



Breath of LIFE

Lung Information & Friendship for Everyone

People with long term lung conditions, their family & carers

Winter 2016

Jun-Aug

LIVING WITH LUNG DISEASE IN WINTER

Q: Why do cold temperatures make it harder to breathe?

Dr. Nicolacakis: Cold air can trigger bronchospasm, a constriction in your airways. This makes it harder for air to get in and out of your lungs. But it's not just the cold that causes irritation. It's the extreme change in temperature and humidity—going from warm, moister air inside to cold, drier air outside, for example.

Q: Is the bitter cold worse than sweltering heat for people with lung disease?

Dr. Nicolacakis: Not necessarily. It's very individual—and it can change. It certainly isn't uncommon for people with lung disease to experience shortness of breath and wheezing when going outside during winter months. But that doesn't mean summer months are without challenges. High heat and humidity can trigger breathlessness too. So can high pollen counts.

Q: How can people with lung disease prevent breathing problems during cold weather?

Dr. Nicolacakis: I suggest my patients cover their nose and mouth with a scarf before going outside. The scarf can trap moisture, so it not only warms but also humidifies the air you breathe. If you're going outdoors for a while, especially to exercise, you may want to pre-treat yourself with your rescue medication (*such as Ventolin*), which you should always have on hand."

Q: Is there anything else people with lung disease should do to stay healthy this winter?

Dr. Nicolacakis: Make sure you get a flu shot. Influenza is bad, but it's especially bad—even life-threatening—for those with chronic lung disease.

Dr Kathrin Nicolacakis, is a respiratory physician at the Cleveland Clinic in Ohio, USA <https://health.clevelandclinic.org>

MEETING VENUE CHANGE!

Since March 2016 we have been meeting at the Perkins Building. Details inside.



NEED A LIFT?

If you need a lift around the QEII Medical Campus, either drop in to the Gairdner Voluntary Group Enquiries Desk just inside the entrance to E block or ring the courtesy buggy service (Charlie's Chariot) on **M 0481 438 731** Mon-Fri 9am-4pm

WHAT'S INSIDE?

LIVING WITH LUNG DISEASE IN WINTER	1
WHAT'S INSIDE.....	2
L I F E MEETINGS & EVENTS COMING UP	2
RECENT EVENTS	3
LUNG LAUGHS	6
NEWS	7
DRINKING WATER.....	8
RESPIRATORY RECIPE	9
SHORTS	10

THE CHALLENGES OF LIVING WITH A LONG TERM CONDITION.....	19
HOW CAN YOU MAKE A DIFFERENCE? .	24
INSTITUTE FOR RESPIRATORY HEALTH	24
GETTING TO L I F E AT THE PERKINS BUILDING	25
ELECTRONIC NOTICEBOARD – USED RESPIRATORY EQUIPMENT?	27
COMING UP	28

L I F E MEETINGS & EVENTS COMING UP

A great turn out at Sizzler in March. Good meals and fine company.

Winter Lunch

To celebrate the next change of season our winter community lunch is at

Hyde Park Hotel

Monday 18 July from 12 noon

**331 Bulwer Street, corner
Fitzgerald St, North Perth**

Seniors special \$10 or a la carte. Thanks to Raema Fitzgerald for this suggestion (following an inconclusive discussion at our April meeting!)

RSVP by Thursday 14 July to Raema
T 9349 0617 or Mary T 9337 1286
E mvfedele@bigpond.com

Getting there Yokine bus # 19 stops near the corner of Fitzgerald and Bulwer. Or ring Transperth Infoline for more options 13 62 13. Enter car park off Bulwer Street, near Dan Murphy's.



Changes to speaker program

The last issue of Breath of L I F E detailed the speaker program for the next several months, but there have been some changes to that schedule. For meetings in June, July and August see the back page.

Bring your burning respiratory questions to the June meeting for Dr Martin Phillips, a well-known respiratory physician at Sir Charles Gairdner Hospital and researcher at the Institute for Respiratory Health. Dr Phillips has kindly offered to run a Q & A session - though it won't be as wild as the ABC's version.

Note: Due to his busy schedule, Dr Phillips will begin at 12 noon (not 1pm). Our usual group meeting will follow at 1pm.

L I F E has moved to the Perkins Building!

After 23 years at the Respiratory Library, in B block, L I F E meetings have moved to the Perkins Building. Since the March meeting we have been holding our monthly gatherings there. As it turned out, the new meeting venue on Level 6 was not quite ready for us on 2 March. Luckily the Perkins Institute staff, Jessica and Meredith (thank you both!), stepped in and provided us with an alternative venue on the ground floor. April and May saw us in the new meeting room 612A.

See the Perkins Building marked on the QEII map [here](#) or see the republished directions on page 25. We've also included an easy walking route from the Charlie's bus stop or the multi-deck carpark.

RECENT EVENTS

Recent Speakers



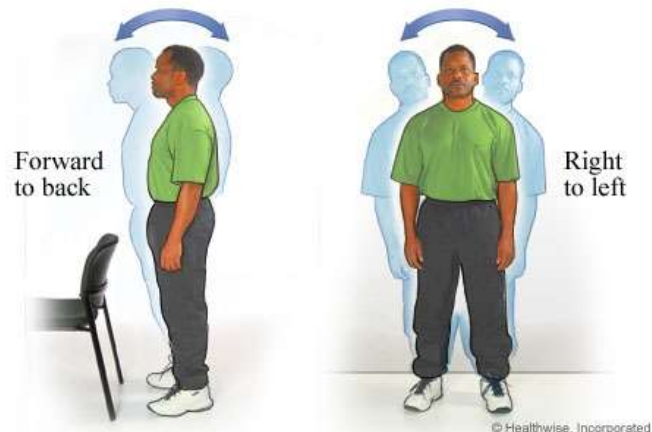
1 MARCH SPEAKER LESLEY SILVESTER PROVIDING A SNAPSHOT OF THE FASCINATING HISTORY OF WESTERN MEDICINE AND HEALING FROM THE GREEK AND ROMAN ERAS TO THE 19TH CENTURY.

