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**Lung Foundation** Australia  
Annual Report



**Lung  
Foundation  
Australia**

*when you can't breathe... nothing else matters®*

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**3 year old Charli is constantly hooked to an oxygen tank, making normal everyday activities like going to the park a challenge.**

At just 12 months old, Charli was diagnosed with a rare lung disease. The doctors have not been able to provide her parents with a clear treatment plan or prognosis, so it is unclear what Charli's long term prospects are.

**As little as \$10 per month can help make a difference to the lives of millions of Australians affected by lung disease. Please call 1800 654 301 or visit [lungfoundation.com.au](http://lungfoundation.com.au)**

# Making an impact in 2017

## Patient support



**546,600+**  
total patient interactions



**10,480+**  
accessed our support services,  
**that's almost 30 people a day.**



**3 new**  
patient support services established:

- Pulmonary Fibrosis Peer Connect
- Lung Cancer Connect Webinar
- Young Lung Cancer Telephone Support Group



**443,280+**  
patient support pages accessed online



This included:

- Information and Support
- Education Seminars
- Support Groups

## Clinical support

**489,770+**  
total clinical interactions



**470,000+**  
clinical pages viewed online



**2,590+**  
health professionals educated via training courses



**first ever**  
Australia and New Zealand Pulmonary Rehabilitation Guidelines launched

## Advocacy and awareness



**681,300+**  
website visits



**15,950+**  
social media followers



**1,471** media articles with  
**229+ million reach**

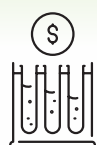


**33,970+**  
Lung Health Checklists completed online



**14** government submissions advocating for people with lung disease

## Research



**\$2.3+ million**  
invested in research



Increased research award funding from  
**\$680K to \$1+ million**



**7** lung cancer clinical trials initiated

## Fundraising



**\$881,149**  
raised through community fundraising



**136+**  
community fundraisers



**Increased funds raised for lung cancer research by 200%**

# Message from the Chairman and CEO

The stigma surrounding lung disease continues to have a devastating impact on the level of research, funding, treatment and support available to people living with a lung condition. It also has significant mental health impacts and causes delays in diagnosis.



Lung Foundation Australia CEO Heather Allan and Chairman Professor Christine Jenkins.

In 2017, we undertook a national consumer survey to uncover the current prevalence of stigma in our society. The results revealed one third of Australians believe people with lung cancer 'have only themselves to blame', while one in ten will say 'they got what they deserved'. This is despite 1 in 3 women and 1 in 10 men diagnosed with lung cancer having no history of smoking<sup>1</sup>. The impact of stigma is evident through the results of another survey conducted among our network of patients living with Chronic Obstructive Pulmonary Disease (COPD), Idiopathic Pulmonary Fibrosis (IPF), lung cancer and many other lung diseases. The results showed 39% see family and friends less often, 29% feel isolated and 60% do the things they love, such as hobbies, less often.

Now more than ever it is imperative that we continue to strengthen our efforts in advocacy to ensure the 1 in 4 Australians affected by lung

disease<sup>2</sup> receive equitable access to care and support, and to increase lung disease research funding from both government and the philanthropic sector.

This was a key focus for Lung Foundation Australia in 2017, as was the continued delivery and enhancement of our evidence-based services and support, which help improve the outcomes and quality of life for people with lung disease.

## 2017 Highlights Research

Despite the staggering number of people affected by lung disease, research funding is disproportionately low. Lung Foundation Australia considers this one of our key priority areas for action. In 2017, we are pleased to report we increased our funding of research awards by 52%. While we still have a way to go to reach our target, we were pleased to be able to distribute over \$1 million in award funding across a wide range of therapeutic areas.

**Read more on page 15.**

## Advocacy

Another Board priority focuses on speaking to government more forcefully on behalf of our patient population. We will continue this work until lung disease receives the level of policy and research support that is proportionate to the burden of chronic respiratory disease and lung cancer. In 2017, our work to advocate for a Medicare Benefits Scheme subsidy for pulmonary rehabilitation continued and our application will be re-heard toward the end of the year.

In 2017, we actively participated in the Post-Market Review of COPD medications and were pleased that the final report included important non-Pharmaceutical Benefits Scheme recommendations around the need for more education of patients and primary care practitioners; increased use of spirometry; and increased access to pulmonary rehabilitation.

We also participated in the Senate Enquiry into funding of low survival cancers. The subsequent report highlights the need for more rapid access to new medications and an increase in research funding for this significant area of need.

Throughout the year, we actively supported the listing of new and proven medications for those with lung disease and were pleased that, for the first time, those with Idiopathic Pulmonary Fibrosis (IPF) now have access to medication that will slow down the progress of their disease. We are also pleased to see government recognising the need to subsidise the new targeted medicines and immunotherapies for lung cancer. We have been disappointed that some important medications have not yet gotten across the line and we will continue to advocate that they be made available.

We were also instrumental in organising the first Lung Health Round Table with the Department of Health, aimed at identifying practical interventions that will make the biggest difference to outcomes and could be implemented over a two year time-frame through a National Lung Health Strategy.

**Read more on page 20.**



*Mrs Joy Owsnett, Mr John 'Wes' Owsnett, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd), Mr Lal Pardasani and Lung Foundation Australia Board Director Mr Tony Hyams AM.*

## Patient and clinical support

Our fundraising efforts and the support of our industry partners have allowed us to continue to increase our reach into the patient, health professional and research communities. Some highlights this year include:

- New patient support program in Pulmonary Fibrosis established.
- Increased support for families of children with a rare lung disease.
- 162 Lungs in Action classes delivered across the country every week, with 17 additional locations coming in 2018.
- 4 new clinical guidelines developed in collaboration with the Thoracic Society of Australia and New Zealand.
- 23% increase in the number of health professionals trained, predominantly in the primary care space.

