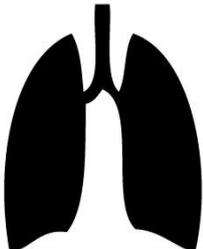


CANBERRA
LUNG LIFE
SUPPORT  GROUP

March Newsletter

Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

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Next Meeting
Thursday 14 March 2013
10.15 am – 12 noon

The Burns Club
8 Kett St
Kambah ACT 2611

**Speaker: Beth Forbes of the Chronic Care Team will speak
about her role in the team,
about breathing techniques
and other topics**

Dates for your diary

Thu 14 March	Lung Life Meeting, Burns Club
Wed 20 March	Concert by the Band of the RMC, Vikings Club, Erindale
Thu 21 March	Seniors Day Expo, Fitzroy Pavilion, Exhibition Park (EPIC)
Thu 28 March	Physio Students at UC
Thu 11 April	Lung Life Meeting
Thu 17 April	Education Day, Southern Cross Club

February Meeting Report

The atmosphere at our February meeting was most welcoming. The air-conditioning was set at a pleasant temperature compared with last month's meeting and the people were warm and friendly. Our speaker, Tanisha Jowsey, works with the Australian Primary Health Care Research Institute (APHCRI), based at the ANU and funded by the Department of Health and Ageing. She has worked there for the last 7 years and it has only existed for about 9 years. The number of researchers has grown from 5 to 35. Tanisha spoke about time, chronic illness and health services.

Two years ago Tanisha "got this crazy idea" to do a Ph.D. Her Ph.D. uses data from the Serious and Continuing Illness Policy and Practice Study (SCIPPS), which is a very large project that looks at Type 2 diabetes, COPD and chronic heart failure. These are the most expensive and preventable

Disclaimer: The information in this Newsletter comes from a variety of sources and is intended as a guide only.

diseases for the government. The Study looks at people's experiences of these illnesses and health services support. The research involves a lot of interviews with patients and allied health professionals. Tanisha's main interest is multi-morbidity (having more than one condition). Her Ph.D. is about time:

- how people experience time,
- how chronic illness can change the way people spend their time,
- how their relationships to time change.
- how people can better manage their time and
- how they can make the most out of health services.

People with lung conditions usually spend between 20 minutes and three hours each day managing their health, but some people can spend as much as 8 hours a day! This is higher than the highest time users of people with other illnesses. Those with multiple illnesses require even more time for health management.

Carers spend on average 20 hours per month on their own health (which does not include "worry time"); compared with non-carers' 10 hours per month, plus the time they spend caring for another person. Carers are truly the "unsung heroes".

Tanisha is recommending that Dose administration aids (eg .Blister/Webster packs), available from pharmacists, be put on the PBS so it will be free to people like us. She suggests patients make plans, get help with tasks and organise a case conference with health professionals by phone or on Skype. Tanisha has also developed a patient-led pocket management plan outlining self-management strategies when health is under control and also detailing a plan when in a health crisis. We checked out the plan and agreed it looks good.

Tanisha gave a most interesting talk - with PowerPoint used to illustrate many of her points and presented in a most enjoyable manner.

Meet the Physio Students

Date: 28 March

The Physio Department at the University of Canberra has organised this year's visit for us to talk to and be checked out by the Physio students. It gives them experience with real people with a chronic illness. If you are interested in participating, contact Pam who will provide all the details: ph: 6288 2053

New Technology improves lung transplants

Wednesday, 16 January 2013 2:00:00 PM AAP reported in www.health.msn.co.nz

More than any other vital organ offered for transplant, the lung is susceptible to injury that is difficult to prevent, detect and predict. To err on the side of caution, 80 per cent of organ donors' lungs are rejected as unsuitable, a waste lamented by doctors and patients alike.

The new **XVIVO** system uses a patented solution named for the final developer, Swedish surgeon Stig Steen which helps to cleanse the lung, reduce fluid build-up and prevent clot formation. It involves cleaning and refurbishing donor lungs while the organ "breathes" in a specially designed machine. Lungs that would normally be discarded can be tuned up, evaluated and, in many cases, reused.

