SPRING IS SPRUNG – DE BIRD IS RIZ!

With the arrival of spring there’s more pollen around, causing allergies for many – hay fever and asthma particularly. People with a chronic lung condition may have an allergic component to their condition: stuffy nose, running eyes, a wheeze.

You may find it harder to breathe due to inflammation in the airways – the tubes which connect your nose and throat to the air sacs at the end of the thinnest tubes. With allergy the diameter of the airways narrows, making breathing harder work. Inhaled and oral corticosteroids like Pulmicort and Alvesco puffers and Prednisolone tablets act to prevent inflammation. That’s why they must be taken regularly, according to your doctor’s recommendation.

If you notice an increase in breathlessness, ask your doctor, nurse or pharmacist to check your inhaler technique, and if that’s OK, speak to your doctor.

NEW TO BREATH OF L I F E?

You may not remember joining Lung Information and Friendship for Everyone, the community arm of the Institute for Respiratory Health (formerly LIWA). We’ve recently decided to offer all current community members of the Institute a free subscription to Breath of L I F E, our quarterly magazine. If you’d rather not receive the magazine, please let us know: E life@resphealth.uwa.edu.au. T Jenni 9382 4678 or Dorothy 6151 0849.

Instead of a printed copy, you might like yours delivered by email. If so, please tell us. You can read old issues online at www.resphealth.org.au/news-and-events/publications/breath-of-life. If you received a complimentary copy at a recent function and would like to receive it regularly, please see the membership section on the back page.
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LIFE MEETINGS & EVENTS
LIFE GOES TO LUNCH IN SPRING
B Shed Café, at the front of B shed, Fremantle Port. Opposite Rottnest Express. The cruise liner Sea Princess is expected to be in port nearby.

Thurs 29 Oct from 12 noon

Bookings - please let us know you’re coming so we can arrange enough places. Contact details below.

Getting there - Bus #106 from Busport takes you to Fremantle station, or take the train. Then Red Freo CAT from opposite the Fremantle Train Station gets you to within 100 m. If you need a pickup from the CAT bus arrange beforehand with Sal on 9331 3651.

RSVP by 26 Oct: Sal 9331 3651 Mary 9337 1286 E mvfedele@bigpond.com or Raema T 9349 0617

RECENT MEETINGS
We were delighted to welcome June speaker, Frances Maber. She fell in love with wombats many years ago and has written three children’s books about them, Willit’s Friends, Willit the Wombat Grows up, and Willit the Amazing Wombat. Read more at www.willitthewombat.com. The wombat poem Frances read to us is reproduced later in this issue.

Our July meeting was a workshop on advanced care planning. Possible wording for treatment plans was discussed and circulated as well as blank Advanced Care Directive and Enduring Guardianship forms. Plenty of discussion ensued about this interesting topic. If
you’d like help in working yours out and would like to take part in a study at Sir Charles Gairdner Hospital of the use of advanced care planning contact nurse Siobhan Dormer on T 9346 7947 or E Siobhan.dormer@health.wa.gov.au. If you missed the July session and are interested, ask Jenni for copy of the printed material.

Our **winter lunch** was Christmas in July at the Rod Evans Centre in East Perth. There was live entertainment, a delicious roast dinner and quizzes and raffles. L I F E members walked off with quite a haul of prizes. As we piled into the bus to take us back to the city centre, we must have looked quite a sight. Many were still wearing their Christmas decorations, including Shirley, pictured.

The **August meeting** was a social one and talk we did. It was terrific to have Denise, Tom and Raema back with us. During the meeting Jack and Sal went off to the Institute for Respiratory Health to take part as healthy controls in Svetlana Baltic’s genetics research into idiopathic pulmonary fibrosis and asthma. Thank you to two great volunteers! Instead of the usual jokes session we told stories. Denise’s story of sharing a bed in Melbourne with her best friend and husband was voted the best!

Sal organised another **working bee** before the August meeting and she, Tom and Raema made up blank patient files for use at the Institute’s Clinical Trials Unit, saving much valuable staff time. Thank you! Call Sal on 9331 3651 if you’d like to join in some time.

**NEWS**

**Warm welcome** to new member **Jennifer Campbell** who came to our August meeting. Welcome back to **Denise** who has missed a number of meetings due to ill health but managed to get to our August meeting at last. **Raema** has been away too, after recent neck surgery and **Tom** with a flare-up. We were glad to welcome them all back.

**Farewell Geoff Bicknell**, former leader of SWILS, the support group that meets in Bunbury. Geoff passed away on 1 June. Our thoughts are with his widow Ivy in Harvey and their family.

**Best wishes** to Meagan Shorten, manager of the Clinical Trials Unit at the Institute for Respiratory Health. Meagan, who has previously spoken to L I F E, went on maternity leave on 3 July, expecting her first baby. Best wishes from L I F E. Annalise Vujcich will be taking the reins while Meagan is away.
CHEMO AT HOME

Do you know someone who is undergoing infusions or chemotherapy and finds it hard to get to the hospital? Did you know that this service may be available in your own home? Owned and run by health professionals, covered by most private health funds. And it’s not just for cancer treatments.

Contact Chemo@Home T 9328 3123 or E info@chemoathome.org.au or W http://chemoathome.com.au/about-chemo

HOME VISITING GP

You may have previously heard about the new bulk billing GP services that visit your home. Breath of LIFE wondered why they had suddenly sprung up. Locum services have always been marketed to GPs, not the wider community. Was this the same thing?

A little research suggested both yes and no. About a year ago Medicare changed the rules slightly, in order to allow overseas trained doctors to practice as GPs in Australia, after just one year of supervised Australian hospital practice, compared with four years previously. Remember, these are fully qualified medical practitioners whose overseas training has been recognised by Australian authorities. However the recent change limits these doctors’ practice to overnight, weekends and public holidays. The aim of this policy adjustment was to take the pressure off emergency departments and enable people to see a GP who cannot feasibly use existing after hours GP clinics because of transport or cost.

