



## September 2022 Newsletter

**Our mission is to provide a supportive and informative environment for people with lung conditions and their carers.**

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**NEXT MEETING:** Thursday 13<sup>th</sup> October 2022  
10:15 am – 12:00 noon  
Weston Creek Labor Club  
Teesdale Close, Stirling ACT 2611

There will be no guest speaker - more time will be devoted to group issues.

### From The Editor

Your editor writes to you refreshed from a road trip to Apollo Bay on the Great Ocean Road in Victoria. It is a beautiful part of the world with its remarkable coastal features and lush rainforests.

As you may be aware your editor - being immune suppressed - has taken a very cautious approach to life through the pandemic. While away he and his wife Dianne kept contact with others to a minimum while enjoying the great outdoors.

Upon his return your editor was asked if he could do a **Zoom session with the first year students from the ANU Medical School** (many of you may recall we used to go to the Medical School to do this face to face). From the comfort of his living room he recounted his transplant journey to a group of students listening online. It was a valuable experience for the medicos of the future.



*Your Editor on a cold day at Gibson Beach on the Great Ocean Road, Victoria*

## September meeting - Helen Cotter

Numbers are still a bit down - for this meeting we had about 14 people.

- Marina reminded us about the **Seniors Expo on Wednesday 28 September** – stall number 122 in the Butterworth Building – and checked that there were sufficient helpers.
- **World COPD Day** is on Wednesday 16 November. We'll talk more about arrangements and helpers at our next meeting.
- Lunch is organised for Friday 23 September 11:45 at **Bella Vista**, Emu Bank, Belconnen.
- Ros Kirk, Palliative Care Manager for Capital Health Network is looking for people with a chronic breathlessness condition to be part of a co-design research team (more details later in this newsletter).
- On Friday 28 October, we are planning a tour of the Botanic Gardens, followed by lunch.
- Next meeting is a discussion meeting.

And then it was on to our speaker to tell us about our **microbiome**.

### Erica Roughton, dietitian at Arthritis ACT *'Food, Mood and Microbiome'*

Erica began with a summary of our digestive system: food starts breaking down in our mouth, then moves down our oesophagus into the stomach, then into the small intestine where it absorbs most of our nutrients. Finally, it enters the large intestine which mainly absorbs water and fluids, creating more solid stools.

The stomach, small and large intestines contain about 3 trillion **microbes and microbiota** (other organisms), together called **microbiota**. Together, they weigh about 2 – 3 kgs. About 60% of our stool is gut bacteria so we need to replenish it every day. Good microbiota contains both a large amount and many different types of bacteria.

We produce between 1 and 4 litres of gas every day. This includes burping and hiccupping. We start to get our microbiota in the womb and this increases as we grow. Eating dirt, worms, bugs etc at an early age all help to add to our microbiota. Antibiotics kill both good and bad bacteria so it's important we replenish the gut bacteria after a session of antibiotics. We can change our gut bacteria over 24 hours, depending on the food we eat.

### Food and Mood

Research has shown that poor diet can change our microbiota, and this can affect our mood. It can:

- activate the inflammatory and immune systems leading to other diseases
- lead to a range of physical and mental problems
- lead to nutritional deficiencies
- lead to diabetes type 2
- lead to gastro-intestinal problems.

Processed and ultra-processed food are as far away from natural foods as could be and increase 'bad' gut bacteria, thereby linking to the issues above.

You need to eat five servings of vegies a day.

These can be frozen or canned vegies as these have good quality. They are snap frozen straight after being picked and so retain their vitamins and minerals.

Vegies include foods like baked beans and chick peas.

