



## Contents

2
5
7
9
10
11
12
14
16
17
18
21
24
25



#### WHO WE ARE

Lung Foundation Australia supports all aspects of lung disease from COPD to lung cancer to rarer lung diseases such as pulmonary fibrosis. We have a proud history of community education and run a freecall Information and Support Centre. We're a national organisation which supports patients, funds research, develops educational resources, trains health professionals, and undertakes community awareness activities and advocacy.

We bring together key opinion leaders in respiratory and lung cancer medicine, physiotherapy, nursing and primary care to develop resources, training, and education to increase awareness of the importance of maintaining good lung health, facilitate early diagnosis, provide better management and help support patients and carers living with a lung disease.

#### **VISION**

To ensure lung health is a priority for all in Australia.

#### STRATEGIC GOALS

- Promote lung health
- Promote early diagnosis of lung disease
- Support those with lung disease and their carers
- Advocate for equitable access to evidence-based care
- Support quality research

#### **OUR VALUES**

- Community focused
- Evidence-based
- Respectful of the individual
- Responsible for our work environment
- Striving for excellence

Our vision is to "ensure lung health is a priority for all in Australia..."

We bring together key opinion leaders in respiratory and lung cancer medicine, physiotherapy, nursing and primary care

#### **Foreword**

## 2014 was a year of growth, change, investment and delivery for Lung Foundation Australia.

Lung Foundation Australia's income continues to grow, with results in 2014 showing a 10% growth in revenue from 2013. Along with the increase in income, Lung Foundation Australia continues to invest in its community. In 2014 the expenditure on our programs increased by 22.7%, reflecting an increase in activity across health promotion, symptom awareness, patient education and clinical resources. Details on the significant activity in all these areas can be found in the following pages.

July saw the retirement of long-time CEO, William Darbishire. William joined the Lung Foundation in 2002, a time of financial and structural vulnerability. By the time he packed up his famous 'Partners' desk', and after a twelve year partnership with former Board Chair Dr Robert Edwards, William left the Lung Foundation in a position of financial health and organisational strength, with a staff of 21 working across a broad spectrum of activity.

2014 also saw significant change in the make-up of the Board. Three new appointments were made this past year: A/Prof Sarath Ranganathan, an experienced paediatric respiratory physician, medical researcher and teacher whose skills will be particularly valuable in developing our *Young Lungs* program; Ms Kathy Cummings, a senior banker with many years' experience with the Commonwealth Bank; and Mr Tony Hyams, AM, the founding CEO of Credit Suisse in Australia who has significant Board experience, including as chair of Commonwealth Superannuation Fund. We are fortunate to add the skills and generous contributions of A/Prof Ranganathan, Ms Cummings and Mr Hyams to the extensive clinical expertise and leadership already on our Board.

Other significant changes this year include the resignation of Prof Michael Abramson from the chairmanship of the COPD Guidelines Committee; the resignation of Prof Peter Frith from the chairmanship of the COPD Coordinating Committee; and the resignation of Prof Adam Jaffe from the chairmanship of our PIVOT Consultative Group. The Lung Foundation is grateful for the clinical leadership provided by all three. As we say every year, we are nothing without the generous contributions of our clinical and community volunteers.

Despite the enormous amount of change, this year was also a year of investment in the future of the Lung Foundation so that we can better serve our patient and clinical communities. The Board recognised the importance of investing in three important areas:

- 1. Promoting the role of Lung Foundation Australia in the community so that we engage with a larger proportion of our patient population and communicate the importance of lung health
- 2. Engaging more closely with our clinical audiences
- 3. Investing in raising funds for the future

As a result, the Lung Foundation:

Launched a five year strategy to raise awareness of the importance of lung health – *Just One Breath*. This campaign is aimed at engaging a younger and wider audience to start thinking about lung health at a time when many make decisions that will affect their lungs in the future. We partnered with famous Australians to challenge the community to think about: "What can you do with just one breath?" If you have not yet seen this innovative campaign, I encourage you to visit www.justonebreath.com.au



A/Prof David Serisier, Chairman



Ms Heather Allan, CEO

Along with the investment in our future, Lung Foundation Australia continued to deliver strong programs across a wide spectrum of areas.



- Agreed on a five year fundraising strategy to support the expanded delivery of programs and, in particular, a significant future increase in Lung Foundation Australia's contributions to research
- Invested in a new Customer Relationship Management system (CRM) which will make it more efficient to communicate with our different audiences and to streamline our management reporting

Along with the investment in our future, Lung Foundation Australia continued to deliver strong programs across a wide spectrum of areas. Highlights include:

- The launch of *Check in With Your Lungs* a campaign primarily run through traditional media aimed at raising awareness of the symptoms of lung disease and encouraging people to complete the Lung Health Checklist
- The completion of important resources, including the COPD-X Concise Guide for Primary Care; COPD Online Patient Education (C.O.P.E), an online education program for patients (due for release early 2015); Let's Yarn About Lung Cancer which encourages people to look, listen and learn about lung cancer risks and symptoms; a Quality of Life Checklist, that serves as a conversation starter for patients with their GPs about how well they are coping with their lung disease
- The publication of *Lung Disease in Australia* with the Woolcock Institute of Medical Research a summary of the overall impact of lung disease in Australia
- The delivery of a suite of regional patient seminars across the country promoting the importance of self-management
- Investing \$410,000 directly in exciting research programs
- In addition, investing more than \$800,000 in developing and supporting platforms for research, including the IPF Registry, the development of an Australian Bronchiectasis Registry, the Australian Lung cancer Trials Group, and investing in setting up a new Global Thoracic Oncology Trials Group

The Lung Foundation owes a debt of gratitude to our Board of Directors who have provided strong strategic leadership helping us achieve the above:

- A/Prof David Serisier
  - Chair
- Mr Andrew Churchill
  - Treasurer
- Dr David Michail
- Prof Martin Phillips
- Prof Peter Frith
- Mr David Hayne
- Prof Christine Jenkins
- Ms Kathleen Cummings
- A/Prof Sarath Ranganathan
- Mr Tony Hyams

Supporting the Board of Directors is the National Council, an important advisory body providing considered advice on strategic direction:

- Or Lucy Morgan
- Mr Peter Stapleton
- Prof Gary Anderson
- Dr James Markos
- Prof Mark Holmes
- Prof Matthew Peters
- Dr Christopher Worsnop
- Prof Kwun Fong
- Prof Ian Yang
- Prof Peter Gibson

Of course, the strong programs delivered throughout 2014 were the result of the enormous commitment and work of our staff, in particular our Executive Management Team of Chris Emery, Director of Operations; Elizabeth Harper, Director of COPD National Program; and Glenda Colburn, Director of Lung Cancer National Program. Thanks also to Damon Cavalchini, Senior Manager, Lung Health Promotion.