Our April speaker, **Karen Levitt** from Stay on Your Feet explained the importance of remaining physically active in order to avoid falls and any consequential hospitalisation and disability. We each received kits about how to:

Move – to strengthen leg muscles and improve balance

Improve health – through medicine check, good nutrition and staying mentally healthy

Remove hazards – through a safer home, eyesight check and safer footwear



Here are pictures taken at the April meeting: Jan, Tom, Jack, Ann and Mary, engaged in discussion about falls prevention.

At the May meeting we had the pleasure of a return visit from peer educator Dr **Bob Zeigler**, a wonderful volunteer speaker from Council on the Ageing. Bob's first ever presentation for COTA was a talk on safe use of medicines which he gave 12 years ago to respiratory support group LISA - or L I F E as we are now known!

This time Bob's topic was **consumer directed care**, a new concept in aged care and disability services. It is a little like the way Home and Community Care (HACC) services are organised in WA, but now the Commonwealth Government wants to introduce this model across Australia, including WA. By July 2017 WA must choose whether to be part of this scheme or not.



The basic idea of consumer directed care is to give the people who need and use support services a lot more control over what types of services they receive and which providers deliver them.



2 DR BOB ZIEGLER

Initially an assessment by the Aged Care Assessment Team (ACAT) determines what level of support and care you need. Levels 1 and 2 are also known as low care, while levels 3 and 4 are high care. With this assessment you can

approach nearby accredited service providers and discuss what services of this level they can offer, the costs etc. (If you live in the country there will unfortunately be fewer choices of provider.) After comparing providers and their conditions you enter into a contract for specified services from the provider you choose. There may be some delays before the services commence.

While you do not hold the funds yourself, you do have a say about how they are allocated and a report of expenditure is provided to you monthly. This applies to any fully or partly subsidised services, so people on part pensions and self-funded retirees are also eligible, though they will pay more than a full pensioner. There are annual and life-time caps on the gaps you pay.

There is a complaints system so if you are not receiving the services that your contract says, you can and must speak up. We each received a copy of the MyAgedCare booklet, Five Steps to Assessing a Home Care Package. Come to the next meeting if you'd like a copy. We have a few spare ones.

More W www.myagedcare.gov.au **T** 1300 785 415 WA Aged Care Framework. Other parts of Australia except WA 1800 200 422 (This number does not provide information and referral services for WA at the current time). The website does include some WA service providers.

Lung Health Education Day

Lung Foundation Australia's annual Lung Health Education Day was held this year on

Friday 27 May 9.00am - 12.30pm
Boulevard Centre, Floreat

The speakers were **Nola Cecins** and Dr **Sue Jenkins** (both newly awarded OAM) on "Am I too sick to exercise?" and Dr **Grant Waterer**, respiratory physician on



Community Acquired Pneumonia, which he is currently researching. The print deadline for this issue was too early to include a report. We trust those who managed to get along did enjoy their time and were well-enlightened.

LUNG LAUGHS

A woman received a call that her daughter was sick. She stopped by the chemist to get her medication, got back to her car and found that she'd locked her keys inside! She woman found an old rusty coat hanger on the ground. She thought, "I don't know how to use this."

She bowed her head and asked God to send her help. Within five minutes a beaten-up old motorbike pulled up. A bearded man wearing an old biker skull headscarf got off the bike and asked if he could help. She said: "Yes, my daughter is sick. I've locked my keys in the car. I must get home. Please, can you use this to unlock my car?"



He said "Sure." He walked over to the car, and in less than a minute the car was open. She hugged the man and through tears said "Thank You SO Much! You are a very nice man." The man replied "Lady, I am NOT a nice man. I just got out of PRISON yesterday. I was in prison for stealing cars."

The woman hugged the man again sobbing, "Oh, thank you God! You even sent me a professional!"

Tradies

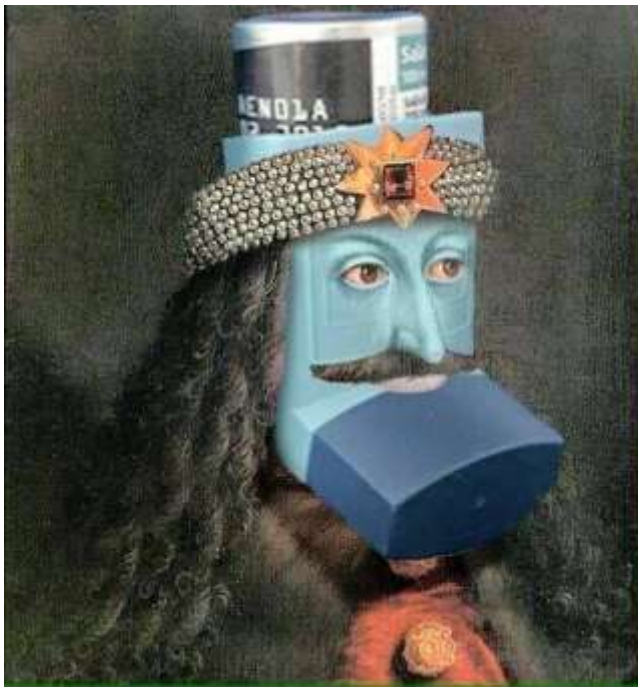
On a plumber's truck: "We repair what your husband fixed."