## Looking after our microbiome

- **We need to have live bacteria every day** and many are found in fermented foods such as sauerkraut, kimchi, pickled foods, olives, kombucha, apple cider vinegar etc. Cheeses are also a fermented food. If you buy foods like kombucha, make sure they are refrigerated as this keeps the bacteria alive.
- **Limit processed food. Eat more fibre** – fruits, vegies, legumes, chickpeas, nuts, and seeds. This helps increase bowel regularity, is beneficial for blood sugar levels, lowers inflammation and feeds good bacteria in the gut to help promote microbiome growth.
- **Limit alcohol** which can irritate the digestive system. Even moderate drinking increases the risk of bowel and other cancers.
- **Identify and appropriately manage food intolerances** which have effects like irritable bowel syndrome. You can get assistance from an accredited dietitian.
- **Manage stress.** Stress affects digestive health. It causes a decrease in blood flow to the digestive muscles and reduces the digestive enzyme. It also increases the desire for ‘comfort’ food.
- **Regular sleep.** Seven to eight hours is our goal. Poor sleep often leads to increased snacking which is not good for our weight or our microbiome.
- **Stay hydrated.** Insufficient water slows down our digestive system, making it harder to pass our stools. If we feel thirsty, it’s a sign of dehydration. If we don’t particularly like water, we can add fruit, vegies or herbs to change the taste. Or make a huge pot of tea, cool it and drink during the day.
- **Stay active.** This moves the muscles around the digestive system and so moves the food through. Being active helps lower the blood sugar level and assists with the management of inflammation.

Erica concluded by saying that our goal is to have a diverse ecosystem with a large amount and a great variety in the microbes and microbiota that make up your microbiome.

**Editor’s Note:** If like your editor, kombucha sounds as much like a branch of martial arts as it does a food or drink, here is a summary to help you out.

**Kombucha** is an ancient Chinese fermented drink that is made from tea, sugar, and ‘SCOBY’ (Symbiotic Colony of Bacteria and Yeast). It can be homemade, and it is also readily available instore to buy.

### **Our speaker, Erica Roughton, works for Arthritis ACT.**

Arthritis ACT provides many services, including a variety of exercise classes, dietitians, occupational therapists, pain management, hydrotherapy, and support groups.

You don’t have to be a member of Arthritis ACT to do these sessions, but it’s cheaper if you are. Currently it costs \$49 pa to join. They have offices and sessions in both north and south Canberra.

To find out more, contact Arthritis ACT on 1800 011 041, see [www.arthritisact.org.au](http://www.arthritisact.org.au) or email [info@arthritisact.org.au](mailto:info@arthritisact.org.au).

## Visiting the Specialist can have its moments – Chris Moyle

It can be an interesting experience attending a certain specialist’s rooms late in the day in the winter months. Not that it’s cold. The place is pleasantly heated and the chairs are comfortable and appropriately spaced so there’s less likelihood of catching someone else’s germs. It’s quite a cosy atmosphere.

By 5:30 pm receptionist staff have packed up and left for the day and a cleaner or two trickles in. Magazines are no longer available on the central table so you either bring your own, play with your phone or sit and contemplate.

Then, quite suddenly, at sometime around 6:00 pm all lights in the reception and waiting areas go off. No warning or flickering – just a sudden plunge into darkness.

I had forgotten about this on one occasion when I came out of the consulting room and entered the toilet next to the waiting area. I'd just locked the door behind me when – shock, horror – lights went out and it was pitch black in there. Luckily, I wasn't too far in from the door and managed to feel for the latch. In a panic I quickly pushed the door open, almost knocking over the specialist, who was looking for his next patient. One knowledgeable patient who'd experienced it all before calmly located light switches and turned on the toilet light for me. Quite a relief all round.

On another occasion I was waiting when lights went out. The specialist appeared, announcing, 'Mrs Jones', but there was no response so he came closer and with raised voice said, '**Wake up!**' It was good to see she hadn't passed out or died as with a rather startled reaction she opened her eyes and said, 'That reminds me of the Wiggles song.'

Yes indeed. If Geoff Cox had been the patient, dozing off, our specialist could have said, '*Wake up Geoff*' (just as the Wiggles sang '*Wake Up Jeff*') and we could have all jumped up and danced around pointing our fingers a la Wiggles. Or, at this stage of life, imagined dancing around and pointing our fingers.

### **From the Editor** – Geoff Cox

Your editor's children grew up as fans of the Wiggles, so much so that they recently went to Sydney to see the original Wiggles (pictured) do one of their adults shows. Your editor liked them as well - which was a good thing since he spent most of the 1990s and early 2000s listening to them - in the car, in the house and anywhere else that they could be played.



One time when your editor was a young dad, he took the kids to see the Wiggles play at the Seymour Centre in Sydney. Now the seats in the Seymour Centre are actually quite comfortable and despite the rousing music being played your editor drifted off to sleep. Clearly in response to this apparent disinterest in the concert the Wiggles began singing '*Wake up Jeff*' but alas even this couldn't wake him.