Thanks to the generosity of the Thoracic Society of Australia and New Zealand (TSANZ), the Lung Foundation now has a physical presence in Sydney within the offices of the TSANZ. Lung Foundation Australia's relationship with the TSANZ continues to be critical to our ability to make a difference. We are, as ever, grateful for the support of the Board and Management of the TSANZ.

Lung disease continues to be responsible for an enormous burden in Australia -10% of the total health burden is due to lung disease. There is a significant amount of work to be done to address this.

Lung Foundation Australia recognises the need to work collaboratively and innovatively to make a difference.

We have a difficult task ahead. However, the Lung Foundation is well-placed and excited to meet the challenges head on. We are led by a Board with a strong sense of the way forward; we are served by a steady, committed and professional staff; and supported by an ever-increasing network of dedicated clinical and community volunteers.

We thank you for your support in 2014 and look forward to your support in 2015.

#### IN 2014 LUNG FOUNDATION AUSTRALIA TOUCHED A LOT OF LIVES





















#### VALE TO PETER TUFFIELD

Lung Foundation Australia wishes to honour the memory of a humble yet courageous patient advocate and fundraiser, Peter "Tuffy" Tuffield, who lost his four year battle with lung cancer in April 2014.

Peter was a highly respected Bundaberg community leader, a devoted husband and father as well as a fun loving and compassionate friend to many. Throughout his illness, Peter generously supported cancer patients and their families. He also took up advocacy roles for the Lung Foundation to raise awareness around the stigma, inequalities, risks and symptoms of lung cancer.

During the last three years, Peter's generous community of family and friends raised more than \$75,000 for lung cancer research and patient support through Tuffy's Kokoda Challenge. Peter's two sons, Daniel and Chris, as well as his best mate Shane Talbot, completed the Kokoda trek together with the help of Peter's wife, Margaret, and son, Matthew. "Team Tuffy" exceeded their original fundraising goal of \$70,000.



## **COPD National Program**



Elizabeth Harper, Director

#### KEY ACHIEVEMENTS

The COPD National Program had a very successful year under the clinical guidance of Prof Peter Frith, Prof Ian Yang, Prof Christine McDonald and Dr Kerry Hancock. The COPD National Program team undertook a significant workload with the support of the experienced COPD Coordinating Committee, dedicated volunteer clinicians and consumers. "Change and new growth" was the theme for 2014 as the strategic plan moved from content development into implementation and marketing. After many years of a static medication landscape, six new COPD medicines hit the shelves in 2014.

In line with the theme of change, several roles changed hands including:

- Prof Peter Frith handed over the role as Chair of the COPD Executive and Coordinating Committees after more than a decade of leadership to Prof Ian Yang
- Prof Michael Abramson stepped down from the COPD-X Guidelines Committee
- A/Prof Vanessa McDonald stepped down from the Chair of the COPD Online Nursing Committee and joined the COPD-X Guidelines Committee. Ms Tod Adams, a long-time member of the committee has taken on the role of chair and is focused on encouraging the education of nurses and promotion of evidence-based resources
- Mr David Hayne handed over the newly developed COPD Pharmacy Program and the Chair of the Pharmacy Committee to Mr Peter Guthrey. David continues to provide support to the Lung Foundation as a Board member

#### **FOCUS POINTS**

## **COPD-X Guidelines and Concise Guide for Primary Care**

In November, we launched the *COPD-X Concise Guide for Primary Care*. Prof Michael Abramson, supported by Prof lan Yang, led the development and consultation with the writing group and key stakeholders. This 40 page, easy-to-read booklet focuses on the key components of COPD-X for application in the primary care setting.

Prof Peter Frith and the members of the Advisory Group provided expert feedback throughout the development and consultation phases. Dr Kerry Hancock and the General Practice Advisory Group members provided excellent guidance and feedback to ensure suitability for their primary care colleagues.

Prof Michael Abramson also provided exceptionally strong leadership to the COPD-X Guidelines Committee who undertook three online updates in 2014 and two updates to *Stepwise Management of COPD*. There has been a 170% increase in registrations for COPD-X over the past two years with a 45% increase in registrations in 2014.

#### **Pulmonary Rehabilitation Advocacy**

Lung Foundation Australia has supported and promoted the benefits of pulmonary rehabilitation for more than ten years, working with the Thoracic Society of Australia and New Zealand (TSANZ) special interest group and pulmonary rehabilitation clinicians across the country. The Pulmonary Rehabilitation Network was re-established to mentor new programs and provide a platform for future discussions during the development of the joint Lung Foundation Australia/TSANZ pulmonary rehabilitation guidelines in 2015, led by Prof Jennifer Alison.

In November, the value of pulmonary rehabilitation was raised in Federal Parliament through a private member's bill. We have also continued to advocate at local and state levels through Medicare Locals, Hospital and Health Services and with state and federal health ministers.

As uncertain funding for pulmonary rehabilitation programs threatens program security, Lung Foundation Australia successfully lobbied the Independent Hospital Pricing Authority in 2013 and 2014 for a specific item number for pulmonary rehabilitation to be delivered in the Hospital and Health Service sector. In December, an application for an MBS item number for pulmonary rehabilitation was submitted to the Medical and Scientific Advisory Committee (MSAC) after receiving advice and support from the Department of Health. It aims to enable wider access to pulmonary rehabilitation in the community.



#### **Primary Care and Pharmacy**

The COPD National Program engaged with 43 of 61 Medicare Locals in 2013/14 to promote the Lung Foundation's resources and education/training for health professionals. The COPD National Program has provided assistance through consultation and/or more formal partnerships including presenting resources and attending meetings with Medicare Locals who identified COPD as a significant issue. In addition, we delivered more than 30 workshops to primary care aimed at implementing COPD-X Guidelines and risk assessment and screening. Our highly successful COPD Online Training Program for Primary Care has seen more than 1,000 enrolments since its launch three years ago with nurses undertaking the training reporting increased confidence in managing COPD patients. With the support of the Pharmacy Guild, the Pharmaceutical Society of Australia, Australian College of Pharmacy, and Australian Consultant Pharmacists Association, pharmacists continued to develop an interest in our COPD risk assessment and screening program. More than 176 pharmacies have been formally undertaking these screening services using the Guildcare Software for record keeping.

