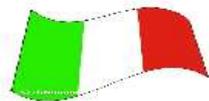




Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

Newsletter July 2011

contact: Helen Cotter ph: 6281 2988
lung.life@hotmail.com



Italian in July

Come and celebrate the mid-year with a luscious Italian lunch in the warmth of the Weston Club

Tuesday 5 July
12 noon for 12.30



**The
Weston
Club**

**1 Lizardet St
Weston**

COST: \$25

Menu

herb'n garlic bread
lasagne and tortellini
with choice of a
tomato or a cream
sauce
accompanied by a
tossed salad
tiramisu
fruit platter
tea'n coffee

rsvp: Pam ph: 6288 2053 or
email: bapjh@live.com.au

**If you have said you'll come and you find that you can't, please let Pam know by the weekend before otherwise you will unfortunately have to pay for your meal.
Look forward to catching up with you all.**

Next Meeting

Thursday 14 July
10.30am – 12 noon

The Weston Club,
1 Liardet St
Weston

This is an informal meeting. It's a good time to talk about some Lung Life issues and catch up with others.

May Meeting

Emma Awizen, Co-ordinator of Respecting Patient Choices Program at the Canberra Hospital's Quality and Safety Unit, workshopped her way through establishing an **Enduring Power of Attorney** and an **Advanced Care Plan** and completing a **health directive**.

Enduring Power of Attorney (EPA)

Anyone over the age of 18 needs to have an Enduring Power of Attorney (EPA). In the ACT a spouse or next of kin has no right to make decisions on your behalf so it is a good idea to have clearly set out what your wishes are when you can no longer make those decisions yourself. The EPA has to be completed where you are a resident and doesn't require a solicitor to complete it.

Advanced Care Plan indicates your medical wishes when you are unable to let others know yourself. You can state, for instance, that you only expect to be resuscitated if a reasonable outcome is expected i.e., you can feed yourself, move around and won't be in a vegetative state. There is a law which states that every person in the ACT will be given palliative care.

Statement of Choices and Health Directive should be discussed with your GP and specialist/s and is another way of indicating your medical wishes. The doctors should keep a copy.

If you need any assistance with these forms, Emma can be contacted on **6244 3344**. Emma will also scan your details into the public hospital system so it is available any time you present at hospital. If visiting a private hospital you will need to show them your Advance Care Plan on each occasion you are admitted. You may like to give a copy to your doctor and to your attorney/s.

Emma can also give you a card to place in your wallet. She suggests you read the booklet "**The Power to Choose**" and contact 6207 0707 to receive a copy.

Feedback

Re the article in last month's newsletter on taking up the harmonica as a way of exercising the lungs. It was pointed out that this may not be such a great idea as the harmonica could harbour bacteria which could infect as the player breathes in and out while playing the harmonica. Perhaps whistling or singing may be a healthier way to exercise the lungs.

ALF COPD Patient Taskforce Teleconference June 6

Caroline is our representative on this taskforce which is part of The Australian Lung Foundation (ALF). Each month, she participates in a teleconference with representatives from around Australia. Helen Reynolds has joined Caroline Scowcroft as an ACT delegate. Helen has been diagnosed with COPD and is looking forward to being part of the teleconference team. Here are some of the issues they discussed in the June teleconference.

ALF reported on a project where hand held lung testing devices would be used by pharmacists, nurses etc, not to replace spirometry testing but as a guide to advise patients where there is a need to follow up. Clinicians have produced a Position Paper recommending the use of the **Piko6** and the **COPD6** as screening devices. ALF envisages an online video as a training tool giving education and information for health professionals.

The ALF is also advocating for an increased rebate for the GP for performing spirometry in their surgery and for a training program for practice nurses.

Later this year, following the success of the Lung Health Checklist, general lung health will be featured with the aim of catching the attention of a younger audience from late 30s and up. The plan is to use humour but with serious messages following the cheeky images.