On another plumber's truck: "Don't sleep with a drip. Call your plumber."

On an electrician's truck: "Let us remove your shorts."

Outside a muffler workshop: "No appointment necessary. We hear you coming."

Thanks Mike Watteau of Bentley Bronchiatrix, for these one liners!



3 WHO IS THIS? YES, IT'S VLAD THE INHALER

NEWS

Shirley Shehan send her regards to members. She's now on 4L/minute of oxygen and still finds herself very breathless. So it's hard for her to get in to meetings. She's been seeking some more support at home through the Aged Care Assessment Team (ACAT). She hasn't forgotten us all and misses the conversations. Sending our best wishes to Shirley.

L I F E member **Jan Maiorana** has kindly offered to take over running the L I F E birthday club which Shirley has sadly had to relinquish.

Thank you **Shirley Shehan** for your valuable contribution marking member's birthdays with a card from all of us!

If you want to join our birthday club please let Jan know the date of your birthday (just the date, you don't have to say which year. We already



know it was last century). Either tell her at a meeting or contact her
E janjohn1968@bigpond.com T 9339 3617. Even if you have previously been in
our birthday club, please let Jan know again. The original list has been misplaced.

READ BREATH OF L I F E ELECTRONICALLY



If you have access to a computer and the internet you can read Breath of L I F E online at www.resphealth.org.au and navigate your way to Lung Health & Information/ Breath of L I F E.

Or you can have a pdf copy emailed to you even before you'd receive a hard copy in the post. (You'll need Acrobat Reader to open the file).

With an electronic copy you see all the lovely coloured print and images, click on the [blue underlined hyperlinks](#) to go to websites with just one click. You can increase the print size on your screen to read it more easily. And, you'll save L I F E some printing costs. With postage increasing markedly this year,

that's a very worthwhile cause.

To let us know you'd like an electronic copy of Breath of L I F E from now on, just email us at E life@resphealth.uwa.edu.au.

More

www.resphealth.org.au/news-and-events/publications/breath-of-life

Adobe Acrobat Reader can be downloaded at <https://get.adobe.com/reader/>

DRINKING WATER

How many people do you know say they don't want to drink anything before bed because they'll have to get up in the night?

I asked my cardiac doctor why people need to urinate so much at night.

My doctor said when you have heart problems gravity holds water in the lower part of your body when you are upright (legs swell).

When you lie down and the lower body, including your legs, is level with the kidneys, it is then that the kidneys remove the water because it is easier.

I knew you need your minimum water to help flush the toxins out of your body, but this was news to me.

There's a correct time to drink water. Very important. According to a heart specialist, drinking water at a certain time maximizes its effectiveness on the body.

2 glasses of water after waking up -
helps activate internal organs

1 glass of water 30 minutes before a
meal - helps digestion

1 glass of water before taking a bath -
helps lower blood pressure

1 glass of water before going to bed -
avoids stroke or heart attack (good to
know!)



A physician also said that water at bed time will help prevent night time leg cramps. Your leg muscles are seeking hydration when they cramp and wake you up with a Charlie Horse.

It also helps thin mucus in your lungs making it easier to cough up.

Contributed by Janelle Griffiths, leader of SWILS, the respiratory support group that meets in Bunbury. Source, the internet.

RESPIRATORY RECIPE

For the first month or so of winter Breath of L I F E editor Jenni Ibrahim will be away on an extended camping trip. Yes, camping in winter! The Kimberley, Darwin, Kakadu, South Australia, Nullarbor. Very cold at night, but dry and quite warm by day in the north. She's sharing some of her easy stand-by camping recipes using ingredients that keep well on the road and warm you on the inside. These amounts serve two.

As usual

T= Tablespoon (20ml)

t= teaspoon (5ml)

c= cup 250ml

Spotted rooster (Gallo Pinto, from Costa Rica)

1 T oil

1 medium onion

1 medium capsicum (red or green)

2 medium tomatoes, cut small, collect
juice separately

6 T chopped coriander leaves (if
available)

1 can (400g) black beans

250 g pre-cooked rice (packet)
1 chicken or vegetarian stock cube
Salt and pepper

Heat oil, add onions and soften, add capsicum and tomato flesh, cook till softened, add in stock cube and tomato liquid, drained black beans, salt and pepper. Cook till all combined and cooked. Mix in the rice, cover till rice is heated up. Garnish with coriander leaves.



Macaroni cheese for campers

150 g elbow macaroni, start in cold water, 3-4 cm over the level of macaroni, using the least amount of water (water is precious when camping)

½ c powdered milk

1 c grated cheddar cheese

2T cornflour

Small can of corn

3T frozen or rehydrated dried peas

Salt, pepper, 1t mustard, 1t

Worcestershire sauce, pinch paprika (optional)

180g can tuna (optional)

Boil macaroni. Drain, keeping 2c liquid. Thicken the liquid with 2T cornflour. Over a low heat, mix in powdered milk into the thickened pasta water, (and tuna if used). Add cooked pasta, grated cheese, spices, corn, peas. Ensure all is heated through. You city folk with your ovens, you can bake it with extra cheese on top. Out in the desert we'll have to make do without.

Serve in bowls. (If you want to make the city version just make a white sauce with 2c milk, ¼ c flour and ¼ c butter.)