#### **Lungs in Action and Pulmonary Rehabilitation**

This community-based exercise program for people who have completed pulmonary and/or heart failure rehabilitation continued to develop and grow. There are 62 locations across seven states with a further 16 locations due to start in 2015, providing more than 95 classes each week.

The Pulmonary Rehabilitation Training Online program successfully achieved accreditation with both the Australian Physiotherapy Association and Exercise and Sports Science Australia. Lung Foundation Australia is working with both organisations and the National Physical Activity Alliance to promote the importance of physical activity for chronic disease, especially pulmonary rehabilitation and ongoing exercise maintenance for chronic lung diseases.

#### **Patient and Community Successes**

Mr Ross Lloyd chaired the COPD and Patient Advocates Group (CPAG) which provides consumer consultation on resource development. The group continued to build connections with the Lung Foundation patient support groups across Australia to ensure the CPAG represents a range of different consumer opinions. The CPAG group also provides grassroots dissemination of communication and health promotion messages within their communities. Their particular advocacy interests include provision of uninterrupted power supply, equitable access to oxygen and air quality improvements.

#### **C.O.P.E - COPD Online Patient Education Program**

This new online training program for COPD patients was piloted in December and will enable patients to undertake the educational component of pulmonary rehabilitation from their own living room at no cost. This project has been undertaken in partnership with BUPA Health Foundation and will be officially launched in 2015.

#### World COPD Day

2014 saw the largest World COPD Day event to date with more than 450 community pharmacies conducting lung health checks using the Lung Foundation Lung Health Checklist, and more than 240 other events being held across Australia.

World COPD Day attracted significant media with a reach of more than one million media impressions through newspapers, TV and radio.



## Lung Cancer National Program



Glenda Colburn, Director

#### KEY ACHIEVEMENTS

The Lung Cancer National Program had a successful year under the clinical guidance of our program chairs: Prof Kwun Fong, Prof Paul Mitchell, Prof Matthew Peters and Ms Mary Duffy. The Lung Cancer National Program team undertook an enormous workload with the support of a large number of dedicated volunteer clinicians and consumers.

- Participated in an Global Roundtable on World Cancer Day discussion on the Australian and New Zealand role in the cancer and non-communicable disease development agenda in the Asia Pacific Region
- Completed a two year Aboriginal community cancer project, Let's Yarn about Lung Cancer
- Delivered the 5th Australian Lung Cancer Conference
- Rebranded our patient support service Lung Cancer Network Australia
- Raised the profile of lung cancer and dedicated lung cancer nurses in Parliament
- Represented Australia at the Global Lung Cancer Coalition members' meeting in Madrid
- Undertook secretariat duties for the International Thoracic Oncology Nursing Forum
- Chaired the Patient Advocate Committee advising the Board for the International Association for the Study of Lung Cancer

#### **FOCUS POINTS**

#### **Supporting Indigenous Australians**

The Lung Cancer National Program delivered multiple Indigenous projects in 2014. Working with the Queensland Health Indigenous Respiratory Outreach Team (IROC), we developed a lung cancer flipchart, lung health awareness poster and launched a story DVD which follows an aboriginal person's journey with suspected lung cancer. To complement this set of patient resources, we developed an *Indigenous Health Worker - Lung Cancer Reference Manual* for health workers who see intermittent lung cancer diagnoses within their region.

In May, we finished a two year regional community and cancer education project, *Let's Yarn with the Albury/Wodonga Aboriginal Community*. The project successfully delivered culturally sensitive cancer resources, education sessions and awareness events around cancer prevention, early diagnosis, treatment options and survival stories to two targeted audiences: the local community and aboriginal health workers.

#### **Lung Cancer Nurse Advocacy**

In 2014, Lung Foundation Australia advocated for the adoption of a model supporting the use of lung cancer nurses by way of budget submission. This submission aimed to build awareness of lung cancer and foster the case for a nationally funded and operated lung cancer nurses program, with a focus on the potential economic and social benefits for Australia. This activity required extensive relationship building with parliamentary representatives, including the Federal Health Minister, and was conducted over a period

of six months. Alan Griffin MP raised a three minute Constituency Statement about lung cancer in the House of Representatives to support our cause.

While recognising the current fiscal climate, we will continue to advocate for this important resource for lung cancer patients as part of a wider advocacy program of equitable access to care for lung cancer patients.

#### **CLINICAL SUCCESSES**

## The 5th Australian Lung Cancer Conference (ALCC)

Lung Foundation Australia successfully hosted ALCC in Brisbane in October. This bi-annual event provided a forum to raise and discuss issues relating to optimal lung cancer care in a multidisciplinary team environment for non-small cell lung cancer (NSCLC), small cell lung cancer (SCLC) and mesothelioma.



Hot topics included lung cancer screening, early detection and the advances in new treatments including targeted therapies, immuno-oncology and radiation oncology.

ALCC attracted 460 delegates, included 92 scientific abstract presentations, and hosted seven international keynote speakers as part of the three day scientific program. Delegates surveyed said the scientific programs content increased their clinical knowledge and rated the standards of the presentations as good (64%) and excellent (30%).

## Australia and New Zealand Lung Cancer Nurses Forum (ANZ-LCNF)



The ANZ-LCNF hosted a satellite lung cancer workshop at ALCC. This workshop provided 80 attendees with practical information on the management and care of lung cancer that could be implemented into clinical practice. This included a keynote presentation by Ms Natalie Doyle, a Nurse Consultant from the Royal Marsden Hospital in the UK.

## Australasian Lung cancer Trials Group (ALTG)



ALTG facilitated participation in the development, conduct, evaluation, and reporting of clinical trials in lung and thoracic cancer, promoted the use of clinical trials in evaluating new treatment and management approaches, and contributed to the translation of trial findings into clinical practice.

