

November 2014 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 13 November 2014

10.15 am - 12 noon The Burns Club

8 Kett Street, Kambah

ACT 2902

Guest Speaker: No speaker. We will be having some business and a lighter program.

Dates for your diary

Wednesday 19 November 2014 World COPD Day Thursday 11 December 2014 Christmas Luncheon

October Meeting Helen Cotter

PamG most efficiently ran today's meeting. Amongst other things, we discussed:

- The Flora excursion at the Botanic Gardens. See report later in this newsletter.
- The World COPD Day on Wednesday 19 November. Our stand at the Canberra Centre is now registered with the Lung Foundation and we are being sent a package of items useful for the event. We will be doing our final organisation at our next meeting.
- The Christmas lunch. We decided to have it on 11 December 2014 instead of our usual meeting. More information later in the newsletter.
- In view of this decision, our final meeting for the year will be on Thursday 13 November 2014.
- The purchase of the Venturi masks after a request for assistance. We agreed to the request and agreed that, in future, we would decide about assistance on a case by case basis depending on our finances, with the decision resting with the coordinator and the treasurer.

As our speaker was unable to attend, we continued with our series of **Why I came to Canberra**. Carolyn Dalton spoke about her experience. Later, we had a 15 minute session on Mindfulness with Marshall O'Brien.

Mindfulness Marshall O'Brien, Psychologist

Marshall talked about mindfulness as an established treatment in psychotherapy for various conditions such as depression, pain and chronic illnesses. Many people connect mindfulness with emptying the mind in order to meditate. However, in psychotherapy, mindfulness is used to focus the brain to assist you in helping the body to run itself. This can help improve your functioning in any part of your life.

The brain is constantly directing the body to keep functioning, most of it occurring behind the scenes without our being aware of it. For instance, most of the time we are not aware of what our feet are doing. Once the word 'feet' is mentioned we suddenly become aware of them. Mindfulness is concentrating on that part of the body you want the brain to intervene in. When you concentrate on it, you bring your brain to focus on the processes. Marshall led us through a small exercise. He asked us to separate our hands and have them placed relaxed. He talked about how most of the time, we have no awareness of what our hands are doing but by concentrating on them, we can bring about changes. For instance, we had to choose a hand, then concentrate on it for a while, imagining it to be cold; then imagining it to be colder. The other hand would then feel warmer and we could think it warmer. Warm hands are good for soothing painful or tight areas. Some people are able to bring about the change in the hands' temperature so that one hand feels really cold and the other sweating.

Marshall went on to talk about breathing. If you are mindful when you breathe in and out, you notice that the air you breathe in is cooler than your body; when you breathe out, the air in the nostril is warmer. It's the front of your brain that is observing that.

The next step is to attach a word to that event – any word that is important to you eg energy, contentment, calmness, confidence. When you breathe in, think that the breath is energy or contentment etc. You are giving a message to the brain, telling the brain what you want. Gradually you will train the brain to think like that so that you improve your energy or contentment or confidence or lessen anxiety or whatever is important to you. That is the benefit of mindfulness.



Christmas Lunch Thursday 11 December 2014 (in lieu of the meeting) At the Burns Club 12 for 12.30

Cost to be announced – approx. \$25 – 30

RSVP at the next meeting or
contact Pam Harris on 02 6288 2053 or bapjh@live.com.au

Would members please bring items suitable for a Christmas Hamper to the next meeting.

Reasons for coming to Canberra

Maddie (Madeline) Fleming came to Canberra from Cootamundra as a young innocent girl in 1953. It was the year the queen was visiting Australia and Maddie's employer, the Postmaster General's Department (PMG) needed additional people in Canberra for this event and also because Parliament was in session. Maddie arrived for a 6 months posting, working as a telephonist, even though her parents were beside themselves with worry about her leaving home at such a young age.

At the end of the six month posting extra staff were still required and Maddie was invited to stay on in Canberra. She agreed. She stayed at the rather ramshackle Mulwala House (old Army barracks) near the Bishop's residence, off Commonwealth Avenue, and in close proximity to a similar



Maddie and husband Perc at the 2013 Christmas Lunch

hostel, Reid House. Later Mulwala and Reid were demolished so Parkes Way could be constructed. Maddie moved upmarket from Mulwala to Barton House and in 1959 moved into the lovely 8 storey Currong Flats in Braddon, along with many others from PMG and Defence Departments.