The teleconference discussed the **World COPD Day 2011** to be held in November. ALF will send out the forms to Support Groups with suggested activities for the day. There will be two main events for lung testing, one in Melbourne and one in Sydney. Other areas may be able to coordinate with health professionals and use the Piko6 for testing.

The ALF was involved with a Men's Health Initiative on June 17 in Brisbane. At this event Ainsley Ringma, the ALF respiratory nurse, conducted PiKo6 screening tests at a local Men's Shed.

ALF is setting up a register to record how many people have Pulmonary Fibrosis. For further information, contact ALF at enquiries@lungfoundation.com.au

Air Sep has put out a "Freestyle" model of a back pack type Portable Oxygen concentrator which weighs only 2-3 Kg. A Gold Coast member has sourced the cheapest one at "Mega Medical Equipment & Gases", Cromer, Sydney at a cost of \$3970 delivered to Queensland as opposed to a cost of \$6300 quoted by another company. Please see attached link on this product <http://www.airsep.com/medical/freestylee.html>

Viagra for children CT May 7, 2011

The European commission has approved the use of Viagra to treat children with high blood pressure in the lung arteries – pulmonary arterial hypertension, a rare deadly lung condition. The rare progressive disease leads to heart failure and premature death. Its cause can't always be determined.

The drug, called Revatio, is already approved for treating adults with the condition by reducing the pressure. It was originally developed to treat blood pressure problems but became famous for improving erections in men and now generates close to \$2 billion for Pfizer in annual sales.

The drug does have side effects including vomiting, nausea, fever, cough, abdominal pain and extreme light sensitivity.

Dialogue between Albert and a rep from ResMed

Subject: VPAP IV with Mirage Micro Nasal Mask

From Albert, I have compiled a video/audio presentation on the impact of chronic disease on my life. I have attached extracts from the presentation that are self-explanatory and may be of interest to ResMed, as they explain what a patient may suffer at the coal face who is prescribed a VPAP.



Albert

From ResMed Rep: *Thank you for sending me this - I am sorry to see you have to wear so much "stuff" on your head to sleep at night. You might be interested to know that we have just brought out a new nasal mask - Mirage FX - which is taking the northern hemisphere by storm, so much so that we have to wait until June 1st to release it here as it just sells out as soon as it arrives in the countries. I have shown it to the hospital sleep labs I visited yesterday and they all want it and I have 2 more days of visits to other hosps here to show it, so I may be lucky to escape their clutches and keep it in my possession until the end of the trip!!! I think you should try it as soon as it is available as it should get rid of a lot of the "stuff" you are now wearing at night all those bandages!! I am guessing you have mouth leaks too! Hopefully we can sort that out as well so you don't have to look like an Egyptian mummy!!*

Albert: Those 'bandages' was a chinstrap hurriedly put on for the photo. I bought a number of chinstraps modified them to the contour of my face.

ResMed Rep: *Thanks for your information. We have just released a brand new nasal mask called Mirage FX which is amazing and walking out the door in Europe and US where it was released first. It is very small, simple to assemble and very comfortable to wear, so you should get one of them from your local distributor.*

Albert: Subjective descriptions like 'brilliant' and 'amazing' convey little to me. I am wondering what improvement the Mirage F nasal mask could possibly offer over my self-modified Mirage Micro nasal mask that does not leak at all? You are indeed brave to assert that ANY nasal mask is comfortable to wear. From a patient who has been at the coal face for 11 years I assure that no face or nasal mask is comfortable and never will be. They can only be improved by making them less uncomfortable.

ResMed Rep: *It is small and very comfortable and soft and my husband is trying it out and says it is the best he has ever worn, so trust me this beats the Micro hands down. In fact that mask was a bit of a failure and my husband wore it for awhile after wearing the Ultra Mirage nasal mask for years which he liked very much.*

Albert: I appreciate that your husband found the Mirage Micro 'a bit of a failure' and trust you restrained him from reporting that to ResMed, who promoted it with enthusiasm. I am baffled why your husband even acquired a Mirage Micro when he was apparently happy with an Ultra Mirage. I trust you did not recommend him the 'New breath-taking Mirage Micro.'