**Read more on page 9.**

## Fundraising

We are very fortunate to work with a wide range of industry partners whose support allows us to deliver patient and health professional resources and support. Our partners are listed on page 23. We also recognise that we need to diversify our revenue sources and have been investing in fundraising activities over the past few years. Despite a competitive environment and uncertain economy, we are already starting to see the fruits of this investment, with total fundraising income doubling since 2014. We must continue to grow these activities to support the planned growth of our services and support. Please take the time to read about some of our local heroes whose efforts to raise awareness and funds have been integral to our fundraising growth.

**Read more on page 21.**

## Patron

We were honoured and grateful to have His Excellency General the

Honourable Sir Peter Cosgrove AK MC (Retd) continue his patronage of Lung Foundation Australia in 2017.

## Acknowledgements

We would like to recognise the hundreds of community and clinical volunteers who generously provide their time and expertise to support the work of Lung Foundation Australia. Thank you also to our passionate, hard-working staff whose experience and dedication underpins our ability to help improve lung health and reduce the impact of lung disease for all Australians.

We thank you all, and we look forward to working with you again in 2018.

**Professor Christine Jenkins**

**Heather Allan**

1 Lung Foundation Australia, Improving outcomes for Australians with lung cancer: A Call to Action (2016) <http://lungfoundation.com.au/wp-content/uploads/2016/08/LFA-improving-outcomes-report-0816-proof10.pdf>  
2 AIHW, 2016, <https://www.aihw.gov.au/reports/australias-health/australias-health-2016/contents/ill-health>

# The facts

Anyone can get lung disease. It affects men, women, children, smokers, ex-smokers and never smokers, all of whom are equally worthy of care and support. No one deserves lung disease.




 **1 in 4 Australians** has a lung disease.<sup>1</sup>

 **1 in 7 deaths** is a result of lung disease.<sup>2</sup>

**Lung disease accounts for 10%** of the total health burden in Australia.<sup>2</sup>

**More than 50%** of all Australians rarely or never think about the health of their lungs.<sup>3</sup>



## Chronic Obstructive Pulmonary Disease (COPD)

 **1 in 7 Australians over 40** has COPD and many don't know it.<sup>4</sup>



**COPD is the second leading cause** of avoidable hospital admissions.<sup>5</sup>


## Lung cancer

 **One Australian dies every hour** from lung cancer.<sup>7</sup>

**Lung cancer is Australia's biggest cancer killer.**

It kills more people than breast, prostate and ovarian cancers combined.<sup>10</sup>

**12,500** Australians were diagnosed with lung cancer in 2017. That's **34 people a day.**<sup>6</sup>



Lung cancer has one of the lowest survival rates of any cancer in Australia with only **15%** of Australians surviving **5 years** after their diagnosis.<sup>7</sup>

 **1 in 3 woman & 1 in 10 men** diagnosed with lung cancer have no history of smoking.<sup>7</sup>

## Idiopathic Pulmonary Fibrosis (IPF)

**IPF is a rare and progressive lung disease causing irreversible scarring of the lungs.**

Whilst it is not currently known exactly how many people are affected by IPF in Australia, experts estimate approximately **1,250 people are diagnosed** with this devastating disease **each year.**

1. AIHW, 2016, <https://www.aihw.gov.au/reports/australias-health/australias-health-2016/contents/ill-health>  
 2. Lung Disease in Australia, 2014, Woolcock Institute of Medical Research  
 3. Galaxy Research Omnibus, January 2014 (wave 1)

4. Toelle B, Xuan W, Bird T, Abramson M, Atkinson D, Burton D, James A, Jenkins C, Johns D, Maguire G, Musk A, Walters E, Wood-Baker R, Hunter M, Graham B, Southwell P, Vollmer W, Buist A, Marks G. Respiratory symptoms and illness in older Australians: The Burden of Obstructive Lung Disease (BOLD) study. Med J Aust 2013;198:144-148

5. Page A, Ambrose S, Glover J et al. Atlas of Avoidable Hospitalisations in Australia: ambulatory care-sensitive conditions. Adelaide PHIDU. University of Adelaide. 2007  
 6. Australian Institute of Health and Welfare 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW.  
 7. Australian Institute of Health and Welfare 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW.

## Pulmonary Arterial Hypertension (PAH)



PAH diagnosis is delayed on average **3.9 years.**<sup>9</sup>



On average it takes **5 GP visits** before a specialist referral is given.<sup>9</sup>

## Bronchiectasis

Bronchiectasis is a common lung disease caused by chronic infection damaging the lungs.



**Females and the elderly** are more frequently affected.<sup>10</sup>

## Rare lung disease in children



In Australia there is currently very limited, if any, information, support, treatment and research available for children diagnosed with a rare lung disease.

## Challenges in Australia

The stigma surrounding lung disease is a major barrier to accessing research, funding, treatment and support.



**Over one third (35%)**

of Australians consider those with lung cancer to be their 'own worst enemy' and 1 in 10 will say they 'got what they deserved'.<sup>11</sup>

**1 in 6**

Australians believe people with lung disease who have smoked deserve less support.<sup>11</sup>



**In a global survey conducted in 15 countries,**

**Australians had the least sympathy** for someone diagnosed with lung cancer, compared with other cancers, based on its association with tobacco smoking.<sup>7</sup>



## Understanding is rare, lung disease is not

"It's something that I was either born with, or grew into, or slowly developed over time. Lung disease has such a stigma attached to it that I think when I tell other people I have a lung disease, they probably assume that it is a recent thing and there is something I did in my lifetime that caused me to have a lung issue. I wish people would react to being presented with a person with a lung disease in a way that was open minded and understanding."

**Tegan is 28 years old and was diagnosed at the age of six with Pulmonary Arterial Hypertension.**

7. Lung Foundation Australia, Improving outcomes for Australians with lung cancer: A Call to Action (2016) <http://lungfoundation.com.au/wp-content/uploads/2016/08/LFA-improving-outcomes-report-0816-proof10.pdf>

8. Jo HE, Glaspole I, Grainge C, et al. Baseline

characteristics of idiopathic pulmonary fibrosis: analysis from the Australian Idiopathic Pulmonary Fibrosis Registry. *Eur Respir J* 2017; 49:1601592 [<https://doi.org/10.1183/13993003.01592-2016>].

