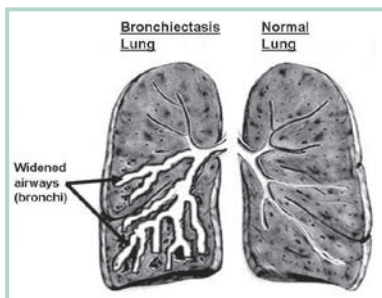


## • Bronchiectasis

Dr Paul King and A/Prof Peter Holmes, Monash Medical Centre, Victoria

### What is bronchiectasis?

Bronchiectasis is defined as widening or dilation (**ectasis**) of the airways of the lung (the **bronchi**). This is shown below:



### How is bronchiectasis diagnosed?

If it is suspected that you have bronchiectasis, a diagnosis is usually made by the use of computed tomography (CT/CAT) scanning of

your lungs. A particular form of CT is used called a high resolution CT (HRCT) which shows the bronchi in detail. The CT scan takes cross-sectional pictures of the chest. Should the CT show that the bronchi are abnormally widened, this is reported by the radiologist as a diagnosis of bronchiectasis.

### How does bronchiectasis occur?

Bronchiectasis is thought to be due to a combination of bacterial infection of the bronchi in association with a defective immune response. The main purpose of the body's immune system is to clear infection, and an ineffective immune response allows infection to persist. Persistent infection causes inflammation which damages the infected organ.

In patients with bronchiectasis, the inflammation produced as a response to infection causes the release of chemicals such as proteases. The proteases digest the lining of the airways, causing damage. The damaged airways become weakened and will widen and become bronchiectatic. There are a very large number of causes of a defective immune response in the lungs. In many people, it is not possible to find a cause for the development of their bronchiectasis.

### Symptoms of bronchiectasis

The main symptom of bronchiectasis is a chronic cough, which produces sputum or phlegm, and is often worse in the morning. Often, your cough will have been present for a number of years before a diagnosis is made. The cough may interfere with sleep, cause significant social embarrassment and can cause urinary incontinence. The colour of the sputum varies from white to deep green. Discoloured sputum usually means more airway infection. Chronic fatigue is another very common symptom and patients generally report reduced energy levels. Other important symptoms include shortness of breath and chest pain.

Many people have problems with inflammation in their nose and sinuses, leading to localised pain and discharge. About a quarter of patients will cough up blood at some stage, which is due to inflammation of the lung airways.

On examination, the most common finding is the presence of crackles (heard by a stethoscope) in the lower lung. These crackles occur because there is infected fluid in the airways.

A feature of bronchiectasis is that your condition will vary and you will usually have at least one exacerbation (acute worsening) of your bronchiectasis a year. Some symptoms of an exacerbation may include increased cough and shortness of breath, a change in the colour of sputum, fevers and malaise and new x-ray changes.

### What tests do I need?

If you have a suspected diagnosis of bronchiectasis, you should have a high resolution CT (HRCT) scan of your lungs to confirm the diagnosis. A sputum sample should be obtained to try and identify any bacteria. You will need a blood test to screen for immune function (the test looks for an underlying cause) and you should also have a formal lung function test in a hospital laboratory. Another test called a bronchoscopy, which is a small telescope, may be used to look at your airways in more detail.

### What treatment is available?

Patients with bronchiectasis usually need long-term treatment, which is normally focused on the management of exacerbations and maintenance management.

Management of exacerbations involves early medical review (the earlier the better). Patients are most commonly prescribed two antibiotics for two weeks (sometimes longer) with regular chest physiotherapy and increased use of bronchodilators (such as Ventolin). On occasions, patients will need to be admitted to hospital to manage their exacerbations.

Maintenance management revolves around chest physiotherapy, the use of bronchodilators, regular exercise (appropriate to your fitness) and vaccinations. Specialist pulmonary rehabilitation programs are often helpful.

A very important aspect of treatment is, that in time, patients will generally know what works best for them and it is important that you work with your health professional and keep them informed.

### What is the prognosis?

The severity of bronchiectasis can vary greatly from patient to patient. Most people will have ongoing symptoms, but with appropriate treatment, you should be able to manage these and have a normal quality of life.



Dear Readers

The Australian Lung Foundation has been saddened by the recent passing of two of its esteemed colleagues. Many of you will have already heard about the tragic death of Professor Rob Pierce

who passed away at his St Andrews property during the Victorian Bushfires in February. Professor Pierce was the leading light and a great motivational force for the proposed Indigenous Lung Health Summit, and plans for this have now been put on hold. Professor Pierce was lead author of a report on respiratory and sleep health in Indigenous Australians. In conjunction with the Thoracic Society of Australia and New Zealand (TSANZ), it is anticipated that the Lung Foundation will publish the report in late July.