Some key achievements for ALTG in 2014 included:

- Increased membership by 5% to 445 members
- Formed inaugural membership and establishment of the Australian Clinical Trials Alliance
- Conducted an ideas generation workshop during which 40 members identified gaps in SCLC, early NSCLC, advanced NSCLC, supportive care, mesothelioma and diagnosis. From this workshop ALTG have four trial ideas in concept development phase
- Collaborated with the National Cancer Institute of Canada (NCIC) on a NSCLC trial and recruited Australian patients. The trial is scheduled to start in 2015
- Directed international moves to establish a global thoracic oncology trials group which will bring together leading international research initiatives in 2015

#### PATIENT AND COMMUNITY SUCCESSES

We rebranded our lung cancer patient carer initiative, Kylie Johnston Lung Cancer Network. After consultation



with Kylie's parents, Ian and Sandra, and widower, Nick, the Lung Cancer Network Australia was launched at ALCC. We believe the name better reflects the intent and services of this initiative, making it easier for patients and carers to find the information and support they need when living with lung cancer.

Lung Cancer Network Australia hosted its first consumer forum in October. More than 50 patients travelled from as far away as Mackay and the Gold Coast to attend this event. Presentations included the latest advances in lung cancer treatments and care including self-management strategies.

#### **Shine a Light on Lung Cancer**

Eleven Shine a Light events were held around Australia including activities in Sydney, Lake Haven, Brisbane, Townsville, Goondiwindi, Gold Coast, Melbourne and Perth. The events included a high tea, a sunset gathering, a workplace luncheon, a riverbank walk, a church vigil, a cancer research centre forum and a backyard BBQ.

## Asbestos Related Lung Disease/Malignant Pleural Mesothelioma (ARD/MPM)

Lung Foundation Australia began working with the Australian Government's Asbestos Safety and Eradication Agency to deliver asbestos safety and awareness activities nationally. These forums or workshops are held in both metropolitan and regional locations in each Australian state/territory through to the end of 2015.

Five workshops were held in late 2014.

In March, the *ARD/MPM Online Nurse Education Course* was successfully submitted to the Australian College of Nursing for endorsement, earning an allocation of 9.5 Continuing Medical Education points. In September, the first nurse cohort of 12 nurses enrolled and has now completed the course. A minimum of three cohort intakes will occur each year allowing up to 45 nurses to undertake this online training.

The ARD/MPM Online Nurse Education Course pilot program and its outcomes were presented at the Cancer Nurses Society of Australia (CNSA) Winter Congress in July and at the International Mesothelioma Interest Group Conference in Cape Town, South Africa in October 2014.

We developed several new resources in the Asbestos/Malignant Pleural Mesothelioma area including a new infographic and brochure. Harcourts Foundation provided a grant to develop, print and distribute our new *Asbestos in the Home* brochure with more than 7,000 copies distributed to Harcourts offices nationally as well as making it freely available online from the Lung Foundation Australia website.



## Rare Lung Diseases



Nigel McPaul, Project Manager

#### **KEY ACHIEVEMENTS**

The Pulmonary Interstitial Vascular Organisational Taskforce (PIVOT) Consultative Group began development of a paediatric rare lung disease information and support program, an IPF Peer Support Program for patients and their carers as well as preparations for the second Australian Rare Lung Disease Short Course.

#### **FOCUS POINT**

2014 was a transitional year for PIVOT with work started on two new initiatives focusing on information and support, particularly in the paediatric and rare lung disease areas.

#### **CLINICAL SUCCESSES**

The Australasian Registry Network for Orphan Lung Diseases (ARNOLD) website/database officially closed in mid-2014. A joint initiative between Lung Foundation Australia and the Thoracic Society of Australia and New Zealand (TSANZ), ARNOLD's primary aim was to gather prevalence data on 30 rare lung diseases from health professionals in Australia and New Zealand. A scientific paper is currently being developed to present the data collected from the ARNOLD website. The disease-specific factsheets posted on the ARNOLD website are now hosted on the Lung Foundation website.

#### PATIENT AND COMMUNITY SUCCESSES

The PIVOT Consultative Group worked diligently to develop two new patient and community focused programs in 2014, both of which will be launched in 2015. The first of these projects is the *Young Lungs* program, an information and

support program for parents and families of children with a rare lung disease. 2014 saw the establishment of a Clinical Advisory Committee and the development of a program strategy. The inaugural meeting of the Clinical Advisory Committee will be held in 2015 to coincide with Rare Disease Day.

Another patient and community program that was initiated in 2014 was the Idiopathic Pulmonary Fibrosis Peer Support Program. This program will provide an opportunity for people living with Idiopathic Pulmonary Fibrosis (IPF), be they patient or carer, to connect with other people through a newly created Facebook page and a telephone peer support program. The aim is to enable those living with this disease to share experiences and provide mutual support.

#### **OPERATIONAL SUCCESSES**

Following the success of the inaugural Australian Rare Lung Disease Short Course in 2013, planning began in 2014 for the second biennial Australian Rare Lung Disease Short Course in 2015. The Organising Committee anticipates an even greater number of delegates and another fascinating program.



## Registries

#### AUSTRALIAN IPF REGISTRY

The Australian Idiopathic Pulmonary Fibrosis (IPF) Registry reached two



important milestones in 2014. More than 575 IPF patients are now registered. The patients, which come from all states and territories, will be followed up every six months to obtain longitudinal data. A linked biobank was established to allow researchers to study both the genetic, physical and clinical characteristics of this complex disease. This unique and internationally acclaimed research platform will continue into 2015, directed by a national multidisciplinary steering committee.

The Registry research is also gaining significant recognition, with Lung Foundation Australia receiving invitations to present at important national and international forums.

The Project is designed to build upon the Lung Foundation Australia's success with development and administration of the Australian Idiopathic Pulmonary Fibrosis Registry.

#### **BRONCHIECTASIS REGISTRY**

Work is under way to establish an Australian Registry for patients diagnosed with non-cystic fibrosis (non-CF) bronchiectasis.

Non-CF bronchiectasis is caused by chronic infection of the airways and results in chronic cough, excess sputum production and in some cases chest pain, shortness of breath and coughing up of blood. There is currently no cure for non-CF bronchiectasis and little information is available on the disease's incidence, diagnosis or mortality rates in Australia.

Due to the large geographic distances in Australia, collaborative studies in this disorder have traditionally been considered impractical. An Australian Registry will serve as a platform to study the epidemiology of non-CF bronchiectasis, and create opportunities for collaborative clinical research in this largely unexplored and currently incurable disease.

The Project is designed to build upon Lung Foundation Australia's success with development and administration of the Australian Idiopathic Pulmonary Fibrosis Registry.