9. Strange G, Gabbay E, Kermeen F, Williams T, Carrington M, Stewart S, et al. 2013;3 (1):89-94

10. Seitz at al 2012, Quint et al 2016, <http://bronchiectasis.com.au/bronchiectasis/bronchiectasis/prevalence>

11. Lung Foundation Australia PureProfile Consumer Survey, 2017

# Who we are

Lung Foundation Australia is the only charity in Australia providing support and a voice for people living with a lung disease.

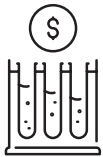
Lung Foundation Australia works to inspire hope for the future by funding life-changing research; facilitating best-practice clinical management; and

supporting those with lung disease. We work to empower those with lung disease to take the important steps they can to enjoy a better quality of life by understanding

and managing their disease. We advocate for people with a lung disease to receive the level of care and treatment they deserve.

## Strategic Priorities

Our five strategic priorities serve as our blueprint, helping us to achieve our mission to improve lung health and reduce the impact of lung disease for all Australians.



### Research

Funding world-class research into treatment, prevention and a cure.



### Awareness

Promoting lung health and timely diagnosis of lung disease.



### Patients

Supporting those with a lung disease to achieve better outcomes and improve quality of life.



### Practice

Providing evidence-based education, training and resources to health professionals.



### Advocacy

Promoting and calling for equitable access to evidence-based care.

Lung Foundation Australia works across all areas of lung disease, with a particular focus on Chronic Obstructive Pulmonary Disease

(COPD), lung cancer, Idiopathic Pulmonary Fibrosis (IPF), Pulmonary Arterial Hypertension (PAH), bronchiectasis, respiratory infection,

and rare lung disease in children. We rely on the generosity of the community, businesses and industry organisations to fund our work.

## Values



### Evidence-based



### Patient centered



### Compassion



### Respect



### Collaboration





# Patient and community support

Providing the first point-of-call linking patients to information, resources and support services.

## Information and support

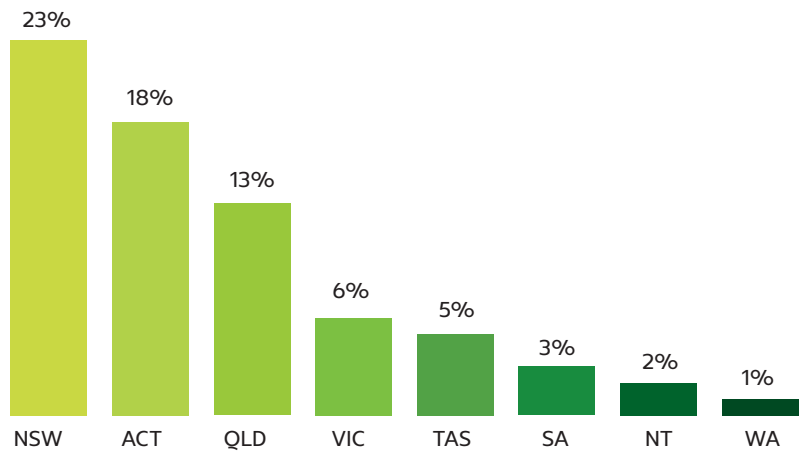
**6,690+**

supported via our Information and Support Line

Our passionate and experienced Information and Support staff provided trusted advice, information and support to patients, carers and health professionals. The graph to the right represents the breakdown of interactions received by our Information and Support Line across Australia, where the location was known. The majority (23%) of the interactions received were from New South Wales, followed by 18% in Queensland and 13% in Victoria.

In addition, we saw an increase in the number of people accessing our online services and resources, highlighting an increasing trend for online communications and support.

## Interactions received by our Information and Support Line, where the caller was known.



*“Many thanks for your help and information - it really helped me get my mother home with her oxygen. You truly are a credit to your team and I really cannot thank you enough. You were a steady hand in my very rough ocean. I will never forget what you did.” - Sharyn, ACT.*



## SNAPSHOT

**10,480+**

ACCESSED OUR SUPPORT SERVICES.

ALMOST **30** people a day.



**3 NEW** patient support services established:

- Pulmonary Fibrosis Peer Connect
- Lung Cancer Connect Webinar
- Young Lung Cancer Telephone Support Group

**443,280+**

patient resources accessed online

## Education Seminars

**11** education seminars  
**732** people educated

Lung Foundation Australia's suite of Education Seminars offered a valuable and informative program

of practical tips and advice. The seminars were delivered all around Australia by clinical experts to help improve the understanding of the important role of patient self-management. Popular topics in 2017 included living well with a lung disease, tips for the breathless patient, exercise and nutrition.



*"I get so much out of attending patient seminars. They allow me to learn more about and better manage my lung disease."*

**- Meredith,  
lives with COPD.**



*"The Education Seminars are always informative, topical and easy to understand, presented by down to earth health professionals. I learn something new at every session."* - **Ian, lives with COPD.**



## Love Your Lungs club

**1,016** members,  
**43%** new in 2017

In 2017, Lung Foundation Australia continued to grow the membership of our Love Your Lungs club, which was established in late 2016. The club is a community for our patients, families and friends to support a good cause whilst keeping up-to-date with the latest in respiratory news. Members can access benefits including the hard copy of LungNet News, discounted entry to our Education Seminars and access to our online supporter discount program.

## Support Groups

**74** Support Groups supporting  
**1,480** members

Lung Foundation Australia facilitated and updated a directory of support groups across the country allowing us to refer patients and their carers to groups where they can meet others like them. We continued to assist group leaders in facilitating these sessions by providing a Support Group Manual, promotional flyers and insurance certificates.