**And linking to page 5...** The Wiggles performed *Morningtown Ride* via media link at Judith Durham's Memorial Service. It isn't the first time they have covered the Seekers classic; your editor remembers it well from one of his kids many Wiggles' videos <https://www.youtube.com/watch?v=JlcQ8WrIav0>

## ***'The Carnival is Over'***

Judith Durham 'A Spiritual Journey' - Chris Moyle

In an ABC 'Talking Heads' interview (circa 2012) Judith Durham talked about her lung disease. 'I got measles at four. A side effect of measles, back in those days, before antibiotics or anything, was often bronchiectasis, and I got this remaining cough after my measles. They said they may have to take part of a lung away, but I've been very fortunate.'

Measles can cause bacterial pneumonia, sinusitis and bronchitis which require antibiotics. Otherwise permanent lung damage can occur.

'My cough has never been very easy to juggle with a singing career. I have a degree of control that I value enormously so I don't have to depend on medication. I cough during applause. A lot of people live to a ripe old age with bronchiectasis. I try to eat a certain way – lots of raw food. I'm a vegetarian. Diet helps a fair bit.'

Judith recently died at age 79 – a good innings. Her sister remembers that at age 8 Judith announced that when she grew up she would be famous and sing on lots of stages around the world. Also as a young girl she had her palm read and it was predicted she'd be famous and have a love marriage. All this turned out to be true. After rising to fame singing with The Seekers Judith met and married her husband, the brilliant pianist, Ron Edgeworth. They travelled to a spiritual retreat in India. Judith writes, 'Our path is a path of meditation. The path has been such a very important part of my life with Ron. I believe, if you are ready, you will be brought into contact with a teacher. In that way, it was my destiny to come into contact with Ron and through him, to have found a path that is totally right for me.'

Judith believed in Karma which helped her come to terms with all the things that happened to her. She also managed to let go of anxiety. Her husband, Ron, died of Motor Neurone disease in 1994 and after his death she continued singing, playing piano and composing songs. It had been a wonderful 'love marriage' as predicted.

At her 60<sup>th</sup> birthday concert she sang the lyrics to a melody she'd composed, called 'My Father's Last Words'. The chorus is '*Live your lives kindly and worthy of praise. Remember one day you'll meet God face to face.*' It was sung in a voice as melodic and strong as it was in her 20s. A lovely song sung by a lovely lady.

At Judith's memorial service fellow Seeker, Keith Potger, recalled how she had fought the effects of a lung disease for most of her life, but had forced herself to go onstage night after night to give knockout performances.

Rest in peace Judith.

References - ABC 'Talking Heads' interview circa 2012; and 'The Judith Durham Story: 'Colours of my Life' by Graham Simpson



## A Research Opportunity – Marina Siemionow

I have been contacted by Ros Kirk who has recently been appointed to the Palliative Care Planning Manager at the Capital Health Network and is developing a pilot 'ACT Home Breathlessness Intervention Service'. She is about to begin the co-design of the model of care and would like to have a couple of consumers involved in this process. If you are interested see the details below.

*Note: This is not an endorsement by Canberra Lung Life and any participation is a personal choice.*

**Expression of Interest: Do you live in the Australian Capital Territory (ACT) and have an experience of daily breathlessness from a chronic illness such as COPD or heart failure, or care for someone in this position?**

- We are seeking people with a chronic illness who experience daily breathlessness or their family carers to be part of a co-design research team.
- You would be paid \$59.53 per hour for approximately 16 hours to be a lived experience collaborator.
- The role will entail attending **eight 1.5 to 2 hour Zoom workshops** to plan and co-design a model of care for people experiencing breathlessness alongside researchers and clinicians. You will also be part of co-designing an evaluation strategy. No travel is required – just an internet connection or telephone so you can access Zoom video/tele-conferencing.
- Additional meetings and time will be required for collaboratively reviewing evaluation findings and, if of interest, contributing to a draft publication.
- An interest in research would be welcome but is not essential.

To find out more about the lived experience collaborator role, please contact Capital Health Network's Palliative Care Planning Manager, Ros Kirk on [r.kirk@chnact.org.au](mailto:r.kirk@chnact.org.au) or call 02 6287 8099.

And finally thanks to Val Siemionow we have a photo of our group with speaker Erica Roughton.