Between 2006 and 2009, **Steen Solution** was approved for use in Europe, Canada, and Australia. It is circulated through the lung using equipment similar to a standard heart-bypass machine. The

organ is continuously evaluated for several hours and then, if the function is satisfactory, transplanted.

Donors' lungs must meet certain criteria, including a limited smoking history, and undergo evaluation with X-rays and other standard tests. But this isn't enough to ensure good outcomes.

Lungs may be injured by physical trauma, cardiac arrest, resuscitation efforts, mechanical ventilation, pneumonia or the irreversible shutdown of the brain, called brain death. (Most donated organs come from patients who are declared brain-dead.)

Even with this high rejection rate, many of the 1700 US patients who do get lungs suffer a sometimes fatal, little-understood complication called "primary graft dysfunction."

The transplanted lungs just don't work properly, perhaps partly because of the physiological shock of having circulation abruptly restored.

This catastrophe can happen despite a technically flawless surgery. It occurs in about 10 per cent of cases at Penn; rates at some centres are two to three times higher.

Lung transplantation remains daunting almost 30 years after the first successful operations in Toronto by transplant pioneer Joel Cooper, who is now at Penn, but this technique is heralding a new period.

"Maybe lung-transplant outcomes will become as good as for kidneys and hearts."

Lung Transplant in Brisbane with new Technique from LARA (LAM Australasian Research Alliance) www.lara.org.au as reported in the **Brisbane Courier Mail, 5 February 2013**

BRISBANE surgeons have performed an Australian first: repairing donated lungs before transplanting them into a Queensland grandmother. The new technique, performed at Prince Charles Hospital, is expected to increase lung transplantation rates in excess of 30 per cent.

Of the 68 lungs donated in Queensland last year, only 25 were able to be used.

The first successful transplant of repaired lungs was performed on 57-year-old Mackay grandmother Sandra Afflick. "I have been going downhill for the past six years," Ms Afflick, who suffered from emphysema and asthma, told The Sunday Mail. "I was down to 20 per cent lung capacity, needed oxygen every night and could barely walk 100m."

She is now walking kilometres each day after having no complications after her surgery.

The article above came from the LAM website. What is LAM?

LAM, or lymphangiomyomatosis, is a rare and progressive lung disease which usually attacks women in their childbearing years, with a variety of manifestations. **Because it is rare, many GPs and even specialists are unfamiliar with LAM and may misdiagnose symptoms as due to asthma, bronchitis, emphysema or depression.**

The first sign of LAM is often breathlessness. This may be accompanied by chest pain, lung collapse, or coughing up blood. Women with LAM may be unaware of changes to their lungs, but have angiomyolipomas (AMLs). These so-called "benign" tumours on the kidneys affect 40% of women with LAM and are asymptomatic unless they burst. Some women develop benign tumours within their abdomen (lymphangiomyomas), enlarged lymph nodes, and free fluid within the abdominal cavity (chylous ascites).

Pneumothorax or lung collapse occurs when a cyst close to the surface of the lung ruptures, letting air leak into the gap between the lung and the chest wall.

In some women LAM develops rapidly. In other/older women the disease progresses more slowly, particularly after menopause.

Currently there is no cure, but several drugs are being investigated. Until a sure fire therapeutic drug treatment is found, lung transplantation is the ultimate remedy for LAM. Several women in Australia are enjoying the benefits of new LAM-free lungs.

Seniors Day Expo

Thursday 21 March

9.30 – 3pm

Fitzroy Pavilion, Exhibition Park (EPIC)

Features over 100 Government and non-government organisations providing information and advice on health, government and lifestyle issues.

We have a place at the Expo.
Come and visit us

Are you itching and scratching? *From Australasian Science, Jan/Feb 2013 p39*

When others yawn, laugh, head nod or scratch, many people have the urge to do the same. This is because of our empathy with others. However a study has shown that the contagious urge to scratch may show negative feelings.