## Lung Cancer Support Nurse

**344** enquiries,  
**95%** increase on 2016

Our Lung Cancer Support Nurse, Claire Mulvihill, continued to provide expert information, support and advice to an increasing number of patients and carers across the nation at all stages of their lung cancer journey.



*I have had no link to my hospital and if it wasn't for the suggestion to call Lung Foundation Australia's Lung Cancer Support Nurse, I would have continued to flounder with my symptoms. Thank you for listening, your kindness and guidance.* - **Anonymous, Regional Australia.**



*The Hope and Light Lung Cancer Support Group 2017 Christmas morning tea.*

## Lung Cancer Support Groups

### Hope and Light Face-to-Face Lung Cancer Support Group

**UP TO** people attended each month  
**14**

Lung Foundation Australia together with Marilyn Nelson, lung cancer patient and advocate, introduced a monthly face-to-face lung cancer support group in Brisbane. The group provides an informal environment for people to share information,

support one another and discuss ways to manage the challenges of living with lung cancer.

### Lung Cancer Telephone Support Groups

**39** people connected across 4 monthly calls

Lung Foundation Australia's weekly Telephone Support Groups, facilitated by our Lung Cancer Support Nurse and specially trained staff, continued to be a valuable support service. The group connects people living with lung cancer with others in a

similar situation. Participants are provided with a safe, friendly and open environment to discuss the challenges of living with lung cancer.

### Young Lung Cancer Telephone Support Group

**6** people connected across a monthly call

In 2017, Lung Foundation Australia piloted the only service in the country linking young people living with lung cancer (50 years and younger) to talk about their journey and strategies to cope and live well with this devastating disease.

### Lung Cancer Connect Webinar

**79** participants across 2 webinars

In 2017, Lung Foundation Australia launched Lung Cancer Connect, a webinar series providing patients,

their families and carers, as well as health professionals, with information, advice and support about living with lung cancer. The topics focused on looking at the needs of newly diagnosed lung cancer patients and the psychological needs of patients living with lung cancer.

The Lung Cancer Connect project is a Cancer Australia *Supporting people with cancer* Grant initiative, funded by the Australian Government.

### Lungs in Action

**1,620** Lungs in Action participants across **162** classes

Lungs in Action is a safe and enjoyable community exercise maintenance program empowering

people with a lung disease to improve their quality of life through exercise. There are now 80 locations offered nationally (an increase of five locations) to equip patients with the skills and knowledge to better manage their symptoms and maintain the improvements gained through pulmonary rehabilitation.

### Pulmonary Fibrosis Peer Connect

**74** people connected

In 2017, Lung Foundation Australia reviewed our Idiopathic Pulmonary Fibrosis (IPF) Peer-to-Peer Support Group through interviews with participants and mentors. The service was simplified and re-introduced as the Pulmonary Fibrosis (PF) Peer Connect service which matches people living with PF and their carers with someone going through a similar experience.



*"I highly recommend the Pulmonary Fibrosis Peer Connect Service. Even though you have not previously met, there is common bond because you are people of Idiopathic Pulmonary Fibrosis. There is such a lack awareness of IPF it is imperative that victims can find support."* - Marion, New South Wales.



### Young Lungs

Our Young Lungs Program continued to support parents of children living with a rare lung disease who often feel alone and isolated. In 2017, we significantly increased activity in this program with the establishment of a Parent Advisory Committee and increased our awareness activities by featuring stories in our communications.



Left to right: 4 year old Olive who lives with Surfactant Protein C Deficiency (SP-C), her mum Rachel and Misty mother of 4 year old Leo who also has SP-C.

### Australian Rare Lung Disease Short Course – Patient Education Seminar

**54** patients educated

Lung Foundation Australia hosted an education seminar for patients living with a rare lung condition such as Idiopathic Pulmonary Fibrosis (IPF), Interstitial Lung Disease and Pulmonary Arterial Hypertension (PAH) as part of the Australian Rare Lung Disease Short Course in 2017. The seminar provided people with the latest evidence-based information and practical tips to help manage symptoms and improve quality of life.

### New or updated resources:

- Better Living with Chronic Obstructive Pulmonary Disease (COPD) – A Patient Guide, Third Edition
- COPD Information Pack
- Better Living with Pulmonary Arterial Hypertension – A Patient Guide
- Better Living with Exercise – Your Personal Guide



To find out more about these and many other resources, visit: [lungfoundation.com.au](http://lungfoundation.com.au)

# Clinical support

Supporting early diagnosis and best-practice clinical management.

## Australia and New Zealand Lung Cancer Nurses workshop

**62** nurses educated

Lung Foundation Australia delivered a workshop in March 2017, Future Directions in Lung Cancer Treatment – Nursing Implications, which provided evidence-based education for nurses across rural and regional New South Wales. The workshop upskilled nurses to provide the latest best-practice management and care for their patients and focused on the new immunotherapies and targeted therapies in lung cancer.

## Pulmonary Rehabilitation Guidelines

Guidelines launched and accessed

**4,126** times

In 2017, Lung Foundation Australia and the Thoracic Society of Australia and New Zealand developed and launched the first-ever pulmonary rehabilitation guidelines for Australia and New Zealand, providing health professionals with evidence-based recommendations for the practice of pulmonary rehabilitation that are specific to the Australian healthcare context. The guidelines assist in translating research into practice to improve quality of life and reduce hospital admissions for patients with a chronic lung disease.

## Online training

**568** health professionals educated

Lung Foundation Australia's online training continued to upskill nurses, pharmacists, clinicians and exercise professionals to ensure they have access to the most up-to-date and best-practice education. In 2017, we released a series of new training modules on Chronic Obstructive Pulmonary Disease (COPD) so health professionals can focus on specific COPD topics that are most relevant to them and their patients, and to complete quick refresher courses.

## Nurse Network face-to-face training

**936** health professionals educated

Through Lung Foundation Australia's Chronic Obstructive Pulmonary Disease (COPD) Nurse Network, nurses across Australia delivered training and education to health professionals on the management of COPD. This included correct inhaler device techniques to empower best-practice management of patients with COPD.