The project has strong support from the global bronchiectasis network, including the COPD Foundation's USA Bronchiectasis Registry and the European Bronchiectasis Registry which is currently under construction. The Registry will be developed in collaboration with the Americans and Europeans and will be implemented over an initial three-year period, with the view to expand the Registry once established.



## Self-management, Supportive and Palliative Care



Melissa Ram, Project Manager

#### KEY ACHIEVEMENTS

#### **Self-management**

The Better Living with Your Lung Disease videos attracted 76,000 online views and we distributed more than 4,200 hard copies of the DVDs nationally. There was an increase in attendance at 70% of our regional seminars in 2014, compared to 2013. The data from the 2014 regional seminars demonstrated an increase in people's lung disease knowledge, and confidence in implementing self-management strategies.

#### **Supportive and Palliative Care**

We achieved two key milestones in 2014; the launch of the Quality of Life Checklist and the development of the web-based interactive checklist.

#### PATIENT AND COMMUNITY SUCCESSES CLINICAL SUCCESSES

#### **Self-management**

Lung Foundation Australia continued to roll out the successful self-management project, Better Living with Your Lung Disease. Focused on increasing access to high quality, evidence-based information for people living with a lung disease, the program has proven an effective way of increasing patients' knowledge about their lungs, how they work, the benefits of exercise and managing lung disease.

Among the project activities this year was the development of the facilitator's guide. This guide assists patient support group leaders to incorporate the series as an educational tool in their regular meetings. Once piloted and published, the guide and the DVD series were delivered to more than 100 patient support groups Australia-wide.

#### **Self-management**

During 2014, several supporting documents were produced to increase the uptake of Better Living with Your Lung Disease in the primary care setting. The Health Professional Kit was developed which includes patient brochures, waiting room posters, a guide on implementing the DVD series into service delivery and a copy of the DVDs, assisting self-management support in primary care practices.

#### PATIENT AND COMMUNITY SUCCESSES

#### **Supportive and Palliative Care**

The Quality of Life Checklist helps patients living with a lung disease identify if they have any unmet needs or concerns in their care and prompts patients to start a conversation with their health professional. The checklist focuses on ease of completing daily activities, problematic symptoms, hospital visits, carer support and obtaining more information on their lung disease. In the first seven months there were 2,700 completions of the Quality of Life Checklist online.



14

## Information and Support Centre



Juliet Brown, Program Development Manager

#### **KEY ACHIEVEMENTS**

It was a huge year for the Information and Support Centre, supporting several public campaigns as well as increased promotional activities in primary care. This expanded promotion of Lung Foundation Australia services resulted in a 60% increase in enquiries to the Information and Support Centre, continued growth in distribution of LungNet news and on-going interest in the Patient Education Days.

#### **FOCUS POINTS**

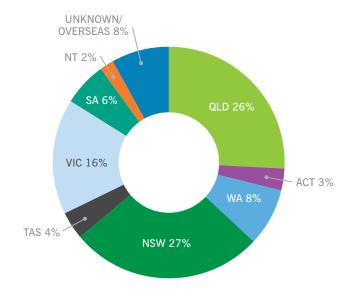
A major project was the introduction of a new Customer Relationship Management system (CRM), which replaced our previous legacy software. The new system will enable more accurate reporting on our activities. For the first time, Lung Foundation Australia will be able to have all its information stored in the one system facilitating better communication and planning of services. Our loyal administrative volunteers helped with the data migration greatly assisting the introduction of the new CRM. Once fully implemented this will be a powerful tool for staff.

#### PATIENT AND COMMUNITY SUCCESSES

## Information and Support Centre Enquiry Statistics 2014

The Information and Support Centre received almost 5,400 enquiries, either through our freecall 1800 number or the enquiries email. A breakdown of the enquiries by state and territory and overseas is shown in the following graph. Enquiries were received from patients, carers and health professionals.

#### **Enquiry Statistics 2014**







#### **LungNet News**

Our quarterly newsletter achieved a remarkable increase in its membership in 2014 with almost 13,200 hard copies of each issue being mailed and more than 2,450 being sent electronically. At the end of 2014 the total number of recipients was 15,650 which represents an increase of about 21%.

#### **Lung Care Nurse**

The work of the Information and Support Centre has continued to be augmented by a Lung Care Nurse who provided confidential support, information and advice to telephone enquirers.

#### **Lung Health Patient Education Days**

Lung Health Patient Education Days provided a program of guest speakers presenting on respiratory health related subjects in all states and in the ACT with more than 1,060 people registering to attend the 2014 program of events. The Information and Support Centre also played a pivotal role supporting 10 *Better Living with Your Lung Disease* Regional Patient Seminars.

#### **Patient Support Group Network**

Lung Foundation Australia continued to maintain our network of Patient Support Groups, with 98 groups meeting regularly across the country. During 2014, two new groups were welcomed: Huffin Puffin in Murray Bridge, South Australia and Gulgong Lung Support Group in New South Wales. Self-help patient support groups are an important means for patients to get mutual support and ongoing education about respiratory conditions. A special thank you to those group members who were able to accept a committee role; your dedication and hard work is very much appreciated.

#### **Pulmonary Rehabilitation Programs**

The Information and Support Centre continued to maintain a list of more than 300 pulmonary rehabilitation programs Australia-wide.

#### **Volunteers**

Our hard-working LungNet News volunteer team has been indispensable in 2014. Their contributions were extremely appreciated given the ever-increasing number of people receiving the newsletter. In addition to labelling and mailing all four editions of LungNet News, the volunteer team took on extra work with additional mail-outs and collating campaign materials. Our Information and Support Centre volunteer, Eileen Perry, is in her ninth year of working with us, assisting with answering calls to the 1800 number, sending out information packages and maintaining our database of LungNet News recipients. We could not do without the invaluable support and commitment she generously provides. We also acknowledge the efforts of Ian Venamore who is conducting a telephone survey with the pulmonary rehabilitation groups (having completed the Patient Support Group survey), and Fabrice Rochat who has been assisting with the new CRM database implementation.

> For the first time, Lung Foundation Australia will be able to have all its information stored in the one system facilitating better communication and planning of services.

# Marketing, PR and Fundraising



Damon Cavalchini, Senior Manager

#### **KEY ACHIEVEMENTS**

#### **Check in With Your Lungs**

March 1 saw the launch of *Check In With Your Lungs*, a three month initiative to raise awareness of the symptoms of lung disease funded by the Department of Health. The campaign involved a mix of television advertising, public relations events and general awareness activities.