There have been mixed responses from people who have used one of these services. Some still chose to go to the emergency department later, having been unsatisfied. Others were reasonably happy with the service, your editor included.

How do the services work and when might it be appropriate to call one of these home visiting GP services?

Typically you phone up and provide information like your symptoms, brief
medical history, your name, address, Medicare number, whether there’s a dog etc. You may be told how long it might be before the doctor gets to your home. The waiting time will depend on how busy they are and where you live in relation to their nearest base. If the matter sounds like a medical emergency the service may suggest you call an ambulance or go to a hospital emergency department instead. The doctor will phone just before they get to your home. You’ll have the porch light on, the front gate unlocked and the dog tied up.

The consultation is as brief as many GP consultations, except that this doctor does not have much detail about your medical history. The doctor might suggest you go to the emergency department if this is warranted by your condition. If a prescription is provided you would still have to go to a pharmacy to have it filled.

The kinds of situations when you might call such a service could include:

- You pretty much know what is wrong, as you’ve had this before. You need a prescription soon, before your usual GP is available, e.g. a chest or bladder infection over the weekend.
- You are concerned about a health matter you might go to the GP about, but wonder whether it is serious enough to bother the hospital emergency department, where ED waiting times can be long.
- You think you may have something which requires early intervention, such as shingles, where anti-viral medication must be started within 48 hours of symptoms.
- You need to see a GP – yours is away or you have no transport.
- You are new to Perth or visiting and don’t have a GP.
- Your daughter is worried about your grandchild and cannot get time off work to take the child to a GP during office hours.

Perhaps there are other situations you can suggest?

More
Dial A Doctor 1300 030 030
DoctorsToHome 1800 DOC2HOME (1800 3622 4663)
Perth After Hours Medical Service 1300 000 DOC (1300 000 362)
WADMS 9321 9133 (only bulk bills concession card holders)

Office hours vary across the services, generally from 5 or 6pm until 8am next morning, Mon- Fri; from 11 am or noon on Sat; and 24 hours on public holidays. Available for people with a Medicare or Veterans Affairs card and bulk bill (except for WADMS). Some are on Facebook or on the web - as well as phone.
LUNG EDUCATION DAY

Lung Foundation Australia’s annual education day for Western Australians with lung disease and their families occurred on 14 May at Floreat.

Speakers this year were

- Pharmacist Grant McGill of Kingsley Village Pharmacy, on medication use, interactions and medication reviews. A related article on the wide role of community pharmacists by Kim Watkins appears in this issue.

- Motivational speaker Peter Dhu, on his personal journey and how you too can unlock your hidden potential despite challenging conditions. His four strategies were: Take responsibility; Form good habits; Expand your comfort zone; and Identify your team.

- Respiratory physician at Sir Charles Gairdner Hospital, Dr Fraser Brims, on asbestos, what it is, how it affects the lungs- pleural plaques, asbestosis, mesothelioma and asbestos-related cancer.

Detailed notes of these talks can be found online at Lung Foundation Australia’s website under Patient Education Days. If you missed it this year make sure you are on the Lung Foundation mailing list (free) and you’ll get advanced notice next year. T 1800 654 301.
TALK ON GLOBAL LUNG HEALTH AND AIR POLLUTION

L I F E members are invited to a special talk on lung health and air pollution across the world. Is air pollution as bad for us as smoking? Is the growing economy affecting our health?

The inaugural Philip Thompson Oration, presented by the Institute of Respiratory Health will cover these questions in detail when Emeritus Professor Norbert Berend speaks on Air pollution and lung health – A global problem with special importance for Asia Pacific on Thurs 17 September at 5.30pm.

Professor Phil Thompson, the founding director of the Institute for Respiratory Health says “I am honoured to have Prof Berend, a visiting expert in respiratory health, to be the first speaker at this Oration in my name. His research has global implications and will be of great interest to the respiratory research community in Western Australia and to anyone with an interest in air pollution and its impact on health.”

The Philip Thompson Oration will be held on Thursday 17 September from 5.30 to 6.30pm, followed by drinks and canapés, in the McCusker Auditorium, Harry Perkins Institute of Medical Research, QQ Block, QEII Medical Centre, 6 Verdun Street, Nedlands.

Only 12% of people in the world live in cities which meet WHO air quality standards, and acute effects of air pollution cause those with lung and heart disease to deteriorate, require hospitalisation or even to die. Long term effects include reduction in lung growth of children and adolescents, worsening lung function in adults, cardiovascular disease and lung cancer. It is a global problem, with ambient air pollution in cities and rural areas estimated to cause more than

SHINE A LIGHT ON LUNG CANCER

A small group of people with lung cancer is organising a November event to “Shine a Light”, to bring people together, to share information and knowledge on lung cancer and to hear about new developments.

They are keen to chat with others who have lung cancer, as they recognise how really positive it is to talk to others living with the same experience. As readers know, it helps to reduce the sense of isolation that comes with being ‘the lonely little petunia in an onion patch’.
As Albert Schweitzer said:

"At times our own light goes out and is rekindled by a spark from another person.

Each of us has cause to think with deep gratitude of those who have lighted the flame within us."

Lois, the person initiating this group, relates her own experience with lung cancer, which was diagnosed in October 2013. It was the last thing she was expecting, as the doctor had talked about asthma and straining a muscle in her chest wall. She thought maybe she was in for a dose of pneumonia, as she felt so lousy.

The hardest part, she reported, was hearing that little could be done, as she was at stage 4 of the disease - and there was no stage 5. Her lung tumour - that she’s named ‘Alfred’ - had metastasised to her chest, lymphatic system and pleural cavity.

Lois is asking us all to spread the word so the group can recruit more people with lung cancer to their network, and help get accurate and appropriate information out to the wider community. Take the stigma out of lung cancer.

More Lois T 9381 1308 E gatm@iinet.net.au

**LUNG LAUGHS**

**GARDENING FOR THE HEARING IMPAIRED**

I was working in the garden this weekend and my wife was about to take a shower. I realised that I couldn't find the rake. I yelled up to my wife, "Where is the rake?"