We also regret to inform you of the passing of Dr Bill Scowcroft in March. Dr Scowcroft was a member of the National Council and an enthusiastic advocate for those affected by lung disease. You will read more about Dr Scowcroft's work elsewhere in LungNet News. His fellow Councillors and all at the Lung Foundation will miss his constructive participation.

### TSANZ Annual Scientific Meeting

In early April, the TSANZ Annual Scientific Meeting was held in Darwin where Dr Bob Edwards presented the Lung Foundation's annual awards to the successful applicants:

- The Australian Lung Foundation/Boehringer Ingelheim COPD Research Fellowship: Dr Benjamin Harris
- Slater and Gordon Asbestos Research Grant-in-aid: A/Prof Paul Reynolds
- Lung Cancer Consultative Group Awards
  - Postgraduate Grant-in-aid for Lung Cancer Research: Ms Morgan Davidson
  - Cochrane Review Scholarship: Mr Robert Smith
- Ludwig Engel Grant-in-aid for Physiological Research: Prof Haydn Walters, A/Prof Shyamali Dharmage and Dr John Morrone
- John Reid Prize: Jason Amatoury

We wish the recipients success with their projects and look forward to hearing the results of their research.

### National Council

The National Council Executive Committee held its first meeting in March with a focus on reviewing the Lung Foundation's strategic planning initiatives and reaching an agreement of the Charter. The Council was delighted

to receive notification that the Governor General, Ms Quentin Bryce had accepted The Australian Lung Foundation's invitation to become Patron.

### Annual Report

The Lung Foundation's 2008 Annual Report is now available on our website, [www.lungfoundation.com.au](http://www.lungfoundation.com.au) for your perusal. Please take the opportunity to review our achievements. 2008 was a year of investment for the future growth of the Lung Foundation, leading to a break-even position in the financial statements. I am particularly pleased to advise that the administrative component of our expenditure is significantly below the national average for not-for-profit organisations.



### Financial Membership

We are appreciative of those who have renewed their 2009 financial membership of the Lung Foundation. This year, a membership card is to be introduced and together with your receipt, will be forwarded in due course. In response to the demand from a number of members, we are considering introducing longer term memberships from 2010. If you have not already renewed or taken out your membership for 2009, please consider doing so as it will give you an opportunity to voice your support of the only Australian charity devoted to serving all Australians with lung disease. Please contact either myself or Margaret Goody with any queries.

Yours Aye

*William Darbishire*

### Diary Dates 2009

LungNet Education Day WA	1 July
LungNet Education Day Qld	9 September
LungNet Education Day NSW	17 September
LungNet Education Day TAS	tba
LungNet Education Day SA	tba
LungNet Education Day Vic	23 October
Lung Health Awareness Month	November
Lunch for Lung Cancer	13 November
National Plant for Lung Cancer Day	15 November
International Lung Cancer Awareness Day	17 November
World COPD Day	18 November

### About the LungNet News

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## News from the World of Interstitial and Orphan Lung Disease

Juliet Brown, Executive Officer of The Australian Lung Foundation's PIVOT Group



Pulmonary Interstitial Vascular Organisational Taskforce

Since my last Pulmonary Interstitial Vascular Organisational Taskforce (PIVOT) update, the Group has convened for its first

teleconference of 2009 in February, and a face to face meeting as part of the Thoracic Society of Australia and New Zealand (TSANZ) Annual Scientific Meeting (ASM) in April. PIVOT's primary focus, ARNOLD (Australasian Registry Network for Orphan Lung Diseases) continues to be a work-in-progress and a website is now under construction. Members of the ARNOLD sub-committee presented a poster at the recent TSANZ ASM to inform the respiratory fraternity in Australia and New Zealand of the aims and objectives of the Registry.

The Australian Lung Foundation and members of PIVOT were saddened to hear of the passing of pulmonary fibrosis patient, Mr Derek Forster from Victoria in March.

Mr Forster had been extremely supportive of the work of PIVOT, and had made a number of generous donations to the cause.

Sydney-based support group, "People Living with Pulmonary Fibrosis" is now in its third year of existence and continues to meet on a regular basis under the guidance of PIVOT consumer representative, Mrs Miriam McLean, who we would like to thank for her continuing hard work.