ResMed Rep: *John works for Resmed so he often is a guinea pig for the mask dept to try masks on. The new one is extremely quiet too, and can handle high pressures so if you can possibly get a trial on it, it might turn out to be just what you have been looking for.*

Albert: I suspected your husband was an employee of ResMed as otherwise things did not add up logically. Unfortunately, that detracts from your recommendations: your husband being bound by his loyalty to ResMed and you to your husband. I sincerely trust your husband does not suffer from COAD (COPD) as respectfully, I

believe only a person so unfortunately afflicted is qualified to know the efficacy of their life supporting appliances. I don't know the conditions under which ResMed carry out trials but to be credible they should be on randomly selected patients not connected to ResMed.

I will carry out the same procedure successfully used to buy a new car or appliance; seek out satisfied customers after they have tested and trialled them for me. I always have an open mind so will definitely trial the Mirage F nasal mask to see if it qualifies for your accolades and my seal of approval.

Food to help you sleep from CT 9 March 2011

Caffeine is known to keep you awake at night, as are big meals and fatty, sugary or spicy foods but certain foods can help you sleep.

Tryptophan is an amino acid used to make serotonin and melatonin, substances that promote sleep.

Where do you find it?

In protein rich foods such as dairy, seafood, meat, poultry, wholegrains, beans, lentils, peanuts, eggs and sesame seeds.

Combine them with complex carbohydrates which allows more tryptophan to enter the brain (protein rich food alone may perk you up!) So, try cereal with milk, a carton of Greek yoghurt or low-fat cheese on wholegrain crackers – or a glass of warm milk.

Add **magnesium**. This helps serotonin production and may help muscles relax. Magnesium is found in almonds, bananas, beans, spinach, soybeans and wholegrain brown rice.

Big fatty meals keep the digestive system working longer. Make sure you keep it light and healthy.

Ready & Able – Keep your brain active by Chris

Last month's words needed to be sorted into categories. Here's the answers. Words following 'water' are fowl, level, mark, pistol, resistant.

'Punctuation marks' are apostrophe, colon, comma, full stop, hyphen.

'Emotions' are angry, frustrated, happy, scared and sad.

'Nuts' are brazil, cashew, macadamia, pecan and pistachio.

Remaining words give you the answer: **OPERA HOUSE**

Here's an easy one called '**Steps**'.

Altering one letter at each stage to form a new word every time, change the word on the top line to the word on the bottom.

FEET _ _ _ _ _ _ _ _ _ _ _ _

MOAN _ _ _ _ _ _ _ _ _ _ _ _

BRUT

Answers next time.

Dates for your diary

Wednesday 16 Nov World COPD Day



“Living a Healthy Life with Long -Term Conditions” 2011 COURSE SCHEDULE

Do you have diabetes, asthma, heart disease, arthritis, cancer,
back pain, obesity or any condition lasting longer than 6 months?

Does it prevent you from living life as you would like?

Cause you stress? Impact on your relationships?

**Arthritis ACT-phone 6288
4277**

October/November
Fridays 12pm-2.30pm
October 14, 21, 28,
November 4, 11 & 18

Phillip Health Centre

July/August
Mondays 10am-12.30pm
July 25, August 1, 8, 15, 22 & 29

Belconnen Health Centre

July/August
Thursdays 2pm-4.30pm
July 28, August 4, 11, 18, 25
& September 1

October/November

Fridays 10-12.30pm
October 28, November 4, 11,
18, 25 & December 2

October/November

Thursdays 10am-12.30pm
October 20, 27, November
3, 10, 17 & 24

**To register for Health Centre courses, or discuss course details please
phone :**

**Community Health Intake
Phone 6207 9977 between 8am-5pm Monday- Friday**

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to subscribe.*

lung.life@hotmail.com or return the mailed newsletter