## Lungs in Action

**162** classes across

**80** locations nationally

A review of Lung Foundation Australia's community-based exercise program, Lungs in Action, was undertaken in 2017 to ensure we can



*"Throughout the Lung Foundation's Lungs in Action Online Theory training, I enjoyed the patient stories and listening to their experiences of living with Chronic Obstructive Pulmonary Disease (COPD). Furthermore, the combination of visual and written material was useful."*

**- Lloyd,  
Exercise Physiologist,  
Brisbane.**



continue to improve the program and deliver high quality training and support for instructors. The Lungs in Action Committee have developed a plan with three key priority areas for improvement to be rolled out over a three year period. These include a focus on research, data collection, ensuring quality training and expanding the program.


John Alexander OAM MP having his lung health tested at a Lung Foundation Australia event.



## SNAPSHOT

 **2590+**  
educated via online and  
face-to-face training

  **138**  
educated at Australian Rare  
Lung Disease Short Course

 **85,800**  
users accessed the  
COPD-X Guidelines

**260**   
health professionals  
educated in lung cancer

### Australian Rare Lung Disease Short Course

**138** health professionals  
educated

Lung Foundation Australia hosted the third Australian Rare Lung Disease Short Course in Sydney in 2017 which provided the latest in scientific research, evidence-based information, real world diagnosis and therapy on Interstitial Lung Disease (ILD) for health professionals. Key topics included the latest in Idiopathic Pulmonary Fibrosis and Pulmonary Hypertension, interesting case studies and the future of ILD.

### Have the CHAT

**1,912**  
supported the campaign

**1,850+**  
accessed our clinical resources

**282,856**  
reach via social media

In 2017, our Have the CHAT winter warning campaign ran for its third year. The campaign aims to keep people with Chronic Obstructive Pulmonary Disease (COPD) well

and out of hospital, by raising awareness of the symptoms of COPD exacerbations among patients, carers and health professionals. In 2017, we focused on a digital approach to the campaign by providing downloadable posters, flyers and promotional packs to extend our reach of the campaign amongst our patient and health professional networks. It also provided evidence-based resources to support health professionals in timely identification and management of COPD exacerbations.

### The COPD-X Plan: Australian and New Zealand Guidelines for the management of COPD

The updating and maintenance of the COPD-X Guidelines remained a key focus in 2017. This evidence-based clinical resource for health professionals assists in the management of patients with COPD, highlighting the latest key clinical recommendations in diagnosis and management. The guidelines are also one of the most regularly updated COPD Guidelines in the world.



Have the CHAT campaign creative.



Lungs in Action participant and instructor.

## Supporting patient referrals

A national survey of our health professional network was undertaken to better understand how we can support them to provide information and care to their patients. It found just over one third of health professionals regularly refer their patients to Lung Foundation Australia.

We are working to increase health professional engagement by continuing to provide education and support through conferences, best-practice resources, training and guidelines.

## Idiopathic Pulmonary Fibrosis Guidelines

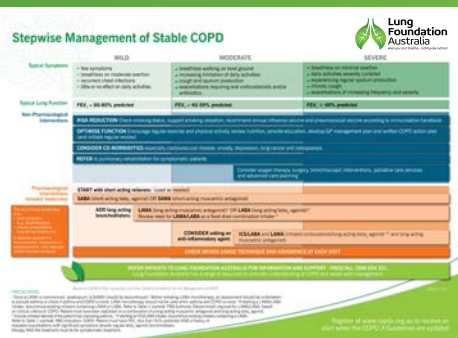
In 2017, Lung Foundation Australia and Thoracic Society of Australia and New Zealand (TSANZ) released a joint position statement, Treatment of Idiopathic Pulmonary Fibrosis in Australia and New Zealand, supporting advances in diagnostic techniques and new anti-fibrotic medications.

## New or updated resources:

- Stepwise Management of Stable COPD
- The COPD-X Plan: Australian and New Zealand Guidelines for the Management of COPD
- COPD-Asthma Overlap
- Pulmonary Rehabilitation Guidelines
- Two Idiopathic Pulmonary Fibrosis Position Statements



To find out more about these and many other resources, visit: [lungfoundation.com.au](http://lungfoundation.com.au)



Stepwise Management of Stable COPD  
**168%**  
increase in use



*"The Stepwise Guide is a great resource and reference point when I am with my patients and also when talking with colleagues about management of COPD. I regularly refer to it in my day-to-day clinical practice. I can cross check the guide to ensure I am prescribing my patients the correct pharmacological therapies and recommend the appropriate non-pharmacological interventions."*

**Dr Kerry Hancock, General Practitioner, South Australia.**



## Asthma-COPD overlap paper

Lung Foundation Australia in collaboration with the National Asthma Council Australia developed a new resource, the asthma-COPD overlap, for people who have features of both asthma and COPD. The paper provides evidence-based information about the clinical presentation, prevalence, diagnosis and treatment of asthma-COPD overlap.



# Research

**Funding world-class research to support advancements in the prevention, treatment and management of lung disease.**

Research offers hope and undisputed benefits for people living with lung disease. Unfortunately, research funding into lung disease is disproportionately low compared to its burden, with only 5.5% of Federal Government funding directed to lung research.

Since 1990, Lung Foundation Australia has invested \$15.6 million into our research program. Our research program includes research awards to support cutting edge studies; initiating and funding clinical trials; and managing two disease research registries that provide researchers an important data source for Idiopathic Pulmonary Fibrosis and bronchiectasis.

In 2017, we saw significant growth across these programs, particularly in our Australasian Lung Cancer Trials Group (ALTC) where funding for lung cancer trials increased from \$83K to

\$7.2 million. We also increased the total funding for our research awards program by 52%.