SHORTS

COMPUTER CLASSES

If you've always wanted to learn about computers COTA's one-on-one computer classes have resumed. Classes run on Tuesday & Thursday mornings, Wednesday afternoons and also some Friday afternoons. **Bookings are essential.** You could also ask at your local library whether there are any classes held there.

ASK TELSTRA

Do you have a mobile phone, iPad, or tablet and feel that you could get much more out of it, if only you knew how? Come along to one of their free 'Ask Telstra' sessions, held on the last Wednesday of every month, 10.00am - 11.30am. **Bookings essential.**



More

The Council on the Ageing's (COTA) WA office is now situated in The Perron Centre (Visability Building), 61 Kitchener Avenue, Victoria Park and is easily accessible from Victoria Park railway station and various bus routes. T 9472 0104 E admin@cotawa.org.au

FINDING A SPOT TO SIT

Deirdre Sabine, who takes part in the pulmonary rehabilitation classes held in Wembley, has some great ideas about where to take a rest when out shopping. If you take a wheeled walker with a seat you cannot manage a shopping trolley as well though you still may need to sit down sometimes.

Shopping centres are huge and, while there are sometimes seats in the central plaza areas **outside** large department stores, what if you're getting breathless and tired **inside** a store? If you are in stores like Big W, K-Mart or Target here are three places you may be able to sit down and catch your breath:



- Where they sell outdoor furniture
- The shoe section
- The area where you upload and print photos.

Great ideas, Deidre! Thank you for your contribution.

If you have a handy tip please share it with us.

LUNG FUNCTION, HEALTH STATUS & COPD FLARE-UPS

Is there a strong connection between your lung function test results, how well you are feeling and your risk of exacerbation or flare up?

This study investigated the relationship between changes in lung function (as measured by forced expiratory volume in one second [FEV1]), health status measured by the St. George's Respiratory Questionnaire (SGRQ), any economically significant outcomes of COPD flare-ups and health resource use (costs, staff etc.). It aimed to provide insight into whether the effects of COPD treatment on lung function and health status are connected with a reduced risk and impact of exacerbations. It was conducted by researchers at Evidera, an international health economics institute.

The St. George's Respiratory Questionnaire can measure persistent and/or uncontrolled disease symptoms and health status by asking about symptoms, impact on well-being, and activities of daily living. If you have ever taken part in pulmonary rehabilitation research for Dr Sue Jenkins or Nola Cecins or their associates, you may have completed a St George's questionnaire.

The study was a meta-analysis of 67 published clinical trials.

There was no statistically significant relationship between FEV1 or SGRQ score and annualised exacerbation rate for any exacerbation or for hospitalised exacerbations.

However there were significant connections between



- FEV1 and any exacerbation (time to first exacerbation or patients with at least one exacerbation, $p = 0.001$);
- FEV1 and moderate-to-severe exacerbations (time to first exacerbation, patients with at least one exacerbation, or annualized rate, $p = 0.045$);
- SGRQ score and any exacerbation (time to first exacerbation or patients with at least one exacerbation, $p = 0.0002$);
- SGRQ score and moderate-to-severe exacerbations (time to first exacerbation or patients with at least one exacerbation, $p = 0.0279$; annualized rate, $p = 0.0024$).

Perhaps these findings seem obvious. But we cannot assume that just because the connections seem obvious that they really are true. This study concluded that there was a significant association between improvements in FEV1 and

SGRQ total score and lower risk for COPD exacerbations. That is, when lung function improved, so did health status and at the same time, the risk of flare ups decreased.

***Source** The association of lung function and St. George's respiratory questionnaire with exacerbations in COPD: a systematic literature review and regression analysis, Martin, A L, Marvel J, and 4 others, Respiratory Research 2016 17:40 <http://respiratory-research.biomedcentral.com/articles/10.1186/s12931-016-0356-1>*

THORACIC SOCIETY OF AUSTRALIA & NEW ZEALAND IN PERTH 2016

The Thoracic Society (TSANZ) is the peak body for health professionals and researchers working in respiratory diseases. In April they held their annual scientific conference for the whole of Australia and New Zealand, here in Perth at the Convention Centre. It was a joint meeting over five days covering both the Thoracic Society as well as the Australia and New Zealand Society for Respiratory Science, the professional body for scientists and technologists employed in clinical respiratory function laboratories – the people who conduct and report on your lung function tests.

Your editor, Jenni Ibrahim, was one of three health consumers and a cardiologist invited to speak at the TSANZ conference in a session about involving consumers in research. Jenni spoke about the many opportunities for health consumers to partner with respiratory researchers in guiding their research, both clinical and laboratory based. Not as the subjects of the research, but as collaborators **with** researchers. There is a well-established consumer participation program based at the University of Western Australia and the



Telethon Kids Institute, which enables this by training interested researchers and consumers.

The Thoracic Society conference hosted an extensive program from 2-6 April, involving dozens of speakers and poster presentations on a really wide range of

topics. Keynote speakers came from the United States, England, Ireland, South

Africa and Canada. The other invited speakers (over 75) came to Perth from all over Australia and New Zealand. They discussed many long term respiratory conditions, from COPD to pulmonary hypertension, pulmonary embolism and lung cancer, as well as acute respiratory diseases, like pneumonia, and adult as well as childhood respiratory conditions.

More

For information about getting involved in respiratory research, contact Involving People in Research which is leading the field in Australia. Join their network of consumers and researchers by visiting the website.

T (08) 6488 8176 W www.involvingpeopleinresearch.org.au/

STEM CELL TREATMENT FOR COPD

You may have come seen this story in the West Australian in early April as the TSANZ conference opened. Very exciting to read this development here in Perth.

