is a keen supporter of Ethan and all local athletes.

The Local Sporting Champions program is an Australian Government initiative designed to provide financial assistance for young people aged 12-18 towards the cost of travel, accommodation, uniforms or equipment when competing, coaching or officiating at an official national sporting organisation (NSO) endorsed state, national or international sporting championships or School Sport Australia state or national championships.

“I can thank Rob enough for the grant as every little bit helps,” Ethan said.

“This grant provides a great opportunity for young athletes to get assistance. Sometimes we don’t get to utilise the full quota of funds so athletes are encouraged to apply,” Mr Mitchell said.

Interested parties can contact Mr Mitchell’s office on 9333 0410 with any enquiries.

Ethan’s quest for glory at the World Transplant Games is an expensive one, with flights, accommodation and registration to compete, and it is not always easy for him to chase up funding around his commitments to work, school and training.

He currently has a GoFunme page at www.gofunme.com/International-transplant-games that welcomes donations to see him on his way to Malaga.

In the meantime he has the upcoming Australian Nationals in April to prepare for as he follows his swimming dream.

This article was sent in by Linda & Ethan Daws printed in the North Central & Whittlesea Review / The Press newspaper

Altona Branch lunch meeting

The Altona Branch of DATA is having their next get together over lunch at 12.00 pm at Pier 35 Bar & Grill in Port Melbourne.

Saturday 27 May
12.00pm
263 - 329 Lorimer St, Port Melbourne
03 9646 0606

RSVP by Wednesday 24 May
Contact George Said
on 0425 753 936

EXpress lunch menu

Available 7 Days 11.30am Till 5.30pm

$14.00

Herb & lemon marinated grilled chicken over a pear & rocket salad
Chor grilled calamari salad with red capsicum pesto
Grilled streaky bacon egg, baked potato, salad dressing, chutney, garlic, with a poached egg and scrambled eggs

$16.50

Seafood Spaghetti with market fresh seafood, garlic, chilli, white wine & basil
Chicken & wild mushroom risotto with baby spinach, sundried tomatoes, truffle oil & parmesan
Grilled fish & skinny cut chips with our house salad on a hot zizzle plate
Chor grilled chicken banger with avocado, rocket, tomato, Spanish onion, citrus aioli & skinny cut chips
Moroccan spiced kofta with chor grilled flat bread, Mediterranean salad & cucumber yoghurt

$17.50

Grilled chicken & vegetable skewers with Mediterranean salad, tzatziki & chargrilled pita bread

$18.50

Lamb shank with root vegetables & rosemary infused mash
March 19, 2017 Members’ Picnic at Caribbean Market and Gardens.

Nineteen DATA Members (including Shelby, Jenny Murphy’s granddaughter) attended and enjoyed their time at the Caribbean Market. It was good to see a couple of new members and as always, those who came had a lovely time catching up with each other.

With the DATA banner flying proudly near our rotunda, we gathered to share stories as we lunched together. The day was sunny and had a light breeze which was refreshing as we sat around tables on the lawn area. Everyone took the opportunity to ride the train around the complex and some even tried the cable chair lift across the lake. The birds in the aviaries were entertaining, the mini golf was a laugh (it’s hard not to have a good time) and for the car enthusiast there were many cars on show with people wandering amongst them for a closer look.

Of course, the day wouldn’t be complete without a visit into the market building - walking up and down the isles – a chance to pick up a bargain (or three!) and purchase lovely vegetables/fruit and some cultural treats to take home.

Please consider joining us in our next ‘adventure’.

We know it can be hard to push yourself out the door once you are at home and have completed all your medical requirements for the week but we would like to get to know you and share experiences (future memories) with you and your families/carers.

Vicki Abbetangelo
Dates to remember

Altona Group Lunch
May 27, 2017

Service of Remembrance
May 28, 2017

Christmas in July
July 22, 2017

AGM
October 22, 2017

Check the DATA website for updates to our list of activities.

Some web pages of interest
- www.homedialysis.org/news-and-research/blog
- www.nw kidney.org
- www.peninsulahealth.org.au/
- www.worldkidneyday.org
- www.cari.org.au
- www.australianialysisbuddies.org
- www.green dialysis.org
- www.transplant australia.org.au
- www.bigdandme.wordpress.com

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.

Write to: The Editor, Shoe String
PO Box 159, Forest Hill 3131
Email: editor.shoestring@gmail.com

Visit us at www.datavic.org

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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 12 JUNE 2017