Canberra provided her with a good social life – going to dances and balls and having lots of fun. Maddie settled in Canberra and has really enjoyed living here.

World COPD Day Wednesday 19 November 2014

We are having a stand from 10 am to 3 pm on the ground floor of the Canberra Centre, near the Bunda Street entrance. Nurses from the Chronic Care Team will be testing the lungs of willing passersby. Group members will be needed to speak to interested parties about COPD and how it has impacted on their life

The A-Z of Preventative Medicine (H) Chris Moyle

Hope is the state which promotes the belief in a good outcome related to events and circumstances in one's life. Psychologist C.R. Snyder and his colleagues say that hope is cultivated when we have a goal in mind, determination that a goal can be reached, and a plan on how to reach those goals.

"There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of something better tomorrow". Orison Swett Marden, wrote (1848-1924).

"You can either be hopeless about your illness, or hopeful. Don't isolate yourself. Be hopeful!" (Brett Michaels – American entertainer with Type 1 diabetes).

Allegory of Hope

Oil on canvas, Francesco Guardi, 1747

http://en.wikipedia.org/wiki/Francesco Guardi



Walker: free to a good home

Ebba bought herself a new, smaller walker more suited to her needs. Consequently she is now looking for a good home for her large model. The walker

- is suitable for a taller person
- has wheels and brakes
- has a basket
- and folds up.

If you are interested, please phone Ebba on 02 6286 4481 or email ebbamarr@hotmail.com

Not suitable but.... Pam Gaston

In August I travelled to Liverpool to see Dr Jonathan Williamson to find out if I was suitable for Endoscopic Lung Volume Reduction (ELVR), the treatment of placing valves in the lungs. I found Dr Williamson informative, easy to talk to and more importantly, he listened to what I had to say.

Treatment has been around for a while where up to 90 to 95 percent of patients were treated but a large number failed. Fine tuning and setting new guidelines and procedures have resulted in approximately 1 in 5 being suitable for the treatment. Treatment is dependent on nuclear lung scans, blood tests and lung function tests. I was kept informed of the test results in a timely manner. Unfortunately I was not a suitable candidate. Medical expenses after the Medicare rebate were \$20.00 and included all tests.

While I was not suitable I feel that what I gained far outweighed the negatives and I am prepared to see Dr Williamson on a regular basis.

Endoscopic Lung Volume Reduction Helen Reynolds

What is it?

Endoscopic Lung Volume Reduction (ELVR) is a form of non-surgical lung volume reduction to treat people with severe emphysema.

How does it work?

- In severe emphysema, damaged lung tissue will gradually lose its elasticity; an inelastic lung has difficulty emptying of air.
- Eventually more and more air gets trapped in the lung, causing over-inflation (hyperinflation).
- Air that gets trapped in the inelastic lung does not contribute to ventilation and makes breathing inefficient and difficult.
- The one-way endobronchial valve is typically implanted such that when a patient exhales, air is able to flow through the valve and out of the lung compartment that is fed by that airway. However, when the patient inhales, the valve closes and blocks air from entering that lung compartment. Thus, an implanted endobronchial valve typically helps a lung compartment to empty itself of air.
- Deflating these areas of hyperinflated lung has been shown to improve breathing parameters, exercise capacity and quality of life in selected people with severe emphysema.
- This can be achieved using one-way valves (endobronchial valves) that are inserted into the airways of the most diseased areas of lung.
- These endobronchial valves gradually deflate the diseased areas of lung and allow the remainder of the lung to function more effectively.
- When one or more diseased portions of an emphysematous lung are made to deflate and collapse, other
 healthier portions of the lung have more room in the chest cavity to inhale and exhale, pressure is
 removed from the diaphragm, and even the heart may function better as the hyper-inflated lung becomes
 smaller.
- Endobronchial valves are typically implanted using a flexible delivery catheter advanced through a bronchoscope, and thus they are minimally invasive.
- The valves are also removable if they are not working properly. When properly used and correctly implanted, endobronchial valves have been shown to improve patients' ability to breathe, walk, exercise and perform their daily activities
- Using the bronchoscope, the endobronchial valves are positioned and deployed into your airways, there is no cutting or surgery involved.
- The whole procedure takes approximately one hour and usually you may go home on the next day.