She couldn't hear me and she shouted back, "What?" I pointed to my eye, and then I pointed to my knee and made a raking motion.

Then my wife wasn't sure and said "What?" I repeated the gestures. "Eye - Kneed - The Rake"

My wife replied that she understands and signals back. She first points to her eye, next she points to her left breast, then she points to her backside, and finally to her crotch. Well, there is no way in hell I could even come close to that one.

Exasperated, I went upstairs and asked her, "What the hell was that?" She replies, "Eye - Left Tit - Behind - The Bush".
SENIORS & COMPUTERS

Sometimes we oldies have trouble with our computers. Yesterday, I had a problem, so I called Georgie, the 11 year old next door, whose bedroom looks like Mission Control, and asked him to come over.

Georgie clicked a couple of buttons and solved the problem. As he was walking away, I called after him, 'So, what was wrong?'

He replied, 'It was an ID ten T error.' I didn't want to appear stupid, but nonetheless asked, 'An ID ten T error? What's that? In case I need to fix it again.' Georgie grinned. 'Haven't you ever heard of an ID ten T error before?'

'No,' I replied.

'Write it down,' he said, 'and I think you'll figure it out.'

So I wrote down: ID10T. I used to like Georgie, the little bugger.

Contributed by Mike Watteau, Bentley Bronchiatrix

RESPIRATORY RECIPES

PUMPKIN FRUIT CAKE

500g mixed fruit
1 ½ c brown sugar
1 T golden syrup
125g butter
1 c apricot nectar
1 t bi carb
2 eggs, lightly beaten
1 c cooked pumpkin, mashed and cooled
1 c plain flour, sifted
1 c SR flour, sifted.


From member Jan Maiorana, who brought some to a recent L I F E meeting

PULMONARY POETRY

TO A DARK LADY ON THE INTERNET

Can I believe this email’s really you?
Plucked from the air, downloaded on the screen,
The phrases look familiar. But how true?
How many hackers eavesdrop on our scene?  
While you wrote airmail there was always hope  
The postman might deliver me a note.  
My name in your script on the envelope.  
Your message secret as a ballot vote.  
Then I could read so much into your hand;  
That hesitation – lest you speak your mind  
And let your heart dictate a gesture grand  
To say you love me. Would you were that kind!  
Unsigned immediacy is not the same  
As that dear page you touched that bears my name.

— Basil Johnson

Children’s author Frances Maber shared this poem with us at the June meeting.

**IN PRAISE OF WOMBATS**

The wombat, unlike early birds,  
Spends half the night creating turds.  
It is the most artistic species  
That makes a statement with its faeces

The leaders of each clan claim rights  
To execrate upon the heights  
They neatly balance piles of poo  
On top of rocks. That’s what they do.

The less ambitious leave their droppings  
On tree stumps close to river crossings  
Where left-bank gallants cross the pools  
Admiring right-bank females’ stools.

The little ones lay theirs in rows,  
Less easy than you might suppose.  
It’s darkest night, let me remind,  
They cannot see what’s left behind!

When wombats hold their parliament  
They celebrate their excrement:  
Just listen to that great commotion!  
The cheers that greet each passing motion.

So let us not leave scats unsung,  
Wombats impress us with their dung.

— Basil Johnson, published 2004 ACT U3A Newsletter
POSITIVE+

*Inspiring words, tips and activities to help you stay positive, a vital part of keeping mentally healthy while living with chronic lung disease.*

What we think affects our mood and behaviour. A psychological study asked one group of people to concentrate on ageing and another to concentrate on youth. Amazingly (or not?) the first group took longer to walk down the corridor “after” the experiment than the second. Why would that happen?

What kinds of thoughts slow you down? In your Positive file or exercise book make your own list now.

How could you replace those thoughts with more positive ones?

*For example:* I can’t breathe. I want to sit down. My legs are aching. I hate walking. I’m going to die.

*Replace with:* I’ll breathe as deeply as I can and walk as well as I can. It usually gets better after a few minutes if I just hang in. I’ll give myself a short rest when I’ve got to that spot ahead. I’ve felt like this before and I’m still here.

If we let negative thoughts grab our attention too regularly they may become automatic thoughts. When faced with a similar situation in future, the same negative thoughts seem to come to mind automatically and the emotion linked with them comes too.

Automatic thoughts are harder to replace. It can be done - but requires a bit more practice.

Here’s an example of how to replace an automatic thought with an equally believable alternative thought. Which automatic thoughts bother you? When do they happen? What else could explain the situation?
<table>
<thead>
<tr>
<th>Situation</th>
<th>Emotion</th>
<th>Automatic thought</th>
<th>Alternative thought</th>
</tr>
</thead>
<tbody>
<tr>
<td>A stranger in a café looks my way</td>
<td>Shame, embarrassment</td>
<td>That woman is pitying me, she’s staring at my oxygen cannula</td>
<td>She could be looking at the picture on the wall behind me or looking out for a friend</td>
</tr>
</tbody>
</table>


## SHORTS

**REVISED OXYGEN PRESCRIBING POLICY**

In March 2015 some changes were made to the WA Health policy regarding the prescription of public funded home oxygen to Western Australian adults. This policy had been revised in 2009 and is fairly similar. You may notice it now because some aspects of the policy had not always been followed by all prescribers.

Here is the gist of it:

**Review and Assessment of all Patients**

All patients, prescribed oxygen in hospital, must be reassessed within 6 weeks after initial assessment and when the person is in a stable condition (usually 4-6 weeks) to determine whether ongoing oxygen requirements remain the same. This is because some people may improve to the point they no longer require oxygen.

The requirements outlined in the WA Department of Health Domiciliary Oxygen Prescription Form must be met for the continuation of oxygen therapy at the 6 week review. If the service provider does not receive a revised or confirmed prescription the domiciliary oxygen equipment will be removed from the patient’s home at 8 weeks. All patients will be reviewed annually by the referring medical officer or appropriately trained health professional with medical officer final approval. The clinical guidelines for the review of patients are as per the WA Department of Health Domiciliary Oxygen Prescription Form. Those requiring blood gases or have complex medical needs will be reviewed and assessed by a medical officer.