Doctors in WA have stumbled on a potential breakthrough for the most common respiratory disease after two severely ill patients improved within a month of being injected with adult stem cells.

The promising research into chronic obstructive pulmonary disease, led by Fiona Stanley Hospital respiratory physician Yuben Moodley, will be released at a major lung conference in Perth next week.



Dr Moodley, an associate professor at the University of WA, will release early results from a trial of nine patients who, after treatment with stem cells from bone marrow, recorded a drop in inflammation associated with the disease.

COPD is a progressive disease with no effective treatments, characterised by difficulty breathing.

An estimated one in seven Australians over age 40 has some form of the disease.

After the injection, researchers tracked the patients' progress.

They found key biomarkers of inflammation dropped significantly within a week.

But an unexpected finding was an improvement in lung function tests for two patients. Dr Moodley said the “surprising” response would now be a major focus in an expanded trial to determine which patients might benefit most from a potential treatment.

“There may be a cohort of people who may respond better and end up with a positive response,” he said. “This disease generally progresses and is a huge burden on the resources of the world.

“If we found a population that would be responsive to these cells, it would be a major step forward.”

Dr Moodley said they would apply to test the therapy in a larger group when the full analysis was finished midyear. Further testing was vital to ensure people were not given false hope.

The Thoracic Society of Australia and New Zealand’s conference started on 2 April.

Published in the West Australian 2 April, 2016

Dr Yuben Moodley has previously spoken about his stem cell research to L I F E members. He is a respiratory researcher and physician who currently practices at Fiona Stanley Hospital, Murdoch and teaches at the University of Western Australia. He is also a member of the Institute for Respiratory Health, based at the Perkins Institute Building.

Source <https://au.news.yahoo.com/thewest/wa/a/31239616/wa-discovery-offers-lung-disease-hope>

PROMISING NEWS FOR PEOPLE WITH MESOTHELIOMA

Mesothelioma is a malignant respiratory disease associated with exposure to asbestos. At last, some promising news.

At the 5th European Lung Cancer Conference in Geneva Switzerland - held about the same time as our TSANZ Australian conference - researchers from the University of California, USA announced some positive results for people with mesothelioma, using an immunotherapy approach with CRS-207, a live bacterium, combined with chemotherapy.

The results showed a more than 90% disease control in patients with **malignant pleural mesothelioma** (MPM), and a 59% response rate.

Standard treatment for MPM includes pemetrexed and platinum-based chemotherapy, which results in a 30% response rate and has only a modest impact on survival.

CRS-207 is a live, attenuated *Listeria monocytogenes* bacterium that was altered to decrease toxicity and activate immunity.

For the current study, 38 patients with advanced inoperable MPM received two CRS-207 infusions two weeks apart, in addition to the standard treatment with pemetrexed and cisplatin, followed by two more CRS-207 infusions three weeks apart.



Eligible patients received maintenance CRS-207 every 8 weeks. Patients were assessed every 8 weeks until disease progression.

Of the 38 patients, 30 completed the full treatment course by August 2015, and 19 had at least one maintenance treatment with CRS-207. After a median follow-up of 9.4 months, there was usable data on 34 patients.

The best overall response was partial response in 20 (59%) patients, and stable disease in 12 (35%) patients. Mesothelioma had progressed in only one (6%) patient. Tumour shrinkage was confirmed in 85% of patients.

There were some side effects associated with CRS-207 - a temperature spike and rigors¹. These were related to the infusion and resolved themselves within 24 hours.

“It really does appear to be safe, and was well-tolerated in combination with pemetrexed and platinum chemotherapy,” said Dr. Jahan. “There didn’t seem to be any cumulative toxicity.”

“CRS-207 is an exciting agent for patients with mesothelioma, which is an aggressive disease with a poor prognosis,” said Dr. Jahan. “Our preliminary results are encouraging, suggesting superior clinical activity when added to standard chemotherapy. This supports assessing the impact of CRS-207 in a randomised trial, which is currently in the planning stages and should be underway within this calendar year.”

¹ **Rigors** means a sudden feeling of cold with shivering accompanied by a rise in temperature, often with copious sweating, especially at the onset or height of a fever

Source: Conference presenters were Jahan, T, University of California at San Francisco, Diller H, Family Comprehensive Cancer Center, San Francisco, California.
<http://tinyurl.com/hoc7fnr>

Did you know?



What are Health Information Technologies?

Health information technology (HIT) is **information technology** applied to **health** and **health care**. It supports **health information management** across computerised systems and the secure exchange of health information between **consumers**, health care **providers**, health care funders (like insurance companies and governments) **payers**, and **quality** monitors. Examples include: Personal electronic health record or e-health, computerised bedside clinician records like those introduced at Fiona Stanley Hospital (the so-called paperless hospital record system), or gadgets you use at home to monitor your health status and communicate it to a health care provider (like the system trialled by Silver Chain a few years ago).

L I F E member **Sal Hyder** heard about health information technologies at the Patient Experience Conference in April and shared the news with members at the May meeting.

HEALTH INFORMATION TECHNOLOGIES HELP PEOPLE WITH CHRONIC LUNG CONDITIONS

Asthma and chronic obstructive pulmonary disease (COPD) are common chronic obstructive lung disorders that in the US affect over 49 million people out of a population of over 318 million. That's about 15% or one in 6². There is

² With a population of about 24 million Australia would have about 3.6 million people with COPD or asthma, assuming comparable COPD and asthma prevalence, and population structure.

no cure for either condition, but clinical guidelines for controlling symptoms are successful in most people who follow their treatment plan.