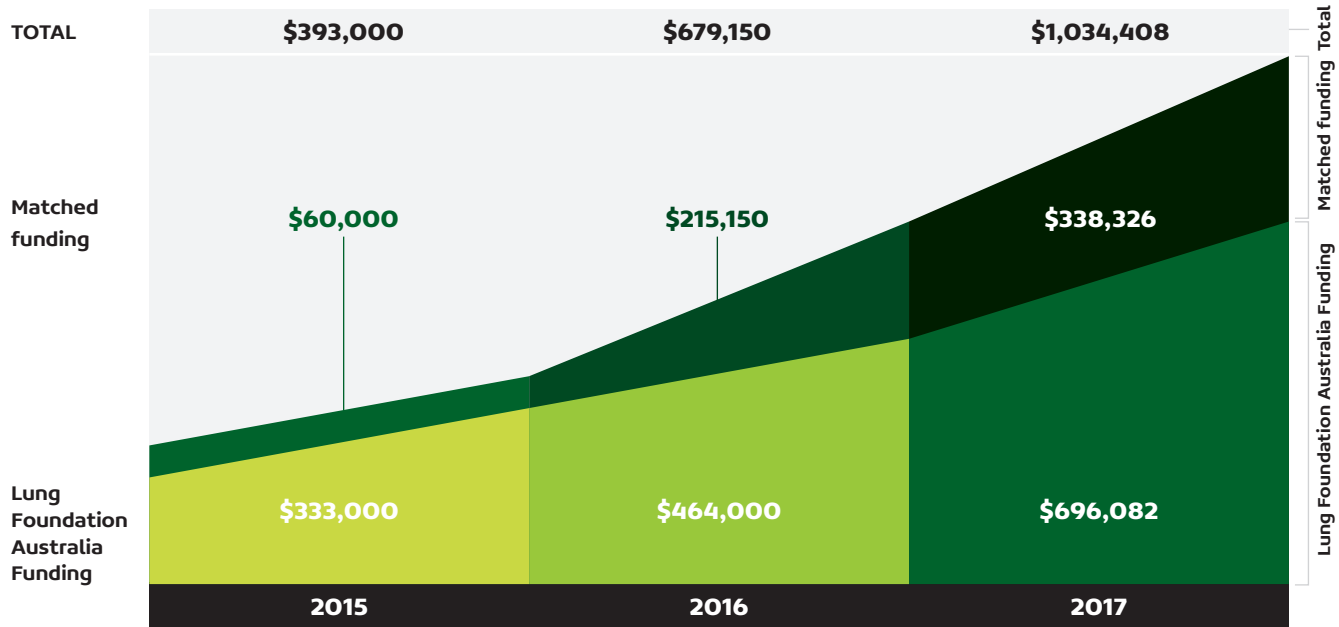
## Research Awards

Through our Research Awards Program, Lung Foundation Australia raises funds to support research into the cause, treatment and cure of all lung conditions. We provide opportunities for individual researchers through fellowships and PhD scholarships, project grants, grants-in-aid and travel grants, allowing researchers to collaborate and showcase their work nationally and internationally. Our program attracts partnerships, researchers and builds a commitment to lung disease research. In 2017, we raised and invested \$1,034,400 into this program, which allowed us to fund 16 research awards. For a comprehensive list of our research awards and 2017 recipients, please visit [lungfoundation.com.au/awards](http://lungfoundation.com.au/awards).

## Acknowledgements

We would like to thank our sponsors and donors who made our 2017 research awards program possible; including CSL Bio, A. Menarini Australia, Boehringer Ingelheim, The Merrin Foundation, the Lizotte Family, the Ivan Cash Family, the Ludwig Engel Family, the Bantoft Family, the David Wilson Family, Rabia Manchanda and Bill Van Neirp.

## Research Award Funding



## 2017 Major Research Award recipients and projects

### Chronic Obstructive Pulmonary Disease Research Fellowship

Awarded to: Dr Anna Hudson.

Anna's research, through detection of neural impairments in Chronic Obstructive Pulmonary Disease (COPD), aims to identify new targets for therapy to reduce respiratory morbidity in patients with COPD.

**Valued at \$160,000 over two years.**

Supported by Boehringer Ingelheim.



Lung Foundation Australia Chairman Professor Christine Jenkins and Dr Anna Hudson.

### Idiopathic Pulmonary Fibrosis Grant-in-Aid

Awarded to: Alfred Health and the Prince Charles Foundation.

With this award funding, Alfred Health and the Prince Charles Foundation will establish the Australian Idiopathic Pulmonary Fibrosis (IPF) Tissue Bank. The Tissue Bank will be a synchronisation of two separate tissue banks (based at the Prince Charles Hospital and the Alfred Hospital) under the umbrella of the Australian IPF Tissue Bank (AITB). This will establish one central source of data and lung tissue samples for researchers to further investigate the causes and treatment of IPF and improve outcomes for people living with this disease.

**Valued at \$90,000.**

Supported by the Merrin Foundation.

### Menzies Idiopathic Pulmonary Fibrosis Genetics Project

Five year project in collaboration with the University of Tasmania.

This research will be undertaken for the first time in Australia and will aim to identify the underlying genetic drivers using contemporary approaches. It is the first step toward determining the role of genetics specific to Idiopathic Pulmonary Fibrosis (IPF) with the aim to improve the detection, treatment and prevention of this devastating disease.

**Valued at over \$1,500,000.**

Made possible by an anonymous family donation.

For a comprehensive list of our research awards and 2017 recipients, please visit [lungfoundation.com.au/awards](http://lungfoundation.com.au/awards)

### Updates from previous winners

#### PhD scholarship facilitates research in earlier lung cancer diagnosis

**\$520,000 co-funded over 2 years**

The Deep Manchanda/Lung Foundation Australia Early Career co-funded Fellowship in Lung Cancer 2016/17 allowed Dr Atiqur Rahman from the University of Newcastle to undertake his research project, in the lab of Professor Phil Hansbro, titled: *Elucidating and targeting genomic and epigenetic changes in the*

*development and progression of lung cancer.* This award was made possible thanks to the generous donation from the Manchanda Family in memory of Deep Manchanda who died of lung cancer.