All the participants in the study took part in personality inventories to measure traits of empathy, extent of extroversion, agreeability, conscientiousness, openness and neuroticism. The person with an itch is less likely to be someone with empathy; more likely to have a higher level of neuroticism. Understanding how itching is related to negative feelings could lead to improvements in treatment of conditions that cause severe itching – eg eczema – or that have no apparent underlying cause. Feeling itchy?

Handy Hint

People using oxygen often get sore around the ears where the oxygen tube sits to keep the nose prongs in place.

One suggestion to ease the pressure is to wear a little cap on your head and attach the tubes to it.

Any type of cap will do – even a hanky.

You attach it by any means you like. Any suggestions?

The A to Z of Preventative Health Care (A-B) by Chris Moyle

Congratulations to Ita Buttrose on her Australian of the Year award. Ita is an ambassador of the Alzheimers Association and promises to bring attention to our ageing population with emphasis on preventative health care. To those of us with lung disease prevention may seem irrelevant, but there is still much we can do to hopefully limit the number of exacerbations we experience and prevent other types of chronic illness arising.

Acidophilus (in capsules and plain yogurt). Take this with antibiotics to replace the good bacteria.

Action As Dr Phil says, "Life rewards action". Every day do what is necessary to maintain your health.

Addictions Eliminate them, especially smoking.

Alzheimers can possibly be prevented by eating a healthy diet, exercising and regularly doing puzzles such as Sudoku and crosswords. Early intervention may help delay onset.

Antibiotics Always finish the course. Often essential for those with lung disease, but best not over-used. Aim to improve your immunity with a healthy diet, regular exercise and plenty of rest.

Antioxidants Eat plenty of green leafy vegetables, red, orange and purple fruits and vegetables to help your body fight free radicals and protect you against cancer and other diseases.

Anxiety is common in patients with chronic illness. Follow a balanced lifestyle and get help if necessary to manage your stress levels. Courses available on-line or see a psychologist.

Assertiveness Know your limits and don't be afraid to say "No".

Balance Walking develops leg muscles which helps maintain balance and prevent falls. Strive for a balance in your everyday life of sleep (at least 8 hours), regular mealtimes, physical exercise, mental stimulation and social interaction.

Blood Pressure Very important indicator of heart disease. Check it regularly. To prevent and treat high blood pressure do regular physical exercise, lose extra kilos if you're overweight, restrict salt and alcohol consumption and manage stress.

Bones Weight-bearing exercise is important for strong bones, as is an adequate amount of Vitamin D, calcium and magnesium. See your GP for a blood test to measure your levels, and also have regular bone scans.

ACT Chief Health Officer's Report 2012

Leading cause of death (p9 and p21)

Cardiovascular 34%

Cancer 29%

Accident & injury 8%

Respiratory diseases 5%

Mental disorders 5%

Diseases of the nervous system (including alzheimer's) 5%

Diseases of the respiratory system 4%

Diabetes 3%

Hospitalisation (p9 and p22): People over 45 most likely to be hospitalised as a result of **COPD**, osteoporosis and osteoarthritis; cardiovascular disease; **lung** and colorectal cancer; chronic kidney disease and diabetes

Medicare Local: 2012-2013 Population Health Needs Assessment (p18)

Respiratory disorders (14.5%) are highest in Weston Creek/Stromlo compared to ACT's average of 13%.

Get healthy information and coaching service

This is a free, confidential telephone based service which helps people with:

- Healthy eating
- Being physically active
- Achieving and maintaining a healthy weight

The service runs for 6 months and delivers coaching support and information to help you reach your health goals. You get:

- Your own personal coach
- Up to 10 free coaching calls
- Support to make changes over 6 months
- An information booklet to assist you
- Access to a website to help you keep track

To start, phone 1300 806 258 or send an email with your contact details to:

contact@gethealthy.act.gov.au

The website is: www.gethealthy.act.gov.au

A date to put in your diary

LungNet Education Day

Southern Cross Club, Woden

Wed 17 April

9.45am – 2pm

Come and hear talks on:

Breathlessness and management strategies

Your own personal plumbing

Respiratory issues

The cost includes lunch and refreshments

To book a place: phone Lung Foundation Australia

Ph: 1800 654 301