Health information technologies (HITs) are revolutionising healthcare by becoming mainstream tools to assist people monitor themselves and make decisions, and this is pushing a shift towards a model of care increasingly centred on people taking up and using digital and web-based tools.

While the number of chronic pulmonary disease HITs is rapidly increasing, most have not been validated as clinically effective tools for the management of disease. Online communities for people with asthma and COPD are becoming that provide

empowerment and support, as well as facilitating person-centred research efforts.

In addition to empowering people and facilitating disease self-management, HITs offer promise to aid researchers in identifying sub-types of chronic lung disease.



With this information they can develop personalised treatments based on person-specific profiles that integrate symptoms and medication usage with environmental and genetic data.

For HITs to be effective, particularly for people from socioeconomic and racial/ethnic groups that are disproportionately affected by chronic pulmonary conditions, these must be designed with input from all of them.

Source Himes B E and Weitzman, E R *Innovations in health information technologies for chronic pulmonary diseases*, *Respiratory Research* 201617:38, DOI: 10.1186/s12931-016-0354-3 <http://respiratory-research.biomedcentral.com/articles/10.1186/s12931-016-0354-3>

DISCHARGE SUMMARIES

After you've spent a spell in hospital has there always been a discharge summary that you took home - or got sent straight to your GP?

The discharge summary tells your doctor what you were in hospital for, your treatment, your health status on discharge and what care you need after that.

Looks like you need to make sure this happens promptly - or you are likely to be back in hospital again. Of course, the hospital **should** be doing this, but a bit of consumer monitoring won't do any harm!

A study of nearly 3,400 past discharges from Adelaide general hospitals over several years found that if there were no discharge summary - or it was delayed in reaching your GP - discharged patients were significantly more likely to be readmitted within a week or a month, especially for people under 80.

If there were no discharge summary within a week of leaving hospital the readmission rate was no different

from not having one at all! So if it is not prompt they may as well not send it. Ensure your hospital doctor to gives you or your GP a copy.



***Source:** Jordan Y Z, Li, Tuck Y Yong, Hakendorf P, Ben-Tovim D, and Thompson C H, Timeliness in discharge summary dissemination is associated with patients' clinical outcomes, Journal of Evaluation in Clinical Practice, Volume 19, Issue 1, February 2013, pp 76-79 <http://tinyurl.com/h7gbfj8>*

THE CHALLENGES OF LIVING WITH A LONG TERM CONDITION

This is a summary of discussion at a workshop held with members of Pulmonary Hypertension WA, a support group for people with pulmonary hypertension, led by Melissa Dumitru.

The workshop was held on 19 April 2016. Jenni Ibrahim facilitated and recorded it. Thanks to our sister support group, Pulmonary Hypertension WA, for your

contributions to the workshop and for giving us an opportunity to share the results with Breath of L I F E readers.

What we did at the workshop

- Write down three things that are challenges for you, living with a long term condition. If you are a carer write down the things that are challenges to you as a carer (not the challenges facing the person you care for).
- (In pairs - but not with the person you came with) explain the challenges you wrote down with the other person. The other person listens to you. Then, listen while the other person reflects back to you what they understood you to say. Clarify as necessary. Then swap roles. The first speaker becomes the listener etc.
- (As a large group) Share the challenges each person heard the other person explain. Discuss common threads, ideas for dealing with them.



Perhaps you can identify with many of these issues yourself or can think of others more relevant to your life. Maybe you could share things you find helpful for addressing some of them? We'd love to hear from you.

People with one or more long term conditions said

Managing my condition with family life (and for some, work life). Others do not take account of my condition and still expect me to do everything I used to do. Or, I feel I should contribute more to family life but I just cannot do as much as I want to. Feel bad about this.

Managing the multiple conditions I have, all day, every day. Sometimes the conditions or their treatments interact with each other and are very hard to balance.

Caring for own long term condition as well as the long term conditions of others. I can manage now, but am worried that when I get worse I will not



be able to manage caring for another family member with a serious long term condition

Thinking about my long term prognosis. Even though I'm not very ill yet, I look at others worse off than I am and worry about my future.

Took a long time to be correctly diagnosed. I still feel frustrated about this.

Mobility

Managing oxygen on a holiday. Have never done it and would like to.

Transport - getting around, especially when I cannot drive and public transport is difficult to use. Leads to isolation, feeling lonely, missing out on events I'd like to take part in. Managing a walker in and out of a car, public transport.

Social and Mental Health issues

Aloneness, especially those who live alone

Staying positive, keeping on going

Dealing with other people who don't understand my long term condition

Socialising

Living within my capabilities

Admitting my frailty and my limitations

Putting my thoughts and feelings into words - with family, health professionals

Carers said:

Taking guilt-free carer breaks

Encouraging the person I care for to be more active

Always having empathy for the person I care for, whether as a family member or a paid carer

Staying positive, keeping on going, for the person I care for

Practical ideas and resources available

(Some of this came from group discussion. Some was added later)



Managing condition(s)

Make a list of the issues you need to discuss with your doctor, most important ones first. Some GP clinics allow you to email or phone requests for repeat prescriptions so you don't need to waste valuable discussion time on that. Or hand the doctor a list of repeats you need so he/she can get them printing while you talk.

Speak to your GP about balancing out treatment for your different long term and short term conditions. It's their job to help join the dots, not your sole responsibility. Specialists are usually interested in focussing only on their speciality.

Draw up a care plan for yourself, with help from doctor if needed. List your usual care, as well as signs of something flaring up and what you can do before making a medical appointment (sometimes you forget some of these things)

Speak to your doctor about taking part in pulmonary rehabilitation classes which strengthen muscles for daily activities and keep you out of hospital.