How do I find out more?

- ELVR is not suitable for everyone and a detailed assessment by a physician is required prior to offering this treatment.
- Your Lung Specialist can give you more information and answer any questions you may have.
- Patient Information Guides and External Links: Olympus Intrabronchial Valves (IBV) for Emphysema.
- The Patient Guide for The Olympus IBV valve can be obtained here:

http://www.olympusaustralia.com.au/Product/Detail/926/IBV-Intra-Bronchial-Valve Also available is the Pulmonx EBV valves - guide for Patients with Emphysema: https://pulmonx.com/en/patients/patient-guide/

Sources: https://pulmonx.com/en/patients/patient-guide/

http://sydneypulmonology.com.au/http://sydneypulmonology.com.au/

http://sydneypulmonology.com.au/procedures/endoscopic-lung-volume-reduction

Video of Pulmonx Endobronchial valve deployment:

[link to be provided]

For a Video of the Olympus Intra Bronchial Valve deployment:

http://www.olvmpus-

europa.com/medical/en/medical_systems/applications/pulmonology/therapeutic_bronchoscopy/emphysema_treatment_with_intra_bronchial_valves/emphysema_treatment_with_intra_bronchial_valves 1.html

Professor Ing talks about Endoscopic Lung Volume Reduction:

http://mqrs.com.au/frontier_magazine_elvr_in_copd.pdf

http://en.wikipedia.org/wiki/Endobronchial_valve

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

Honour for Shirley Helen Cotter

In the same year as Lake Burley Griffin turned fifty, so did the suburb of Curtin. Recently a celebration was held to commemorate the event at the Curtin Shops and our long term member, Shirley Dillon, was asked to talk about the early days of Curtin. Shirley, with her husband Ron and their children, was the first resident in the Curtin area, moving there in 1964. They lived in the first house to be built and were surrounded by tractors and graders, dust and noise. Shirley still lives in Curtin.

Ron Dillon began work in Canberra in 1960 with Shirley joining him in 1962, living in the Allawah Flats. Ron had an eminent career in the Police Force and was much respected; Shirley was the homemaker. Ron was, like many at that time, a smoker who later developed emphysema/COPD.

In 1998, Ron and Shirley were founding members of the Lung Life Support Group along with twelve others, including Esther and Ray Fitton. Since Ron's death, Shirley has stayed on as a much loved member of the group.



Shirley was the auctioneer at our Christmas in July Luncheon. She is adept at anything she turns her hand to.

It is lovely that Shirley was asked to talk about Curtin's early days at the Commemoration. A great honour.

Flexible Bus Service

A localised, flexible transport option for Canberra seniors and people with a disability.

For bookings call: 02 6205 3555
Email: flexibilebusservice@act.gov

Bookings must be made two days prior to travel.

- > Free service
- ➤ Local shopping centre drop-off
- Hospital drop-off on request
- > Wheelchair accessible mini-bus
- Servicing selected Canberra areas.

Call 02 6205 3555 for more information

A day in the National Botanic Garden Helen Reynolds

The day was perfect. Everyone was on time and waiting in the correct place. We even had time for a chat while we waited for Flora the Explorer to arrive. Getting us all aboard took some time but eventually we were all seated with our seat belts buckled and we departed for our tour of the National Botanic Garden.

Everything looked spectacular: the waratahs were blooming in all their glory; for an almost extinct pine the Wollomi Pine looked extremely healthy; the bottle tree looked to be full; the Red Centre was like a desert with Sturt Desert Peas blooming and the Sydney Region Gully looked like the Sydney landscape.



Back at the café we settled back at our circular table (made conversation much easier) and enjoyed each others company.







'Dinosaur tree' or 'living fossil', the Wollemi Pine is certainly one of the greatest botanical discoveries of our time.

http://www.rbgsyd.nsw.gov.au/plant_info/wollemi_pine

Photos courtesy of Helen Cotter and Pam Gaston.