Atiqur's research aims to identify changes that occur as lung cancer progresses using a world-first short-term mouse model of cigarette-smoke/tobacco carcinogen-induced lung cancer. It will identify early genetic changes in lung cancer such as when adenomas (benign) progress to adenocarcinomas (cancerous). The research hopes to advance diagnosis and treatment of lung cancer to

improve the lives of people living with this disease.

As a result of the exciting developments in this research project, the University of Newcastle have recruited an additional three PhD students to progress this world-class research. The team are now sequencing tumours from three mice that were only exposed to cigarette smoke to further refine potential mutations.

To discover early diagnostic biomarkers and better treatment for lung cancer, these mutations will be examined earlier as well as assess samples such as blood or sputum.

### 2017 SNAPSHOT



**\$2.3+ million**  
invested in research



Increased research award funding from

**\$680K to \$1+million**



## Lung Cancer clinical trials groups

### ALTG preceptorship

**34** health professionals educated

In 2017, the ALTG held its third annual preceptorship in lung cancer in Melbourne, providing early career researchers, advanced trainees and junior consultants the opportunity to further advance their critical thinking and assessment skills to apply to research. The intensive and interactive educational program involved senior clinicians facilitating a review of literature to understand the evolution of treatment for lung cancer.

### ALTG symposium

**144** health professionals

The second ALTG Symposium was hosted in November in Sydney and saw almost a 20% increase in attendance from 2016. The one day event is a key educational activity supporting the ALTG strategic objective to translate research findings into clinical practice. It featured respected local and international speakers and leaders in the field who discussed topics including combination trials and their implications, the costs of new therapies and treatment for thoracic malignancies and adjuvant therapy trials.

## Thoracic Alliance for Cancer Trials

**14** active group members

The Thoracic Alliance for Cancer Trials (TACT) is a unique collaboration of international lung cancer research groups that work together to conduct clinical trials. In 2017, the first TACT trial was approved to study a rare EGFR mutation and aims to be initiated in 2019.

## Australasian Lung Cancer Trials Group

**7** trials initiated worth

**7.2 million**

**700+** patients to be enrolled

**1** trial completed

In 2017, The Australasian Lung Cancer Trials Group (ALTG) continued to work to drive high quality clinical research. The ALTG initiated and continued funding for seven new trials worth \$7.2 million which will involve 700+ patients. This work is critical to providing hope and a better quality of life through new and advanced treatment options.

## Registries

### Australian Bronchiectasis Registry

**851** participants, an increase of **70%** since 2016, across **14** centres.

Lung Foundation Australia's Bronchiectasis Registry continued to grow in 2017, more than doubling the original target with over 850 participants registered. The registry works to identify and collect data on patients with bronchiectasis to facilitate research, improve clinical management practices and maximise opportunities for patients to participate in clinical trials.

In addition to the registry data, the Department of Human Services has approved access to Medicare and pharmaceutical data. By combining this with our registry data, we can provide prospective researchers a rare and exceptional opportunity to learn more about healthcare utilisation and costs associated with bronchiectasis, as well as access to patient behaviours and outcomes.

### Australian Idiopathic Pulmonary Fibrosis Registry

Ongoing data collection on

**690** patients

This unique research platform

collects information on patients living with Idiopathic Pulmonary Fibrosis (IPF) to better understand this rare and complex disease. In 2017, recruitment of a new group of participants started to re-orientate the registry to support the newly established Centre for Research Excellence - Pulmonary Fibrosis requirements. Data collection for these participants focuses on treatment and management, including anti-fibrotic medications, which were approved by the Pharmaceutical Benefits Scheme for Medicare reimbursement in 2017.

## Centre for Research Excellence-Pulmonary Fibrosis

Lung Foundation Australia is proud to be a founding partner of the Centre for Research Excellence-Pulmonary Fibrosis (CRE-PF), a comprehensive and integrated clinical research program that aims to change the approach to Pulmonary Fibrosis (PF) in Australia. The Pulmonary Fibrosis Australasian Clinical Trials (PACT) Network, was established in 2017, as part of the CRE-PF. The PACT Network aims to be a national leader in designing and implementing clinical trials and studies for patients with PF. It will provide a powerful springboard for Australia's world-class PF researchers to drive the search for new evidence to guide future PF care.

## LONG-TERM SNAPSHOT



**\$15.6 million**

directly invested in research over 26 years



**\$11.6 million**

additional research funding generated by the ALTG since established in 2004

# Awareness

Working to break down the stigma associated with lung disease and raise awareness about the symptoms, prevalence and impact.

## Pneumonia Awareness Week

**485** media stories reached  
**7.9 million** people

During Pneumonia Awareness Week, Australians were reminded to recognise the seriousness of pneumonia and protect against the infection, particularly with increasing age.

## Lung health awareness in Canberra

**122** people's lungs tested at Parliament House

**1,700+**

Lung Health Checklists completed online over three weeks.

## National news story reaching

**6million** people over  
**20** TV stations

To coincide with the Thoracic Society of Australia and New Zealand (TSANZ) conference in Canberra in April, Lung Foundation Australia hosted a lung function testing event at Parliament House and delivered a broader community awareness campaign. The lung function testing of politicians and parliamentary staff was covered by WIN News Canberra and syndicated nationally. The community campaign included advertising on buses, and a social media campaign encouraging

Canberra residents to check their lung health through our online checklist.

## Pulmonary Fibrosis Awareness Month

A challenge for doctors is accurately diagnosing Idiopathic Pulmonary Fibrosis (IPF), because many of its symptoms are similar to other lung diseases. During Global Pulmonary Fibrosis Awareness Month in September, Lung Foundation Australia raised awareness about the signs, symptoms and support for IPF amongst our patient and health professional networks through a suite of videos, social media and email marketing campaigns.