PIVOT is fortunate to be able to call upon a number of dedicated consumers who have advocated for greater recognition and awareness of interstitial and orphan lung diseases. We would especially like to thank Ms Rebecca Bayalance, a patient with follicular bronchiolitis from Adelaide, who was able to secure a meeting with her local Federal Member of Parliament in January.

If you would like any further information about PIVOT, please call Juliet on 1800 654 301.

### Triumph for COPD



Jack Evans of Armidale in NSW has decided to turn his passion for car restoration into an awareness raising campaign for Chronic Obstructive Pulmonary Disease (COPD). Jack lost his dear wife, Gill in June 2006 after she had battled COPD for some 16 years.

Jack, a father of five and grandfather of nine, has been restoring Triumph motor cars for nearly 30 years and bought the

wreck of a Triumph Super Seven 35 years ago, which has sat in his back shed for decades. After many hours of laborious work, the car is nearing completion and Jack intends to retrace the journey taken by Percival Armstrong and George Manley. Armstrong and Manley drove from Perth across the Nullabor to Sydney in 1929 in just eight and a half days in the same make and model car. This epic journey was to prove that the Triumph was more than "a nice little town car". On the 80th Anniversary of the trek, Jack will be travelling with his daughter, Alison, and intends to make many stops along the journey to raise awareness about COPD and hopefully raise much needed funds to assist the ongoing support and services provided by The Australian Lung Foundation.

Jack intends to drive his Triumph from Armidale to Adelaide where the car will continue its journey to Perth via rail. The estimated departure from Perth will be late September 2009 and Jack's drive should include the following locations: Perth - Kalgoorlie - Norseman - Eucla - Ceduna - Port Augusta - Peterborough - Broken Hill - Nyngan - Tamworth before arriving home in Armidale. Jack has altered the trek to avoid both Sydney and Melbourne due to his concerns about traffic. Members of the Triumph Car Club will meet Jack and Alison on the final leg of the journey in Broken Hill and escort them all the way back home to Armidale - which will be a sight to behold.

Sponsorship from Shannon's Insurance has been secured and The Australian Lung Foundation will be supporting Jack with the provision of car signage, brochures, t-shirts, hats, banners etc. We will be calling on all support groups and interested parties along the journey to rally their support and welcome Jack and Alison. You can follow Jack's progress on The Australian Lung Foundation website [www.lungfoundation.com.au](http://www.lungfoundation.com.au) and if you would like any further information, please contact Karen Wright on 07 3251 3637 or [projects@lungfoundation.com.au](mailto:projects@lungfoundation.com.au)

### Heart/Lung Transplant Discussion Group at The Alfred Hospital, Melbourne



The Alfred Hospital's Heart Lung Transplant Trust (Vic) has established a new website - [www.hlttv.org.au](http://www.hlttv.org.au) which provides valuable information about topics such as the transplant journey and organ donation, as well as practical information post-transplant and patient stories.

An online discussion group has also been set up and is available at <http://health.groups.yahoo.com/group/heartlungtransplantaustralia/> The group provides a forum for patients from Heart and Lung Transplant Units around Australia and New Zealand to communicate with one another for the purpose of support throughout the journey.

### Vacancy - The Australian Lung Foundation National Council (Australian Capital Territory)

The Australian Lung Foundation National Council has a vacancy for a representative member from the Australian Capital Territory. We are seeking a Council member who brings a business-minded perspective to our professionally run not-for-profit organisation. You will be invited to attend up to four meetings annually (two face-to-face meetings and two teleconferences) and promote and support programs of the Lung Foundation. Terms are for two years with the possibility of renewal.

If you are interested in this role, please contact National Council Chairman, Dr Robert Edwards, ([Bob.Edwards@Wesley.com.au](mailto:Bob.Edwards@Wesley.com.au)) or Secretary, William Darbishire ([williamd@lungfoundation.com.au](mailto:williamd@lungfoundation.com.au)) with a copy of your curriculum vitae and covering letter before 10th July 2009.

For further information about The Australian Lung Foundation, please visit [www.lungfoundation.com.au](http://www.lungfoundation.com.au)

## • Clinical Trials – The Who, What, When and Why?

Glenda Colburn, Program Development Manager, The Australian Lung Foundation

During the course of your treatment/disease, you may be asked if you would like to participate in a clinical trial.