**Intra State Travel**

All providers will develop a policy and procedures to supply oxygen for eligible patients to travel within WA. This will include the supply for the duration of the
journey to the travel destination and back to the usual residence and supply when residing for prolonged periods away from their usual place of residence. The policy and procedures will include patient information on the prerequisites for access to the service, safe transport and storage of equipment and funding arrangements.

The only people authorised to prescribe oxygen to people outside hospitals are: respiratory physicians, geriatricians, cardiologists, general physicians and palliative care physicians or officers.

More The full details can be read at www.health.wa.gov.au/circularsnew/circular.cfm?Circ_ID=13238

HELP TO STAY INDEPENDENT

Like most people you are probably trying to stay independent as long as possible. If things are starting to get you down a bit, have you thought about getting a bit more help? Have your support needs changed recently? You might just need some temporary help after an infection, flare-up or surgery. Commonwealth Respite and Carelink Services offer advice about services in your area, both paid and subsidised. As the title suggests, they also advise on assistance or a break for your (unpaid) carer.

One phone number from anywhere in Australia gets you directly to an advisor in your area. Smart use of technology. T 1800 052 222 (free call except from mobiles) W New website www.myagedcare.gov.au which covers information about:

- What help is available?
- Help at home
- Aged care homes
- Caring for someone
- Find a Service (links to Commonwealth Respite and Carelink Services)

It is good to have a current Aged Care Assessment (ACAT) if appropriate, so you can tell the advisor what you are eligible for. Speak to your GP about getting an ACAT Assessment.

If you are aware of the Independent Living Centre at the Niche building, on the grounds of QEII (beside Charlie’s), you’ll know about the wide range of aids and equipment displayed all in one place, and how you can get advice from qualified occupational therapists, rather than salespeople. Well, if you live in the south west metropolitan area there’s a satellite Independent Living Centre setting up
at Cockburn Integrated Health and Community Facility (wow, that’s quite a mouthful). To start from 1 July.

This new facility will house the assistive technology service, Aged Care Assessment Teams, the Cockburn GP Superclinic, and more. It’ll all be at 11 Wentworth Parade, Success, next to Cockburn Gateway Shopping City, the rapidly developing Cockburn Central retail, commercial and residential precinct. Near to Cockburn Central train station and Kwinana Freeway.

Find out more from the ILC website http://ilc.com.au or T 1300 885 886.

Thanks to Jo Cockram for drawing our attention to these items.

PHYSICAL ACTIVITY PATTERNS OVER THREE YEARS

A German study of the physical activity levels of people with COPD was tracked over three years. It found that people with COPD became less and less physically active, whatever the severity of their lung condition at the start. Their lung function and health status showed a corresponding decline.

The less active they were, the more difficult they found it to exercise, the worse their lung function and the more their muscles wasted. This would seem rather obvious, but apparently had not been systematically studied before.

But what was cause and what was effect? Do we become more inactive because of physical changes in our lungs and muscles which make it harder to exercise, or do these physical changes occur because we exercise less? Or is it a bit of each? Past studies had established the link between decreased physical activity, and the increased likelihood of hospitalisation and death.

To try to tease out the difference, researchers followed a group of 163 people with COPD forward in time, rather than just taking a cross section of people and looking at the correlation between activity levels and disease markers. Physical activity was measured by a pedometer in steps/day, energy spent in kilocalories and by a standard physical activity questionnaire. Lung disease severity was measured by a standard symptom checklist and lung function test (FEV1).
Exercise capacity was assessed by the 6-minute walk test and muscle mass, by fat-free body mass.

“Treatment guidelines call for regular physical activity for COPD patients at all levels of severity, and our study clearly supports this recommendation,” said Dr. Benjamin Waschki, of the Pulmonary Research Institute at Lungen Clinic, Grosshansdorf, Germany. “Regular exercise will improve their health and quality of life.”

Source Waschki, Benjamin et al. Physical Activity Decreases Over Time at All Levels of COPD Severity Am J Respir Crit Care Med. First published online 28 May 2015 as DOI: 10.1164/rccm.201501-0081OC and cited in DG News

EARLY SIGNS OF PULMONARY HYPERTENSION

People with (idiopathic\(^1\)) pulmonary arterial hypertension have raised blood pressure inside the blood vessels in their lungs, severely disrupting the exchange of oxygen and carbon dioxide across the thin skin of the alveoli. They may be frustrated by the long time it can take to be diagnosed with this fairly uncommon disease. This study attempts to discover what might be the earliest signs of pulmonary hypertension.

Given the difficulty of diagnosing early-stage pulmonary arterial hypertension (PAH) due to the lack of signs and symptoms, and the risk of an open lung biopsy, the precise pathological features of pre-symptomatic stage lung tissue remain unknown. It has been suggested that the maximum rise in the average pulmonary arterial pressure is achieved during the early symptomatic stage, indicating that the rise is mainly driven by the pulmonary vascular tone and/or some degree of pulmonary vascular remodelling\(^2\) completed during this stage.

Recently, the examination of a rat model of severe PAH suggested that the severe PAH may be primarily determined by the presence of lesions inside the blood vessels and/or the vascular tone\(^3\) in the early stage. Human data seem to indicate that interior vessel lesions are essential for the severely increased pulmonary arterial blood pressure in the late stage of the disease.

However, many questions remain. For instance, how does the pulmonary haemodynamics\(^4\) change during the course of the disease, and what drives the

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1 Idiopathic pulmonary hypertension means the condition is of unknown cause, and not caused by another condition like sarcoidosis or fibrosis.
2 Vascular remodelling means alteration in the structure of resistance vessels contributing to raised systemic vascular resistance in hypertension.
3 Vascular tone reflects the relative degree of contraction or relaxation of the blood vessels in the lungs.
4 Haemodynamics means the blood flow, motion and equilibrium under the action of external forces.
development of severe PAH? Although it is generally acknowledged that both pulmonary vascular remodelling and the vascular tone are important determinants of an elevated pulmonary arterial pressure, which is the root cause of the time-dependent progression of the disease? This joint Japanese and American study reviewed the recent histopathological concepts of PAH with respect to the progression of the lung vascular disease.