The campaign successfully encouraged people to 'Check in With Your Lungs' by doing the interactive Lung Health Checklist on our website. Almost 50,000 people engaged with the checklist at an average of 3,755 visits per week during the three month campaign.

While the paid component of the campaign ran for three months, community service announcements, brochures and other materials continued to be distributed throughout the year.

The campaign won the Global award for Patient Educational Awareness. During the project timeframe we raised the community perception that lung health is important from 80% to 84%.

#### **FOCUS POINT**

#### **Just One Breath**

Our second major public health campaign, *Just One Breath*, launched on November 1 as part of Lung Health Awareness Month. This was the first phase of a new multi-year campaign.

Lung Foundation Australia joined with several well-known Australians who shared their story about what 'Just One Breath' means to them and to celebrate the precious gift of breathing. With a focus on positive health and wellbeing, *Just One Breath* aims to inspire long-lasting conversations about lung health.

#### **One Breath Gala Dinner**

The One Breath Gala Dinner was held on November 1, 2014 and incorporated the official launch of our new *Just One Breath* campaign. It was a significant success with 180 guests enjoying a unique evening at the Australian National Maritine Museum. More than \$37,000 was raised to support the work of Lung Foundation Australia.

#### CLINICAL SUCCESS

#### **Pneumonia Awareness Week**

Pneumonia Awareness Week was held from April 28 to May 4, 2014. The Lung Foundation marked the week by launching a campaign aimed at educating Australians about the seriousness of pneumonia and the importance of protecting yourself during winter months. The campaign received significant support from the professional community. During the week, there were more than 17 million media impressions and more than 450 stories across television, radio and print/online media.

#### PATIENT AND COMMUNITY SUCCESSES

#### **Breath of Life**

In March, we worked with Opcon on the Breath of Life Music Festival in Launceston. A range of high-profile international and Australian acts led to a wonderful day which helped in raising more than \$25,000 in vital funds to support the Australian Registry for patients diagnosed with Idiopathic Pulmonary Fibrosis.





#### **OPERATION SUCCESSES**

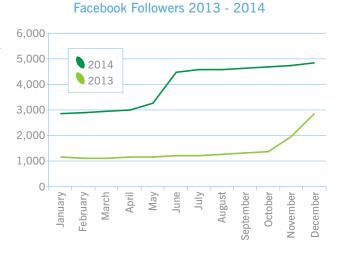
#### **Fundraising**

Thanks go to our supporters who donated so generously in 2014. In all, we received more than \$460,000 in donations including support for our annual tax and Christmas seal appeals. We also raised funds through the sale of our popular Christmas cards and our new calendar. Without the support of our generous community donors we would not be able to achieve the work we do.

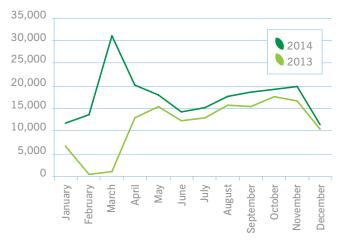
#### Website and Social Media

We redesigned, revamped and relaunched the main Lung Foundation Australia website in March. This saw an initial spike in the visits to the site, thanks in part to the launch of *Check in With Your Lungs* campaign.

Our Facebook page continued to be strong and our followers steadily grew from 2,843 on January 1, 2014 to 4,847 on December 31, 2014.



#### Website Visits 2013 - 2014



## CORPORATE COMMUNICATIONS AND ADVOCACY

During 2014, several companies joined as Corporate Partners including Oxygen Solutions, Pulmonx and Smiths Medical.

We continued to nurture relationships with key Federal MPs and senators during the year. The Parliamentary Friends of Lung Foundation Australia was ratified for the 44th Parliament early in 2014. There were two successful meetings held in Parliament House Canberra. Two bi-partisan Private Members Bills promoting the value of good lung health and work of Lung Foundation Australia were raised in the Parliament.

#### Research

Each year, Lung Foundation Australia facilitates and funds lung disease research. The Lung Foundation is constantly working to increase the number and size of the research awards we can offer the clinical community. In 2014, we offered an additional two awards for research into lung disease. In all, we received a large number of excellent applications across 11 different awards totalling \$322,500.

Lung Foundation Australia would like to thank our research award sponsors, Boehringer Ingelheim and A Menarini Australia for their great support which allows the Lung Foundation to make a number of research awards available through their ongoing support.

We would also like to thank the members of the Research Sub-committee of the Thoracic Society of Australia and New Zealand (TSANZ) for their efforts in reviewing the applications.

Lung Foundation Australia congratulates the 2014 research award winners:

- Lung Foundation Australia/Boehringer Ingelheim COPD Research Fellowship 2014/2015 Dr Andrew Jarnicki
- Lung Foundation Australia/A Menarini Australia COPD Research Top-up Grant 2014 Prof Greg Hodge

- Lung Foundation Australia/A Menarini Australia COPD Travel Grant 2014:
  - Primary Care and/or Rural/Remote Dr Julia Walters
  - Young Investigator Dr Christian Osadnik
  - Nursing or Allied Health Dr Cristino Oliveira
- Lung Foundation Australia COPD Fellowship 2014/2015 Dr Shaan Gellatly
- Lung Foundation Australia Lung Cancer National Program 2014 Grant-in-Aid for Lung Cancer Research – Dr Anne Tierney
- Lung Foundation Australia/Australian Cochrane
  Airways Group Scholarship 2014 Ms Rebecca Disler
- Lung Foundation Australia/Ivan Cash Research Grant-in-Aid 2014 – Dr Ian Glaspole
- Lung Foundation Australia/Lizotte Family Research Award 2014 – A/Prof Janette Burgess
- Lung Foundation Australia/Ludwig Engel Grant-in-Aid for Physiological Research 2014 A/Prof Anne Holland



Dr Andrew Jarnicki (Right)



Prof Greg Hodge



Dr Julia Walters



Dr Christian Osadnik



Dr Cristino Oliveira



## Operations



Chris Emery, Director

We continued our investment in the business development capacity of the organisation during 2014, with the implementation of our new Customer Relationship Management system (CRM), the development of a new fundraising strategy and the development and implementation of the *Just One Breath* awareness campaign. We are already starting to see benefits flow from this investment and are expecting great outcomes in 2015. Due to the investments in these activities, our financial results for 2014 show a small deficit of \$55,445. However, these initiatives will provide Lung Foundation Australia with an important platform for future growth.