### What are clinical trials?

A clinical trial is a scientific study that involves volunteers and constitutes the formal testing of new medical treatments for humans. It is vital to measure the effects and safety of new medicines and other treatments, such as surgical procedures before they become widely available to the public. Through clinical studies, doctors find new and better ways to prevent, detect, diagnose, control, and treat illnesses. Each clinical trial is led by a doctor and a research team, which may include nurses, pharmacists and other health care professionals. This team is responsible for checking the health of each participant during the entire trial phase, until the trial has been completed.

In Australia, each clinical trial must be approved by an independent ethics committee established by each hospital and health service and is in accordance with the National Health and Medical Research Council (NHMRC) Guidelines.

Participants in clinical trials are required to give their informed consent. This means that the participants **must** be provided with **extensive** information about the trial, its objectives, risks, benefits, number of visits, tests and other requirements before agreeing to become involved. The informed consent also explains that you have a right to leave the study at any time, but be sure to discuss this with your research team prior to any departure.

Many clinical trials have a **control group** which means that you may not receive the treatment under investigation during your participation in the trial. Usually, one group is given the **trial treatment**, while the other group is given the **standard treatment** for the disease, or if no standard treatment, a **placebo** (dummy medicine with no active ingredient) may be given.

### Who becomes a trial participant?

Participating in a clinical trial is an important personal decision. Don't hesitate to ask the research team any questions at any time before, during, or after the study.

When researchers are designing a clinical trial, they develop a summary of criteria for participant selection, that is, who should be in the study and who should be excluded. This is known as the **inclusion/exclusion** criteria. These criteria are based on factors such as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. It is important to note that inclusion and exclusion criteria are not used to reject people personally, but rather to identify appropriate participants and keep them safe. Inclusion/exclusion criteria should be explained to each potential participant in a clinical research trial before they are enrolled in the study.

Generous individuals volunteer for research because they trust that their participation will contribute to improved health for others and that researchers will minimise the risks to participants. In return for their selflessness and trust that makes clinical research possible, the research enterprise has an obligation to conduct research ethically and to report it honestly.

### Why are they so important?

Clinical trials are designed to extensively test new treatments and are needed to thoroughly understand how they actually work in humans. The purpose of a clinical

trial is to collect data that is required by the Australian government to demonstrate that the medicine is safe and effective. A new treatment can only be prescribed once the Australian government's Therapeutics Goods Administration (TGA) assesses the data after completion of a clinical trial and gives approval. Findings from clinical trials can assist in preventing thousands of deaths each year and improve the lives of people suffering from various medical conditions.

### What are the advantages and disadvantages of participating?

Advantages include:

- Playing an active role in your treatment
- Access to new treatments not available to the general public, which may be more effective
- Obtaining the clinical trial treatment at no cost – at least during the trial
- Extensive medical care, at leading institutions, usually at no cost
- Contributing to the development of future life-saving or life-enhancing treatments
- Helping others who are diagnosed with the same condition in the future

Disadvantages include:

- Possible side effects
- New treatments may not work
- You may be in the control group and may not receive the new treatment
- Inconvenience of more frequent visits to the hospital or doctor's rooms

All treatments can be associated with unwanted side effects and it is important that you develop an appreciation of likely side effects before becoming involved in a trial. This will allow you to consider the likely risks alongside the likely benefits before making your decision to participate.

### When do you decide whether to participate or not?

If you are invited by your doctor to participate in a clinical trial, you need to weigh up the risks and benefits of this decision. Refusal to take part in a trial will not compromise your treatment in any way. You are also able to leave a clinical trial at any time without prejudice to your ongoing treatment. The consent form you sign ensures this.

If you decide you would like to participate, you should make an informed decision by discussing it with your doctor and other healthcare professionals. You should also seek to understand the credentials and experience of the people and the company involved in the study. Discuss with them the trial and the implication it may have for you.

You might like to make a list of questions that you can ask the clinical trial doctor before agreeing to participate.

### Need more Information?

- The Australian New Zealand Clinical Trials Registry – [www.anzctr.org.au](http://www.anzctr.org.au)
- National Health and Medical Research Council (NHMRC) – [www.nhmrc.gov.au](http://www.nhmrc.gov.au)
- Therapeutics Goods Administration (TGA) – [www.tga.gov.au](http://www.tga.gov.au)

## • The Kylie Johnston Lung Cancer Network (KJLCN) Update

Kerrie Callaghan, Projects/Communications Coordinator,  
The Australian Lung Foundation

### Join our Brisbane KJLCN Lung Cancer Support Group

With the recent relocation of The Australian Lung Foundation to its new office in Bowen Hills, we now have the space to start a Lung Cancer Support Group for local patients and carers.