EATING NUTS IMPROVES LONGEVITY

Nuts and peanuts - but not peanut butter - may protect you against death from cancer, heart disease, respiratory disease and other major causes, new study finds. A paper published in the International Journal of Epidemiology confirms a link between peanut and nut intake and lower mortality rates, but finds no protective effect for peanut butter. Men and women who eat at least 10 grams of nuts or peanuts per day have a lower risk of dying from several major causes of death, compared with people who don't consume nuts or peanuts.

The reduction in mortality was strongest for respiratory disease, neurodegenerative disease (such as dementia, motor neuron disease and Parkinson’s disease) and diabetes, followed by cancer and cardiovascular diseases. The effects are equal in men and women. Peanuts show at least as strong reductions in mortality as tree nuts (like almonds and walnuts), but peanut butter is not associated with mortality, researchers from Maastricht University (the Netherlands) found. They studied 120,000 people aged 55-69 years old.

Peanuts and tree nuts both contain various compounds such as monounsaturated and polyunsaturated fatty acids, various vitamins, fibre, antioxidants, and other bioactive compounds, that possibly contribute to the lower death rates. In contrast no association was found between peanut butter intake and mortality risk. But peanut butter also contains added components like salt and vegetable oils. In the past, it has been shown that peanut butter contains trans fatty acids. The composition of peanut butter is therefore
different from peanuts. The adverse health effects of salt and trans-fatty acids could inhibit the protective effects of the peanuts in peanut butter.

Source: *Daily consumption of nuts and peanuts linked to lower mortality rates, part of Netherlands Cohort Study, 11 June 2015* and cited in *Science Daily*

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**LONG TERM EFFECTS OF COMMUNITY-ACQUIRED PNEUMONIA**

*Being a person whose lung condition was caused by a life threatening bout of community-acquired pneumonia, this article caught the editor’s eye.*

Information on the long-term prognosis after community-acquired pneumonia (CAP) is limited. Having had community-acquired pneumonia (CAP) even just once greatly increases the risk of long-term hospitalisation and death compared with those who have never had CAP, according to a study published recently in the American Journal of Respiratory and Critical Care Medicine. This study involved over 6,000 Canadian adults (average age 59) from six hospitals, half of whom were treated for CAP either in hospital or as outpatients.

They were followed up over a number of years when they came to hospital or to an emergency department. Unsurprisingly the difference in rates of hospitalisation and death between having had CAP and having not was largest in older people and smallest in younger people. However the effect was significant at all ages. People who had had CAP were significantly more likely to be hospitalised, than those who hadn’t, regardless of cause of hospitalisation, i.e. it was not necessarily respiratory problems that brought them to hospital again.

Source: *Eurich, Dean T et al., Ten Year Mortality Following Community Acquired Pneumonia: A Prospective Cohort, Am J Respir Crit Care Med. First published online 11 Jun 2015 as DOI: 10.1164/rccm.201501-0140OC*

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**NEW GUIDELINES FOR IDIOPATHIC PULMONARY FIBROSIS**

Updated guidelines on the treatment of idiopathic pulmonary fibrosis (IPF) have been released by an international group of leading respiratory societies. The new guidelines, issued by the American Thoracic Society, the European Respiratory Society, the Japanese Respiratory Society, and the Latin American Thoracic Association, were published in July 2015 in the Journal of Respiratory and Critical Care Medicine.

“In these updated guidelines, we analysed new evidence reported since our 2011 guideline was issued and updated our treatment recommendations accordingly,” said Ganesh Raghu, MD, University of Washington, Seattle, Washington. “The updated guidelines do not recommend one treatment regimen over another. All of these recommendations must be weighed individually, considering all the factors used to grade each one, including the
confidence in effect estimates, evidence from outcomes studies, desirable and undesirable consequences of treatment, treatment costs, the implications of treatment on health equity, and the feasibility of treatment.”

Evidence was assessed using the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach, with recommendations rated as either “strong” or “conditional.” Conditional recommendations are synonymous with weak recommendations.

The following recommendations are new or revised from the 2011 guidelines:

- The recommendation against the use of the following agents for the treatment of IPF is strong: anticoagulation (warfarin); imatinib; combination prednisone, azathioprine, and N-acetylcysteine; ambrisentan.
- The recommendation for the use of the following agents for the treatment of IPF is conditional: nintedanib and pirfenidone.
- The recommendation against the use of the following agents for the treatment of IPF is conditional: phosphodiesterase-5 inhibitors (sildenafil) and dual endothelin receptor antagonists (macitentan, bosentan).
- Recommendations remaining unchanged from the 2011 guidelines include a conditional recommendation against the use of N-acetylcysteine monotherapy for IPF and a conditional recommendation for the use of antiacid therapy.

“Our systematic review of the available evidence on IPF treatments points to the need for additional research and long-term studies of their safety and efficacy,” said Dr. Raghu. “This is especially true for treatments that received conditional recommendations in the guidelines. The guidelines empower the clinician to make the most appropriate treatment choices for the patient confronted with IPF and encourage shared decision-making with the well informed patient to choose the most appropriate treatment options tailored to the individual patient’s needs.”

SAFETY OF E-CIGARETTES

These battery-powered devices deliver nicotine to the user through a vapour by heating a solution of propylene glycol or vegetable glycerine, flavouring, and other additives. They are sold in many countries with various flavours. But are they safe? How does their safety compare with actually smoking cigarettes or not smoking at all?

E-cigarettes have become increasingly popular in recent years. In 2015, the US Centers for Disease Control and Prevention (CDC) reported that the use of e-cigarette devices among middle school and high school students tripled between 2013 and 2014. That means about 13 percent of students now use them — outstripping the number who smoke conventional cigarettes. By 2017, sales of e-cigarettes in the US are expected to surpass those of conventional cigarettes, reaching $10 billion. The three major tobacco companies, through their buying up of small e-cigarette companies, could share 75 percent of these profits over the next 10 years.