Use the Living Life to the Full with a Chronic Condition brochure distributed at the workshop. Melissa has extra copies.

Social and Mental health

Visit the Act Belong Commit website to find some enjoyable activities to get out more www.actbelongcommit.org.au

Join a support group for the other conditions you live with as well. Connect Groups has an online directory www.connectgroups.org.au/directory

Think about exactly what stops you from being as sociable as you would like to be. Work out ways of overcoming these barriers. Eg if transport is an issue, invite family member or friend to come to your place, bringing a plate. Keep the event short, or tell your guest that you are tired (give them a good hint!). If visiting someone else, leave before you get too tired.

Mobility

Melissa will research taxi vouchers, HACC, local council and other transport options and share with the group. Or you could ask your local ACAT person.

Read the Guide to Flying with Oxygen, by Jenni Ibrahim and Philip Thompson www.resphealth.org.au/wp-content/uploads/Flying_with_Oxygen_Guide_2015.pdf

Visit an Independent Living Centre to find out what aids and equipment could help you manage things more easily. Identify what activities are of most concern to you. Make an appointment first to get personalised assistance from

an occupational therapist there (free). Independent Living Centres are at the Niche, near Charlie's in Nedlands and at the Cockburn Integrated Health and Community Facility, 11 Wentworth Parade Success. Reach both at T 1300 885 886

Communication

Role play how to speak to others about my condition. Future group activity.

General

Ring WA Aged Care Framework to find out about paid and subsidised services in your area, including transport options. See article about consumer directed care on page 5.

Carer

Go for a gentle walk with the person you care for, drive to a place they really love to visit, e.g. Kings Park wildflowers, a local park. Start with a short distance and gradually build up walking time. Discourage the person you care for from chatting while walking as this increases breathlessness.

Contact Carers WA, Red Cross or Commonwealth Respite and Carelink to access some subsidised carer time out.

More

Carers WA T 1800 242 636 W www.carerswa.asn.au

Red Cross Respite Service T 1800 422 737 W <https://respite.redcross.org.au>

WA Aged Care Framework 1300 785 415

MyAgedCare www.myagedcare.gov.au

Connect Groups T 9364 6909

Beyond Blue 24/7 T 1300 22 46 36

What about you? What are your challenges in living with one or more long term conditions? Do some of these issues resonate with you? What different ones would you have recorded?

What strategies do you use to deal with them? Other readers would undoubtedly love to hear of your tips and experiences.

HOW CAN YOU MAKE A DIFFERENCE?

Doing something that helps make the world a better place, feels good too. There are lots of things you can do, no matter how advanced your condition.

1. Volunteer for L I F E - help with our L I F E group (like Raema and June are doing here with the magazine mail-out).
2. Join the L I F E working bee which helps the Institute for Respiratory Health's Clinical Trials Unit. Just speak to Sal at the next L I F E meeting or call her T 9331 3651.
3. Register with the Institute for Respiratory Health's Clinical Trials Unit to take part in the trial of a new respiratory medication. Call Leisa T 9346 4482 E leisa.wilson@resphealth.uwa.edu.au.
4. Become a simulated patient at the University of Western Australia's School of Medicine and help train doctors of the future. Call the Doctor of Medicine Team T 6488 7528 E mdpatients-fmdhs@uwa.edu.au
5. Volunteer to be a subject in one of the research projects advertised here every issue. For example, LungScreen WA is looking for smokers or ex-smokers aged 55-74 to help test a system for detecting early stage lung cancer. T 1800 768 655



RAEMA AND JUNE FINISH THE NOVEMBER MAIL OUT

INSTITUTE FOR RESPIRATORY HEALTH

The [Institute for Respiratory Health](#) is a collaborative research organisation.

It aims to improve the life of Australians living with respiratory conditions by bringing together world class researchers and dedicated clinicians to investigate, diagnose, treat and prevent respiratory conditions.



The Institute conducts and fosters innovative basic and clinical research and translate their work into improved treatments for people with respiratory conditions in Australia.

The Institute includes a Clinical Trials Unit and the community support group – L I F E for people living with chronic respiratory conditions.

[Membership](#) is open to community members, researchers, health professionals and research students.

[Your tax deductible donation to the Institute](#) or bequest supports respiratory research.

GETTING TO L I F E AT THE PERKINS BUILDING

Since our move to the Perkins Building may have been missed by newer L I F E members, we re-publish directions on getting to the new meeting room as well as adding an additional easy walking route from the Charlie's bus stop or the multi-deck carpark.

Your destination: Level 6 of the (Harry) Perkins Building at the Queen Elizabeth II medical campus, where Sir Charles Gairdner Hospital and the New Children's Hospital are also located.

The Perkins Building is in the centre of the map below (Ref 2D). One of the newest buildings on site, it stands next to the new red PathWest building (covered with images of red blood cells). It is also near the Lions Eye Institute (Ref 2C).

From the north access the Perkins Building via Aberdare Road, Gairdner Drive and Verdun Street. There is some paid visitor parking (including a few ACROD bays) nearby and a drop-off point in front of the building.

From the south access the Perkins Building via Monash Avenue and Caladenia Crescent (opposite Hamden Road). There is a row of angle-parking paid visitor bays (Carpark 3A - Ref 2E). No ACROD bays but you'll be able to see the Perkins building close by and it's accessible via ramps.

Multi-deck carpark, access from traffic lights on Winthrop Avenue. Many bays, including ACROD, on ground floor (inside and outside) and level 1.