### "Greek Taverna" night is top Lunch for Lung Cancer fundraiser in 2008

We would like to thank and acknowledge the fantastic efforts of Helen Cayas and her community of family and friends, who raised more than \$7000 in November with a fabulous "Greek Taverna" evening in Sydney, making their event our top Lunch for Lung Cancer fundraiser for 2008. Helen and her family are very proud of their Greek heritage, and what better way to celebrate life than with a fabulous feast of Greek food and lots of dancing?



Top KJLCN fundraiser Helen Cayas with her family

"We had so much fun on the night and it was wonderful to see my children dancing to the traditional Greek songs and music that I danced to as a child – I really relived my childhood" Helen said. "My aunties and uncles danced the night away in between bidding for silent auction items and buying raffle tickets".

You can read more about Helen's fundraising achievements on our website – [www.kjlcn.org.au](http://www.kjlcn.org.au)

We would like to take this opportunity to sincerely thank everyone who hosted a Lunch for Lung Cancer event last year – your contributions are very much appreciated.

### KJLCN Fundraising Events 2009 – Date Claimers

**The KJLCN/Rotary Club Charity Golf Day - Friday 21st August 2009** at The Colonial Golf Club at Robina on the Gold Coast. All proceeds will go towards our long-term goal of establishing a part-time lung nurse on an 1800 number.

**Gala KJLCN Lunch for Lung Cancer in Brisbane - Friday 13th November 2009**

Further details of this event will be available shortly.

If you would like more information about the Lung Cancer Support Group, or any of the KJLCN events and initiatives, please phone Kerrie on 07 3251 3641 or email [kerrie@lungfoundation.com.au](mailto:kerrie@lungfoundation.com.au)

### Better Living with COPD – A Patient Guide

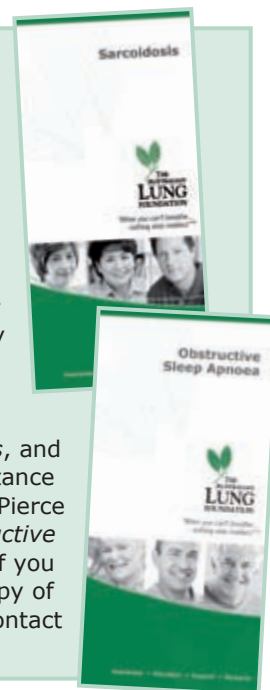
Response for the new patient resource, *Better Living with COPD – A Patient Guide* has been overwhelming, and to date, patients, physiotherapists, respiratory care practitioners and allied health professionals have ordered 4658 copies. Current stocks have almost been exhausted and an additional print run is due for delivery shortly.

If you haven't yet seen the resource, please visit our website [www.lungfoundation.com.au](http://www.lungfoundation.com.au) and view the resource online. The Guide is available on the website to download and print chapter by chapter, however, should you wish to order your own copy, please use the link available and complete and return the Order Form along with your payment. Although copies of the Patient Guide will continue to be available at a cost of \$7.50 plus postage and handling, stocks are limited at the current price, so to avoid disappointment, please order your copy now. Should you have any queries, please contact Lisa Morris on 07 3251 3600, [lisa@lungfoundation.com.au](mailto:lisa@lungfoundation.com.au) or toll-free on 1800 654 301.



### New Brochures

We are pleased to announce the recent review and revision of the educational brochures, *Sarcoidosis* and *Obstructive Sleep Apnoea*. We would like to thank Associate Professor Peter Holmes, Respiratory Specialist at Monash Medical Centre for his assistance with reviewing the content of *Sarcoidosis*, and to acknowledge the assistance of the late Professor Rob Pierce with reviewing the *Obstructive Sleep Apnoea* brochure. If you would like to receive a copy of either brochure, please contact us on 1800 654 301.



## • Griffith University Wellbeing and Chronic Illness Survey

Griffith University in Queensland is looking for participants in a study investigating the impact of positive-focused actions on well-being among Australians living with Chronic Obstructive Pulmonary Disease (COPD). Participants will be required to answer questions on a survey relating to illness status, emotion, coping, wellbeing and current performance of positive-focused actions (such as acts of gratitude or forgiveness). The survey will take approximately 20-30 minutes to complete. No information of a threatening nature will be requested and participation will be anonymous and confidential.

If you are interested in finding out more about the study, please contact the Student Experimenter. To maintain your confidentiality and anonymity, no contact details will be retained after survey materials have been sent out.