The major appeal of e-cigarettes is that they don’t contain tobacco and the exhaled vapour carries no harmful smoke, tar, or carbon monoxide. They also seem to have significantly fewer toxins and carcinogens than regular cigarettes.

What is known: E-cigarettes are probably better for you than conventional cigarettes, but worse for your health than not smoking or “vaping”5 at all.

What is not known: What the long-term health effects of e-cigarettes are, whether they actually help people quit smoking, and how they’ll affect the use of other nicotine products, such as gum or patches.

What it means for you: If you’re a chronic smoker, e-cigarettes could be a less destructive way to get your nicotine fix. If you don’t currently smoke at all, stay away from vaping; we still have no idea about its long-term health impact.

5 “vaping” is a new word used to describe inhaling an e-cigarette
Source: Vox.com suggested by Jo Cockram, pulmonary physiotherapist

Post script: Are e-cigarette even legal to sell, import or use in Australia? There are no laws specifically regulating electronic cigarettes in Australia. Instead, a number of laws relating to poisons, therapeutic goods and tobacco control apply to electronic cigarettes in some circumstances. This makes the regulation of electronic cigarettes complex. It cannot be briefly summarised here but a good up to date summary is given here and comes from the Quit campaign people.

PRECISION MEDICINE AND LUNG DISEASE

Perhaps you recently saw the BBC TV program What’s the Right Diet for You?, which attempted to divide dieters into different groups in order to devise a specialised weight loss diet for each group, based on their common metabolism, motivation and behaviour. This is an example of precision medicine, a medical model that proposes the customisation of healthcare—with medical decisions, practices, and/or products being tailored to the individual patient. Similarly with cancer, treatments are usually tailored to the precise type of cancer, after testing the genetics of tissue samples. Unsurprisingly pharmaceutical companies are very interested in precision medicine.

A recent key note paper at the Thoracic Society of Australia and New Zealand (WA chapter) alerted Breath of L I F E to the application of a precision medicine approach in understanding and treating lung conditions. The speaker, Prof Peter Gibson, a researcher and respiratory physician at the John Hunter Hospital and Medical Research Institute in Newcastle NSW argued that the idea of asthma being a singular disease was no longer appropriate and that similar arguments could be put for Chronic Obstructive Pulmonary Disease.

Researchers studying cellular and molecular functions of lung diseases have developed tests that discriminate between different elements of a condition. For example, in asthma there is usually a component of narrowing of the airways caused by smooth muscle contraction as well as an inflammatory (swelling) component caused by swelling of the linings of the airways.

Researchers look for biological markers of inflammation and of airways narrowing which can be measured through blood or breath analysis, so clinicians
can work out which type of medication is needed in higher doses to stabilise the asthma. Breathing tests alone are sometimes not effective in identifying these differences. This approach helps explain why some people of a similar age and lung function seem not to function as well as others and why some medications seem to have little to no effect for some.

More

Prof Peter Gibson at Hunter Medical Research Institute
Precision medicine and lung conditions research at the University of Leicester, Institute of Lung Health in England

RED CROSS COMMUNITY SUPPORT SERVICES

(Our April speaker, Bev Wilkins, Manager, Community Care Services, Red Cross, WA)

Red Cross speaker, Bev Wilkins was very informative and gave members a new outlook on the many support services currently provided by Red Cross. In Australia Red Cross was set up in NSW in 1914 under the Geneva Convention. It remains headquartered in NSW with branches in all states. For many of its services it relies on volunteers. (L I F E member June Keane has been one of those tireless volunteers for many years – decades). Here are some of the services you may be interested in:

Telecross - a short daily wellness call especially for those living alone. Even with lung disease perhaps you could be a volunteer for this service. L I F E has had several members take part from home in this services as vollies.

Telechat – a longer social and support call. Currently supported by the Australian Government under the Health and Community Care program (HACC).

Recycling shops

Community visitors scheme – visiting people who are socially isolated at home or in aged care.

Carer support – training, advice and respite services

Food Sense courses at community centres which can especially help those on low incomes, singles and refugees.

Transport to appointments and meetings
Breakfast clubs at schools with support from Coles
Support for families with multi-births (twins, triplets etc) or post natal depression
Soup kitchens in Perth and Fremantle (ask June Keane about this one)
More T 1800 810 710 or 9225 8888

Thanks to Sal for taking these notes

LIVING WITH CYSTIC FIBROSIS

(Our May speaker, Gary Smallacombe)

My name is Gary Smallacombe, I’m 36 years old and I have a condition called Cystic Fibrosis. For those who don't know about Cystic Fibrosis (CF for short), it’s a genetic disorder that mostly affects the lungs.

It’s primarily a defect that affects the salt transfer between cells in the body causing thick sticky mucus to build up. The collection of mucus results in severe lung infections and difficulty breathing, as well as serious digestion issues that require me to have enzyme tablets every time I eat something. Other things that are issues are sinus infections, infertility, and usually poor growth. But not with me! CF affects people differently, and there are some CF people that are in hospital more often than at home, so I’m probably one of the luckier ones.

Currently there is no cure for Cystic Fibrosis, and most of the drugs I take are to combat the symptoms of what the sticky mucus does to the body, mainly to the lungs. Later I will briefly talk about a drug trial that I am currently undertaking that goes further than just treating and managing symptoms.

I was diagnosed with Cystic Fibrosis when I was 18 months old and my parents have said when they were told that they had no idea what CF was, or more importantly how serious a disease it was. I’m not sure if they knew at the time as well, but in the early 80's the average life expectancy of a CF child was around 12 years of age. I grew up in Albany, and from what I remember and what my parents have told me, there was an awful lot of travelling to Perth for appointments at Princess Margaret Hospital - almost every two months, so I’m pretty sick of travelling on Albany Highway. So much so, that when I go down to visit I take the back way through Narrogin to avoid it!