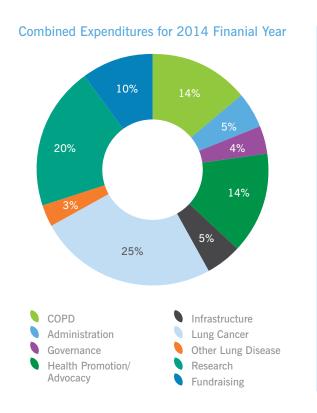
In October 2014, we replaced our Funds Manager with Morgans Financial Limited, who assumed responsibility of the management of the Lung Foundation's investments in December 2014. The benefits of the change in Funds Manager have already started to flow through to our year end results. Lung Foundation Australia management believes a more active approach to the management of our investment portfolio will achieve greater returns.

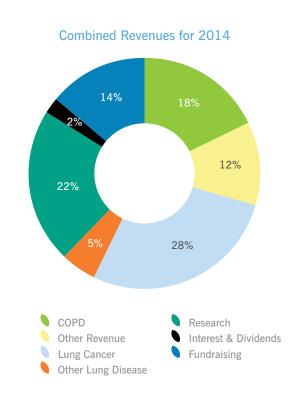
As a result of the small deficit this year, our net assets have just dipped below \$2.5 million, a level that continues to provide a level of financial stability. During 2014, we maintained our Prudential Reserve (an initiative of the Board of Directors), which ensures the Lung Foundation has financial cover for at least six months of operational expenditure.

As shown in the chart below, fundraising expenditure has increased to 10% (2013: 8%) of total expenditure as we embark on a new five year fundraising strategy to identify, develop and grow new revenue streams to support our ability to deliver more programs into the community and to fund additional research.

Our full-time equivalent employees increased to 19.7 FTEs (2013: 18.4 FTEs) with the growth due to the addition of business development personnel, and new staff working on the development of the Australian IPF Registry.

2015 promises to be another year of measured and sustainable growth as we continue to invest in the Lung Foundation's capacity to serve our community.





## Corporate Partners and Acknowledgements

#### CORPORATE PARTNERS AND SUPPORTERS

#### **Industry Partners**

- A Menarini
- Air Liquide Healthcare
- Aradigm Corporation
- AstraZeneca Australia
- Bayer HealthCare Pharmaceuticals
- Bio CSL
- Boehringer Ingelheim
- Bristol-Myers Squibb
- GlaxoSmithKline
- InterMune
- Lilly Australia
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- Merck Sharp & Dohme
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- Pfizer Australia
- Roche Products
- Slater & Gordon Lawyers

#### **Corporate Partners**

- Oxygen Solutions
- Pulmonx
- Smiths Medical

#### **Supporters**

- Aspen Australia
- Clayton Utz Lawyers
- Elekta
- Global Lung Cancer Coalition

- Golden Door
- Greg Zapalla, Ord Minnett
- Pharmaceutical Society of Australia
- O Pharmacy Guild of Australia
- Pierre Fabre Australia
- Sullivan Nicolaides Pathology
- Thoracic Society of Australia and New Zealand (TSANZ)
- Turner Freeman Lawyers
- Verastem

## Government and Granting Bodies

- Asbestos Safety and Eradication Agency
- Aurizon Community
- BUPA Health Foundation
- Cancer Australia
- Cancer Institute NSW
- City of Darwin
- Department of Health
- Gold Coast City Council
- Harcourts Foundation
- lan Potter Foundation
- Queensland Government

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- Scowcroft Ms Helen Reynolds
- Ms Megan Rushton Mr Dean Sherry
- Mr Ian Venamore Mr Mike Watteau

## Lung Foundation Australia Summary Financial Statement

for the year ended 31 December 2014

## Contents

Statement of Front of Loss and	
Other Comprehensive Income	22
Statement of Financial Position	23
Statement of Cash Flows	23

The unaudited summary financial statement has been prepared for presentation in the 2014 Annual Report of Lung Foundation Australia for the year ended 31 December 2014. It has been prepared on an accruals basis and is based on historical costs modified by the revaluation of financial assets and financial liabilities for which the fair value basis of accounting has been applied.

The unaudited summary financial statement has been derived from the audited financial report for the year ended 31 December 2014, which has been passed by the Board of Directors, who are responsible for the preparation and presentation of the financial report and the information that is contained therein.

The unaudited summary financial statement is not a financial report in accordance with the Australian Charities and Not-for-profit Commission Act 2012, and as such, reading the summary financial statement is not a substitute for reading the audited financial report of Lung Foundation Australia for the year ended 31 December 2014. Members of Lung Foundation Australia are able to obtain a full financial report, directors' report and auditors' report by contacting Lung Foundation Australia, PO Box 1949, Milton QLD 4064.

## Lung Foundation Australia Summary Financial Statement

#### STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME

Lung Foundation Australia		
For the year ended 31 December 2014	2014 \$	2013 \$
Continuing operations		
Revenue from projects	4,312,555	3,513,491
Revenue from donations and bequests	467,394	948,362
Revenue from specifically designated funds	313,116	368,895
Other income	588,693	319,587
Total revenue from continuing operations	5,681,758	5,150,335
Project expenses	(4,312,554)	(3,513,491)
Specifically designated fund expenses	(313,116)	(305,250)
Other expenses	(1,198,283)	(967,719)
Surplus/(deficit) from continuing operations before finance income	(142,195)	363,875
Finance income	86,750	86,019
Net surplus/(deficit)	(55,445)	449,894
Other comprehensive income		
Fair value gains/(losses) on available-for-sale financial assets	28,453	32,292
Total comprehensive income	(26,992)	482,186
Items that may be reclassified subsequently to profit or loss:		
Fair value gains/(losses) on available-for-sale financial assets	28,453	32,292
	28,453	32,292
Net surplus/(deficit) for the year is attributable to:		
Non-controlling interest	-	-
Members	(55,445)	449,894
	(55,445)	449,894
Total comprehensive income for the year is attributable to:		
Non-controlling interest	-	-
Members	(26,992)	482,186
	(26,992)	482,186