#### Student Experimenter Contact Details:

Rebecca Eaton B.Psych (Hons) B.Bus, PhD Candidate  
School of Psychology, Gold Coast Campus  
Griffith University, Queensland 4222

Phone: 07 5552 8029  
Email: [r.eaton@griffith.edu.au](mailto:r.eaton@griffith.edu.au)

## • Patient Support around Australia

### ACT

The sudden passing of Canberra's "Lung Life Support Group" Leader, Bill Scowcroft has been reported elsewhere in the newsletter. The group would like to extend their sympathy to Bill's wife, Caroline, and family. Caroline has advised she will be continuing her work with the group and will remain the contact person.

### NSW

The pulmonary rehabilitation team from Shoalhaven Hospital held a COPD Conference in Nowra on 3rd March and the day was well attended by COPD patients, their families and carers. Presentations covered a range of topics and included lung infections, sleep disorders, incontinence and the latest advances in COPD. Carer, Bev Bloomfield spoke about the challenges of caring for someone with COPD, and Carer

Co-ordinator, Kate Roberts gave an overview of the resources available to carers. Lastly, the Patient Panel wrapped up the day with each member giving their personal perspective of something that has helped them better manage living with COPD. The last speaker, Barbara Farrelly gave a particularly moving account of her own journey as a COPD patient.



Participants at the Shoalhaven Hospital COPD Conference

"LungNet Southern Highlands" recently held their AGM and welcomed a new committee, with Hazel Mellor being elected Chairman. The group is looking forward to the year ahead and has planned a full calendar of events for both meetings and social outings. If you would like to join in with the group, please call Hazel on 02 4872 4980.

### WA

"South West Impaired Lung Support Group" (S.W.I.L.S.) welcomed recent guest speakers, Maria Fitzgerald from the Australian Red Cross who provided valuable tips on being a carer, and Denise Hine, Practice Liaison Officer from the Division of General Practice in Greater Bunbury, who presented on medicines and their correct use.

Don't forget the WA LungNet Education Day will be held on 1st July at The Boulevard Centre in Floreat and further details can be obtained from the enclosed invitation.

A pulmonary rehabilitation program has now commenced in Margaret River. If you are interested in further details, please contact the Lung Foundation's Information and Support Centre on 1800 654 301.

### SA

The "WestAIR" group has recently elected their 2009 committee. May Perks, a tireless worker for "WestAIR" since its inception 12 years ago and Chairperson for the last two years, has decided to step down. However, she will continue her involvement with the committee and will be taking on the role of Minute Secretary. The group has planned its 2009 activities and reports a number of social activities as well as the usual meetings. The members are presently raising funds for the Victorian Bushfires Appeal.

### QLD

"Bundaberg and District Lung Support Group" recently farewellled two of its long-term committee members - Chairman, Barry Payne and Treasurer, Jack Mordue who have stepped down to take a well-earned break from committee responsibilities. Barry has been Chairman for the past six years, and Jack, Treasurer and guardian of the group's funds since its inception in 2001.

Tenth birthday congratulations to the "Redlands Lung Support Group" who recently celebrated with a morning tea and guest speakers.

Due to ill health, Yvonne Bedson has resigned as Secretary of "Lung and Respiratory Friends" (L.A.R.F.) on the Gold Coast. Yvonne has been a dedicated advocate for both L.A.R.F. and the Lung Foundation for many years and her contribution to raising awareness and supporting those with lung disease cannot be underestimated. We wish Yvonne all the best and thank her most sincerely for her efforts.



Redlands group members, Paula Manger, Buena Hensler and Mick Bright celebrate the group's 10th birthday

### TAS

The "Lungs In Poor Shape" (L.I.P.S.) Treasurer for the past 12 years, Ray Everett has resigned and the group would like to thank him for his hard work maintaining the books, as well as his fantastic fundraising efforts. L.I.P.S. would like to welcome the 2009 committee and wishes them a successful year. The group is always looking for new members and if you would like to join in, please contact Rod Morse on 03 6435 3396.

Some sad news from Faye Booth, Group Leader of the Kingston support group, "Two Heads, Two Lungs" (THTL) who has advised that founding member, Colleen Beck, passed away on Good Friday after a long battle with COPD. Faye says, "Colleen was an inspiration to us all and we will miss her knowledge, inspiration and friendship". Our thoughts are with Colleen's family and all her friends and fellow group members.