There were also the hospital admissions that I only really remember starting to need once I was 11 or 12 years old, and I'm sure this was pretty tough time for my family to get me to Perth, while still having my sister two years younger than
me, needing to go to school as well. So I feel for my parents - how much they had to manage.

While my parents ensured I was having the tablets, vitamin supplements, nebulized antibiotics, and other treatments I required during my childhood, they didn’t wrap me in cotton wool, and I am very thankful for this. From 11 or 12 I tried to act like any other normal kid. I rode my bike around with friends - slowly compared to them i must add! I went out with friends a lot; and on occasion when it aligned with a hospital visit or check up, I used to attend Cystic Fibrosis Camps.

These were where all the people with Cystic Fibrosis met up and took part in activities that you wouldn't normally do such as abseiling, and other outdoor activities. I got to meet a lot of famous people. One I remember vividly back in the early 90’s was meeting Ricky Grace from the Wildcats, and him taking me for a ride in his Capri convertible – probably a flash car for the time!

Unfortunately later on, they found that these camps were helping the transmission of bugs that can only be transmitted between people with CF, so they were put to a stop. While I guess now people can use the internet and social media to connect and converse with people with similar conditions, at the time none of that existed or was in its infancy, so while I was glad to experience the camps, it would have been good to have them for a lot longer during my late teens. I feel sorry for others that didn't experience them at all, but as mentioned, at least now with Facebook and so on, people can at least connect and chat without being face to face.

Because of my limited lung capacity, I didn't really get much into team sports that involved a lot of exertion such as footy or soccer, but did get into other activities that I still enjoy to this day.

One of my two main passions is competition shooting, which I started at the Police and Citizens Youth Club (PCYC) shooting air rifles from about the age of 10. I still do competitive shooting in Perth in a number of different categories. This was a good way for me to still be involved with friends doing things. We used to go on camps to competition shoots in places like Bunbury, Collie, Perth and Kalgoorlie. I ended up being quite involved in the administration side of things as well, including the first youth committee of the PCYC in Albany, as well as being assistant coach in air rifles.

My other passion from a very early age has been computers. I started using them from about nine years of age, and have now have worked all my life in the IT industry. I was very lucky as during my teen years was the rise of the internet which was just perfect in my line of work, and for filling in time when sick. I find sitting on the computer is a good alternative to sitting in bed or on the lounge watching TV.
I recall back in towards the end of year 10, it was planning time for year 11 and 12, and being in Albany, we had a limited set of subjects to select from - only one computing course. I knew that computing was all I wanted to do, so I decided to look at other avenues. I ended up finding a TAFE course which was an Advanced Diploma taking three years to be fully qualified and in the workforce much better than the school wanting me to do two years more schooling then three years at uni.

It was a good time in my life, I was feeling healthy, and starting to make decisions about my future. What made it even better is that my life-long friend, who was my best man at my wedding a few years back, also joined this path and we have worked together for periods.

Towards the end of the three years at TAFE however, just as we were preparing our final projects, and exams, I got quite sick and ended up in hospital in Perth for a few weeks throwing all of my preparation away. Luckily I was able to organise to sit the exam in Perth and only just passed getting my certification. If I had been fully prepared I could have strived for a distinction, though it hasn’t seemed to hurt my job prospects.

Life continued to be pretty good, until it all started to catch up with me. I worked in Albany for a year or so, then moved to Perth with my (now) ex. We built a house, and had quite a future planned out. I was going out like a normal 18 year old attempting to keep up with everyone else. Once I had moved out of home and away from my parents during my late teenage years I had a fairly negative attitude and tried everything in my power to ignore I had any disease at all. While it allowed me to try and live as normal life as possible, it did lead me down a very dangerous path of not doing my treatments at all to try and hide it all away from view.

I wouldn't tell anyone I had CF, and if anyone asked why I coughed so much, I would tell them I used to smoke but don't anymore. Anything but talking about it. I partied hard and my health would go downhill slowly so slowly I wouldn't notice until I was really sick, at what point I would rock up to the hospital, and have to be admitted for a few weeks of intense physio and intravenous antibiotics.

But that was ok, I accepted this, and disappeared off the radar for a week or two. Then I would be back to my best, hopefully lasting out another year before coming come back in. The doctors reminded me that what I was doing will hurt me later in life. But with my ‘do not care’ attitude I continued down this path.

Then all the not taking medications and ignoring everything, started to take its toll. In the meantime and unrelated to my health, I had split up with my wife, sold our house, moved to a rental and had started seeing my now wife, Jo. She had just moved in, and we started to think about a life together. She was only
starting to learn about my condition, and in my late 20s we went for one of our first holidays together to watch the AFL in Melbourne, one of our passions. Over there I was finding I could only walk 50 metres or so, then have to have a break from being out of breath. Despite this I was avoiding thinking that I was sick. When I returned to Perth I knew I was going to have to go to hospital. What I didn’t realise is what damage I had already done to myself. This is when it really hit me.

After a week in hospital, I was still was on oxygen and not got any better. My charts had not improved at all and for the first time in my life, I thought about the things I had done over the last ten years. I carried on, but that had thrown me so much. When I left hospital five weeks later I was three times better than when I went in, but my lung function was still only 45% of a normal person.

The second instalment of Gary’s story will be in the next issue of Breath of LIFE. A huge thank you to Gary for sharing his experiences and feelings so openly. We wish him and Jo a joyful life together. Always welcome at LIFE Gary!

**OPPORTUNITIES FOR YOU TO MAKE A DIFFERENCE**

You can help in medical research and presenting the views of consumers

Take part in a clinical trial that might improve your respiratory health

The Institute for Respiratory Health’s Clinical Trials Unit is the largest respiratory trials centre in Australia and is respected internationally for the high quality of its work. Participants say that not only do they appreciate having the opportunity to get access to new treatments, they also feel like they’re getting great care and assistance in managing their condition from friendly IRH staff.