(new) Cancer Centre basement car park in building DD (Ref 3C) has many bays. Follow signs on Gairdner Drive to the underground carpark.

(Car park 4 (Ref 2D) is now a building site and no longer available)

Courtesy buggy can pick you up. Call Charlie's Chariot M 0481 438 721 (Mon-Fri 9am-4pm) or ask at the Gairdner Voluntary Group Enquiries Desk just inside the main entrance in E block.

Perkins Security Desk Tell the concierge on the ground floor of the Perkins Building that you are attending the L I F E lung support group meeting in the Level 6 meeting room. He'll swipe the lift control to persuade it to take you there. The meeting room is in front of you as you exit the lift.

Drop-off point

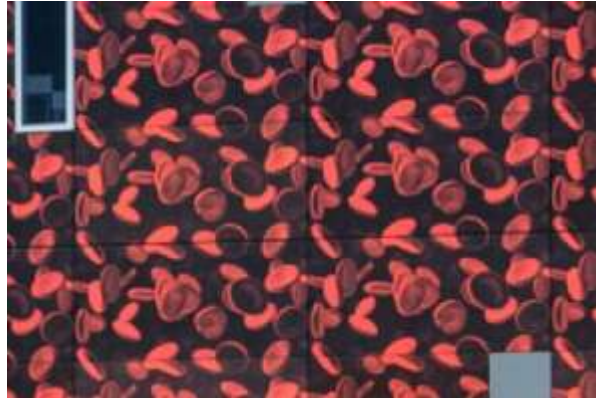
If you are very disabled, for example, in a wheel chair, there is a drop-off spot right in front of the Perkins Building, near Café Anatomy. Your driver can then go and park elsewhere.



Easy walking route from multi-deck carpark or Charlie's bus stop

Get yourself to Watling Walk, the long wide corridor linking together all the main buildings at Charlie's. Walk towards the blue lifts, passing the post box and the entrance to A block (physiotherapy). Walk past the blue lift lobby on your right. Pass through the next automatic doors and continue until you reach a coffee cart and bright green chairs, on your right hand side.

Turn right through the middle of the green chairs and go outside through the automatic doors. Straight ahead of you is the new PathWest building, covered in red blood cells like the picture here. Turn right and walk around PathWest with it on your left and the Perkins Building on your right. A direct route, all flat, no stairs or ramps.



ELECTRONIC NOTICEBOARD – USED RESPIRATORY EQUIPMENT?

Would you be interested in an Australian website where people who have used respiratory equipment, such as portable oxygen concentrators, CPAP machines and nebulisers to sell could "post a notice" electronically?

Likewise people in Australia seeking to buy such equipment could find out who is wanting to sell. No quality guarantees of course, buyer beware etc.

Contact L I F E if you are interested or add a comment to L I F E's Facebook page where this issue was raised on 11 March.



About Lung Information & Friendship for Everyone (L I F E)

L I F E - a group for anyone with a chronic lung condition, their family and carers. It's run by, and for, people with chronic lung conditions. Started in 1992 as LISA, our name changed to L I F E in 2009. L I F E is the community support group of [the Institute for Respiratory Health](#). More about the Institute on page 24.

L I F E is also a member of [Lung Foundation Australia](#)'s network of respiratory self help groups T 1800 654 301. L I F E is thankful for the support of the Department of Respiratory Medicine at Sir Charles Gairdner Hospital.

Breath of L I F E magazine

Our magazine is published 4 times a year - March, June, September & December. It is distributed to all community members of the Institute, including L I F E members. Send your contributions to the editor, Jenni Ibrahim E life@resphealth.uwa.edu.au 7 Ruislip St, W. Leederville, WA 6007. [Read it online](#).

L I F E Membership

Join L I F E by becoming a community member of the Institute. Come to a meeting or contact the Institute T 6151 3198 or E life@resphealth.uwa.edu.au. Membership fee of \$20 a year (incl. GST) is due each 30 June. Members' help and ideas are always welcome - magazine, speakers, social events. Please tell us if you change address.

Contacts

Phone Coordinator **Jenni Ibrahim** T 9382 4678 M 0413 499 701

Postal L I F E c/- Institute for Respiratory Health, Ground Floor E Block, Hospital Ave, Nedlands WA 6009

Email life@resphealth.uwa.edu.au **Web** [L I F E on the Institute website](#) [L I F E also on Facebook](#)

Meetings

1st Wednesday of every month, February to November from 12 - 2.30pm. Speaker starts at 1.00pm, **Level 6 Meeting Room, Perkins Institute Building, Queen Elizabeth II Medical Campus, Nedlands**. Wheelchair and gopher accessible. Light refreshments. If you can, please bring a plate to share. We no longer meet at the Respiratory Library, Department of Respiratory Medicine, 1st floor, B Block.

COMING UP

Wed 1 Jun	**Starts at 12 noon** Q&A	Dr Martin Phillips, Respiratory Physician, SCGH
Thur 30 Jun	Your membership fee is due	You'll receive a reminder letter from the Institute
Wed 6 Jul	Social meeting	No speaker. Come and share a coffee and a chat
Tues 19 Jul	Winter Lunch	Hyde Park Hotel, North Perth
Wed 3 Aug	Respiratory research	Dr Andrew Lucas, Senior Research Fellow, Institute for Respiratory Research
Wed 7 Sep	Genetics and lung disease	Dr Svetlana Baltic, Senior Research Fellow, Institute for Respiratory Research



**Seeking information
about your lung
condition and how to
cope with it?**

**Like to meet others in
a similar situation?**

Join L I F E!



**MEETING
VENUE HAS
CHANGED**