### VIC

We are delighted to welcome a new patient support group into the LungNet fold. The "Breezy Wheezers" from Bairnsdale recently held their first meeting and will meet at the Bairnsdale Community Health Centre on the fourth Monday of the month. For further information please contact Cathy Schaeche on 03 5152 0230.

### NT

The pulmonary rehabilitation programs at Royal Darwin Hospital and Palmerston are progressing well and if you would like to obtain details of either of these programs, please contact the Lung Foundation's Information and Support Centre on 1800 654 301. The "NT Breatheasy S.T.A.A.R.S." recently travelled by bus to the Adelaide River War Memorial for a most enjoyable day out.

## Tribute to Dr William (Bill) Scowcroft

BScAgr, PhD, FAIAST

It is with great sadness that we advise that Bill Scowcroft lost his long battle with Chronic Obstructive Pulmonary Disease (COPD) on 16th March 2009. Dr Scowcroft, supported by his energetic wife, Caroline, was a loyal volunteer and dedicated patient advocate for The Australian Lung Foundation. Co-Chair of the COPD Patient Taskforce, Bill was also a member of the Lung Foundation's National Council and Convener of the Canberra based "Lung Life Support Group".



Bill's passion and drive has been an inspiration for many. With the support of Caroline, he worked tirelessly to improve the lives of those with COPD. Bill was very well informed and he will be sorely missed by all who hold dear his goals and ideals. Let us all strengthen our resolve to keep his vision alive. For his many years of service, we express our appreciation. Our thoughts are with Caroline and the family at this sad time.

## • The Lighter Side

by Larry Emdur

Hello Everyone

I received this great letter from Albert Richards from Page in the ACT who has come up with the ultimate revenge for his problematic oxygen tube. He writes:

*Advice to All Victims of Oxygen Tubing Abuse*

*Plastic oxygen tubing is not the inanimate object that most folks believe, but a very much alive, mischievous imp whose sole purpose is literally your downfall. It is quite capable of surreptitiously tying intricate knots that any boy scout would be proud of. Using these knots it tightly binds the ankles of innocent victims without them being aware of it, until they fall head first into a bag of kitchen waste, or if they are lucky, into the less odious dry garbage waiting to be recycled.*

*Stealing precious oxygen to generate the energy, the tubing is able to leap great heights in order to latch onto any protrusion that it passes within range. Gripping the object firmly, it then attempts to rip off your nose by thrusting its twin-barbed end firmly into your nostrils to gain leverage, if you dare to walk but a few metres. And to add insult to injury, the tubing splits its sides with laughter at your distress, and thereby reduces your oxygen supply without you being aware of the danger.*

*No one has used more profound expletives than I to chastise my oxygen tubing, and very few of them can be found in a dictionary. My advice to all fellow sufferers who have been abused by oxygen tubing is: whenever it misbehaves, give it a damn good thrashing. It will not deter the tubing from repeating its annoying antics but oh boy, won't it make you feel good.*

*I intend to get my final revenge by inserting a clause in my Will to ensure that my oxygen tube accompanies me on my final journey.*

Great advice Albert!

OK, from troublesome tubes to clever kids...

A Grade One teacher collected some well-known proverbs. She gave each child in her class the first half of a proverb and asked them to come up with the remainder of the proverb. There are some classic responses... prepare to smile...

Strike while the... "insect is close"

Never underestimate the power of... "ants"

Don't bite the hand that...  
"looks dirty"

If you lie down with dogs  
you'll... "stink in the morning"

You can lead a horse to water  
but... "how?"

No news is... "impossible"

You can't teach an old dog new... "maths"

Love all, trust... "me"

Where there's smoke there's... "pollution"

Happy the bride who... "gets all the presents"

A penny saved is... "not much"

Two's company, three's... "The Musketeers"

Don't put off til tomorrow what... "you put on to go to bed tonight"

Laugh and the whole world laughs with you, cry and... "you have to blow your nose"

Children should be seen and not... "smacked or grounded"

If at first you don't succeed... "get new batteries"

You get out of something only what you... "see in the picture on the box"

When the blind leadeth the blind... "get out of the way"

Hey, Albert, perhaps we should ask this bunch of kids how to solve the oxygen tube dilemma, sounds like they've got an answer for everything.

Take care and remember there's always a lighter side.