If you are living with any of the following conditions and would like to know more about taking part in a trial please visit the Institute website or call 346 4964 for a confidential discussion.

The Institute’s Clinical Trials Unit is now targeting:

    Asthma | Bronchiectasis | Cystic Fibrosis | COPD | Pulmonary Fibrosis

If you need help to get to Sir Charles Gairdner Hospital for the trials, mention this when you ring up.
LUNGSCREEN WA

Lung cancer remains the number one cause of cancer death in Australia. Most lung cancer is found after it has already spread outside the lungs and so overall survival rates are not good. Although declining smoking rates will reduce the rate of lung cancer in the future, smokers who have quit are still at an increased risk of lung cancer.

In the past screening current and former smokers has not been recommended because the screening method exposed people to too much radiation. In 2011 a large scientific study in America showed that lung cancer screening can save lives. The newer screening test is a low radiation dose CT chest scan. When compared with chest X rays, the CT scan screening approach with people at risk of lung cancer reduced lung cancer deaths by 20%.

There are both potential and real harms from CT screening for lung cancer. The screening CT scan is not a perfect test. Up to half the people who have a CT scan will show abnormalities called nodules. Very few nodules turn out to become lung cancer, but they can cause stress and anxiety when found. Expert care is needed to determine what is required for any nodules detected. Most nodules require close observation with another CT scan to see if they change, though some may need early tests such as a biopsy.

Currently, CT scan screening for lung cancer in Australia is not recommended as we have neither the infrastructure nor adequate information about the overall Australian costs.

The LungScreen WA Project is a pilot lung cancer screening trial being undertaken at Sir Charles Gairdner Hospital investigating the role and cost of lung cancer screening in Perth.

The study, led by Dr Annette McWilliams and Dr Fraser Brims, is enrolling people aged 55-74 years old who are either current or former smokers. Subject to their individual lung cancer risk participants will be offered a CT scan at no cost. The information gained will help with the planning of a future lung cancer screening program in Australia.

More If you are interested call LungScreen WA T 1800 768 655
HEALTH CONSUMER REPRESENTATIVE OPPORTUNITY

If you live in the Lower Great Southern region of Western Australia you could help guide a project for people living with chronic conditions so that they can better navigate the health system.

The Health Navigator Project Support Group is looking for a health consumer representative with a chronic lung condition. (They have one consumer rep but would like another, with lung disease).

The Health Navigator Program aims to improve the health outcomes of people with diabetes, long term lung conditions or heart disease. It aims to encourage people with any of these conditions in Albany, Denmark, Mt Barker, Bremer Bay, Jerramungup and Ravensthorpe to use the Health Navigator Program. It encourages them in self-management, keeping their health on track through the help of a trained health provider who’ll discuss their needs and support them to manage their care over time. The local doctor and other health professionals are also important members of the Health Navigator team.

The WA Country Health Service is looking for a consumer representative to:

- Give an experienced consumer view on issues about the Health Navigator Program
- Attend a monthly one hour meeting in Lower Great Southern - either face to face or via video or teleconference

Contact
Stephanie Tchan, WA Country Health Service, Southern Inland Health Initiative
T (08) 98427508  M 0400 912 108  E Stephanie.Tchan@health.wa.gov.au

DISCLAIMER

The information contained in Breath of LIFE is provided in good faith and believed to be reliable and accurate at the time of publication. However, the information is provided on the basis that a reader will be solely responsible for making their own assessment of the information and its accuracy and usefulness.

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**LIFE**

*LIFE* (Lung Information & Friendship for Everyone) is a self help group supporting people with chronic lung disease, family and carers. It is the community group of the Institute for Respiratory Health and it’s run by and for people with chronic lung conditions. Started in 1992 as LISA, it changed its name to *LIFE* in July 2009. *LIFE* is also a member of [Lung Foundation Australia](https://lungfoundation.com.au)'s network of respiratory support groups T 1800 654 301. *LIFE* is grateful for the continuing support of the Department of Respiratory Medicine at Sir Charles Gairdner Hospital.

**Breath of LIFE magazine**

Our magazine is published 4 times a year - March, June, September & December. It is distributed to all LIFE members and other community members of the Institute. The editor is Jenni Ibrahim. Send contributions to E [life@resphealth.uwa.edu.au](mailto:life@resphealth.uwa.edu.au) or 7 Ruislip St, W. Leederville, WA 6007. [Read online](https://lifeforphrealth.org/).

**Institute for Respiratory Health**

The Institute for Respiratory Health (formerly LIWA) is a collaborative respiratory research organisation. [Donations to the Institute](https://lifeforphrealth.org/donations) are tax deductible. Membership is open to interested community members, as well as researchers, health professionals and medical research students. Join *LIFE* through the Institute for Respiratory Health.

**LIFE Membership**

Contact Dorothy at the Institute for LIFE membership enquiries. E [life@resphealth.uwa.edu.au](mailto:life@resphealth.uwa.edu.au) or T 6151 0849. *LIFE* membership fees are due each 30 June - $20 (incl. GST). Please advise us of any change of address. Members’ help and ideas are welcome - magazine, speakers, events.

**Contacts**

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Postal:  LIFE c/- IRH, Ground Floor E Block, Sir Charles Gairdner Hospital, Hospital Ave, Nedlands WA 6009

Email:  [life@resphealth.uwa.edu.au](mailto:life@resphealth.uwa.edu.au)  [Web: LIFE on the Institute website](https://lifeforphrealth.org/)  LIFE on Facebook

**Meetings**

1st Wednesday of every month, 12 - 2.30pm, Feb-Nov. Speaker usually starts at 1.00pm. Respiratory Library, Department of Respiratory Medicine, 1st floor, B Block, Sir Charles Gairdner Hospital Nedlands. Wheelchair and gopher accessible. Light refreshments. If you can, please bring a plate to share.

**COMING UP**

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<td>Wed 7 Oct</td>
<td>Self management; managing your lung disease</td>
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<td>Wed 4 Nov</td>
<td>New directions for the Institute for Respiratory Health</td>
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