#### STATEMENT OF FINANCIAL POSITION

Lung Foundation Australia For the year ended 31 December 2014	2014 \$	2013 \$
Current assets		
Cash and cash equivalents	1,537,023	3,747,516
Receivables	476,109	448,298
Inventories	22,491	15,203
Financial assets	2,400,025	202,607
Total current assets	4,435,648	4,413,624
Non-current assets		
Property, plant and equipment	180,506	207,310
Intangible assets	89,000	-
Total non-current assets	269,506	207,310
TOTAL ASSETS	4,705,154	4,620,934
Current liabilities		
Payables	2,041,411	1,875,180
Employee Benefits	34,902	100,373
Total current liabilities	2,076,313	1,975,553
Non-current liabilities		
Payables	62,644	66,844
Employee benefits	92,098	50,957
Total non-current liabilities	154,742	117,801
Total liabilities	2,231,055	2,093,354
Net assets	2,474,099	2,527,580
Facility		
Equity	0.400.000	1 700 500
Retained earnings	2,429,099	1,706,593
General reserve	-	300,000
Reserves for specifically designated funds	-	477,951
Available-for-sale financial assets reserve	45,000	43,036
Total equity	2,474,099	2,527,580

### STATEMENT OF CASH FLOWS

Lung Foundation Australia For the year ended 31 December 2014	2014 \$	2013 \$
Cash flows from operating activities		
Receipts from customers	6,752,277	6,269,561
Dividends received	15,909	13,114
Interest received	93,311	133,288
Payments to suppliers and employees	(6,807,884)	(5,531,331)
Net cash flows from operating activities	53,613	884,632
Cash flows from investing activities		
Investing in term deposits	(1,748,771)	76,224
Acquisition of securities and equities	(758,396)	-
Proceeds from sale of securities and equities	347,518	-
Proceeds from sale of plant and equipment	1,523	862
Acquisition of plant and equipment	(16,980)	(45,672)
Acquisition of intangible assets	(89,000)	-
Net cash flows used in investing activities	(2,264,106)	31,414
Net increase/(decrease) in cash and cash equivalents held	(2,210,493)	916,046
Cash and cash equivalents at the beginning of the financial year	3,747,516	2,831,470
Cash and cash equivalents at the beginning of the financial year	1,537,023	3,747,516

## Looking Ahead... Plans for 2015

2015 is the third and final year of our current three year strategy. This strategy has focused on:

- 1. Working across the entire health continuum, but particularly focusing on primary care. A significant amount of work has been done translating guidelines and evidence-based care for use across a variety of primary care settings
- 2. Developing our health promotion programs. During the past two years, we have developed community campaigns that raise awareness of the importance of lung health and facilitate the recognition of symptoms of lung disease
- 3. Broadening our services to support a wider range of lung disease

The result has been the development of many new resources and programs.

2015 will be about promoting these resources and engaging with a larger proportion of our patient and clinical communities. We will be developing fewer new things and focusing on the promotion of those we have already invested in.

Four priority areas will drive our work in 2015:

- 1. Increasing our engagement with our clinical community to ensure they are aware of the resources we have to support their patients.
- 2. Providing support to a greater proportion of our patient populations. We know we have excellent resources and we make a difference in the lives of many of those living with lung disease. We also know there are still too many who are not aware of us and the support we can provide.
- 3. Engaging a wider and younger audience in the discussion about lung health through targeted programs and the use of online technology and social media.
- 4. Improving Lung Foundation Australia's infrastructure to support strategic fundraising and to support streamlining our administrative processes.

To achieve these goals, programs we will deliver on in 2015 include:

#### Engaging the clinical audience

- Develop a directory of dedicated lung cancer multi-disciplinary teams in Australia
- Proactive distribution of patient flyers
- Stablish the Australian Bronchiectasis Registry

- Develop a strategy to support younger researchers
- Stablish the Global Thoracic Oncology Trials Group
- Promote a modular approach to primary care training that can be rolled out nationally

## Reaching and making a difference for more people affected by lung disease

- Developing and distributing "Supporting the Journey" packs for lung cancer patients
- Establishing IPF support program
- Launching new *Young Lungs* support programs support program for families of children with a rare lung disease
- Connecting those entering emergency due to COPD exacerbation with Lung Foundation Australia

#### Engaging the wider community in their lung health

- Rolling out phase two of our *Just One Breath* campaign www.justonebreath.com.au
- Distribution strategy for Lung Health Checklist
- Promotion of immunisation messages

#### Advocating on behalf of those affected by lung disease

- Advocating for support for Lung Foundation Australia's application for an MBS rebate for pulmonary rehabilitation
- Advocating for equitable access to care for lung cancer patients

#### Calendar highlights

- Second annual *Just One Breath* Gala dinner October 17, Sydney
- Second Lung Foundation Australia/TSANZ Australian Rare Lung Disease Short Course – October 16 and 17, Sydney

We have a big year ahead and can't do it without your support.

**Become a member** – If you would like to become a Lung Foundation Australia member, please contact us on **1800** 654 301 or visit www.lungfoundation.com.au

**Donate** – You can help the Lung Foundation provide support, resources to and advocacy on behalf of the millions of Australians affected by lung disease.

#### Ensure lung health is a priority for all in Australia

#### **GOALS**

#### How?

#### **STRATEGIES**

## Translating strategies across settings

#### **Promote Lung Health**

It's time for all in Australia to take their lung health seriously

## Promote early diagnosis of lung disease

Early identification of lung disease can lead to better outcomes

## Support those with lung disease and their carers

Ensure those affected by lung disease have access to information, support and are encouraged to self-manage

## Promote equitable access to evidence-based care

Advocate on behalf of those with lung disease and develop clinical resources for use across a variety of settings

#### Support quality research

Raise funds for research and work collaboratively with others to support research

1

## Broaden services to include all aspects of lung disease

LFA will provide some level of support across the broad range of disease areas and focus on areas where impact is high

2

## Work across the entire Health Promotion continuum

LFA will raise awareness of the importance of lung health amongst the wider community, particularly those at risk

3

#### Communicate well and often

Through our work LFA will become widely regarded as the primary body for lungs. We will do good and we will also be seen to be doing good

4

## Develop and promote clinical resources

Through our work with clinicians and key stakeholders, LFA clinical resources will be well-used and well-regarded

5

## Develop and foster strategic relationships to achieve our goals

LFA will be regarded as an important organisation with which to collaborate on lung health and wider health promotion/chronic disease

Clinical

The wider community, particularly those at risk

Patients and carers

Stakeholders including government

Research