*Larry*



We look forward to receiving more of your stories for the next issue of LungNet News – without them we wouldn't be able to have a column. Please share them with us and send to:

Larry Emdur - "The Lighter Side"  
The Australian Lung Foundation  
PO Box 847  
Lutwyche QLD 4030

Fax: 07 3852 5487

Email: [enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au)

### Donations to The Australian Lung Foundation are Tax Deductible for Income Tax Purposes.

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Phone: 07 3251 3600 Fax: 07 3852 5487 Email: [enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au)

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## • The Benefits of Patient Support Groups

### Rodney Morse, Secretary, "Lungs in Poor Shape" (L.I.P.S.) Patient Support Group, Somerset, Tasmania

From early childhood, I have had lung problems and constantly suffered from a persistent productive cough, which was treated as asthma for many years. Chest and sinus infections have almost always been a part of my life. In 1996, I was diagnosed with bronchiectasis, followed by COPD in 2002. In 2005, I was found to have a part of my immune system missing and this was the reason why I was constantly unwell.

Due to my continued lung problems, I became interested in learning more, and so about five years ago, I joined the local "Lungs in Poor Shape" (L.I.P.S.) patient support group. The group opened up so much information and I have learnt a great deal from fellow group members, guest speakers, LungNet Education Days run by The Australian Lung Foundation, my local pulmonary rehabilitation program and LungNet News.

Two years ago, the position of group Secretary became vacant and I was elected. I started by compiling a monthly newsletter, which is printed for us at the offices of our local Federal Member of Parliament. Copies are distributed to all our members as well as local medical practices. This has been a valuable way of promoting our group and membership has grown as a result. This year, we are hoping to increase our numbers even further and in doing so, make a greater contribution to our community.



We meet monthly with an invited guest speaker on alternate months, followed by a social outing the next month. One of the things that we are very proud of is an annual raffle that raises much needed funds for our group. One of our members, Ray Everett, spends many hours selling these tickets in the two months prior to Christmas and raises around

\$2,000 a year. These funds have been used to support members in need, and help with costs associated with some of our activities. Donations of \$1000 each have also been made to the Coastal Cancer Bus, The Alfred Hospital, The Austin Hospital Burns Unit (following the Victorian Bushfires) and The Australian Lung Foundation.

In 2008, a highlight for L.I.P.S. was the "Breath of Life" gala dinner that we were able to attend in Devonport. This was part of a three day music festival, which was the brainchild of Hank Lizotte and his family.

Joining L.I.P.S. has been a wonderful and fulfilling experience, which has allowed me to learn so much about my condition, help other people and last, but not least, to make some lifelong friends.

### Kay Tompkins, "Hornsby Huffers" Patient Support Group, Sydney

I am honoured, yet humbled, to have been asked to write a few lines for this newsletter. After completing a pulmonary rehabilitation program, I was invited to join a support group of fellow COPD patients known as "Hornsby Huffers".



We meet every three months where we are helped to understand our illness and how we can better manage our day to day lives. Guest speakers are invited to each meeting and we discuss many issues, such as techniques to assist in coping with chest infections, breathing more efficiently, and how to cope with the many obstacles, both physical and emotional, that we have to deal with. We are also introduced to, and educated on the different aids and equipment that can assist us in living as normal a life as possible.

I have found these meetings very informative and educational, but to me personally, they are also a wonderful way to meet new friends. We have a very specific bond and it is comforting to know there is a group of people who fully understand what I am going through and are there for me, and I for them, when in need.

There are several groups in the Sydney area, which are free to join, so I urge all of you who are not in a group to visit the one closest to you. I am sure you will find it of great benefit. Please come and join us – we look forward to meeting you.

#### Editor's Note

For details of your nearest group, or if you would like to set up your own group, please call the Information and Support Centre on 1800 654 301.

## • Healthier Living with Ongoing Health Problems Internet trial in South Australia

*Healthier Living with Ongoing Health Problems* is the online version of the community-based Chronic Disease Self Management Program (CDSMP) in South Australia, also known as the *Moving Toward Wellness Course*. The program is open to residents of South Australia with a long-term health condition, and is being run by SA Health and Country Health SA in partnership with Stanford University in the United States.

To complete the program, participants work through six weekly sessions online, in conjunction with a group of other participants also diagnosed with a chronic condition. The program is password protected and provides self management instruction and bulletin board discussion groups. It is not done in "real time" but can be accessed by individuals at any time of the day or night.

Each program is monitored by two online moderators whose responsibility is to motivate individuals and to make sure that all posts are appropriate. The benefits of joining are:

- Learn to manage your symptoms better
- Learn tips to manage your day-to-day activities
- Get support from others with long-term health problems
- Share your experiences and help others

If you are interested in participating, please go to the website <https://sahealth.stanford.edu>