## Quit4october

**8.5million** people reached

Our annual QUIT4october campaign is a unique month-long smoking cessation program dedicated to helping people quit smoking. Now in its third year, the 2017 campaign efforts were focused in Tasmania and Australian Capital Territory with support from ACT Pharmacy Guild of Australia, the Australian Association of Smoking Cessation Professionals, Professor Renee Bittoun and Pfizer. This involved a media launch in both states, an education event for GPs in Tasmania, the distribution and display of promotional materials throughout pharmacies and GP practices, as well as a broader national social media campaign.

## Lung Health Awareness Month

**6,038** Lung Health Checklists completed online

**619K+** reached via social media

**255,900** video views

**19.6million** reached via advertising

In 2017, the results of a national consumer survey revealed the prevalence of stigma in our society associated with lung disease, and lung cancer in particular. During Lung Health Awareness Month in November, Lung Foundation Australia used the results from this consumer research to bring the issue of stigma into the spotlight under the campaign theme 'Understanding is rare, lung disease is not'. The key message was 'Judgement is never a cure, but understanding is a step towards one.' The campaign theme of stigma united our efforts and messaging across all of our November activities, including Lung Cancer Awareness Month, World COPD Day and Pulmonary Hypertension Awareness Month, as well as bronchiectasis awareness activities.



Lung Foundation Australia CEO Heather Allan with Glenda Colburn, Jane Kerr and Mary Bishop.



## SNAPSHOT



**681,300+**  
website visits

**229+** million people reached via  
**1,471** media stories



**33,970+**  
people completed the  
Lung Health Checklist online

**15,950+**  
social media  
followers



### Judgement is never a cure, but understanding is a step towards one

“My compulsion to tell people I have never smoked and was born into a family of never-smokers comes from an entrenched community stigma around lung cancer being brought on by people themselves. Since being diagnosed with lung cancer, I’ve found myself sitting in the same room with people who smoke, who used to smoke and who have never smoked. At the end of the day, we all have lung cancer and we need to be treated the same way.”

**Prof Nghi Phung, wife, mother and specialist in gastroenterology and addiction medicine, diagnosed with lung cancer in February 2017 at the age of 49.**

### Lung Cancer Awareness Month

**547** media articles with  
**133million** people reached  
**31,700** video views

While the theme of stigma for Lung Health Awareness Month ran through all of our disease awareness efforts, there was a particular focus and feature on lung cancer. The national consumer survey focused on the prevalence of stigma surrounding lung cancer, and these results drove a national media campaign for the month. The November campaign also included 25

Shine a Light on Lung Cancer events which were held by patients around Australia to raise funds for lung cancer research.

**World COPD Day**  
**310** events held across the country

World COPD Day in November focused on breaking down the stigma surrounding Chronic Obstructive Pulmonary Disease (COPD) and raised awareness about the symptoms, risks and treatment. Lung Foundation Australia supported patients and health professionals across the country and the campaign was promoted heavily throughout the overarching Lung Health Awareness Month campaign, which featured real stories from COPD patients.

### Pulmonary Hypertension Awareness Month

**ALMOST**  
**4K** video views

November marked Pulmonary Hypertension Awareness Month and Lung Foundation Australia focused on raising awareness amongst our health professional and patient networks about Pulmonary Arterial Hypertension (PAH) and the symptoms and support available for this rare and debilitating disease. The month was promoted throughout the overarching Lung Health Awareness Month campaign with the theme of stigma, and featured real stories from PAH patients.

**We continued to advocate at the highest levels for a National Lung Health Strategy to ensure all lung disease patients have access to the same level of service and support as those with other chronic diseases.**



*John Alexander OAM MP, Prof Nghi Phung patient advocate, Steve Georganas MP and Lung Foundation Australia CEO Heather Allan.*

## Parliamentary Friends of lung health

In 2017, Lung Foundation Australia held two Parliamentary Friends of Lung Health events to bring key opinion leaders, including politicians and members of parliament, together with patient advocates and clinicians.

### Turning the spotlight on rare lung disease

This Parliamentary Friends event aimed to raise awareness about the impact of rare lung diseases, particularly in children, and the steps required to build a framework that will allow equitable access to care, treatment and support.

### Understanding is rare, lung disease is not

Results from the national consumer survey on stigma were released at a Parliamentary Friends of Lung Health event on 26 October. This event officially launched Lung Health Awareness Month and focused on raising awareness amongst our nation's politicians and key opinion leaders about lung disease and the prevalence of stigma in our society.

## Occupational lung disease

Lung Foundation Australia, together with the Thoracic Society

of Australia and New Zealand, advocated for a centralised national occupational lung disease register through a submission to the Senate enquiry on Coal Workers Pneumoconiosis (black lung).

## Funding for research into cancers with low survival rates

Lung Foundation Australia, together with key clinicians and patient advocates, participated in the Senate Select Committee enquiry into Low Survival Rate Cancers. Together we made recommendations to improve access to funding, research, education, medication and support for people with low survival cancers.

## Department of Health round table discussion

Lung Foundation Australia and the Department of Health hosted a Lung Health Round Table discussion which brought together representatives across different lung diseases to identify practical clinical interventions to improve patient outcomes. A suite of recommendations were developed and will be sent for consideration to the Australian Health Ministers Advisory Council.

## Enquiry into the Use and Marketing of Electronic Cigarettes

In a submission to the Senate Enquiry on the Use and Marketing of E-cigarettes and Personal Vaporisers, Lung Foundation Australia and Thoracic Society of Australia and New Zealand urged the government to take a precautionary approach to e-cigarettes. The evidence for their use in smoking cessation is not at all clear which is why we are suggesting that, like all other cessation products, they

be regulated by the Therapeutic Goods Administration (TGA) and that ongoing trials be conducted to continue to review their safety and efficacy.

## Federal Budget Submission

Lung Foundation Australia's Federal Budget Submission for 2018-19 urged the government to ensure lung disease receives the funding and support needed to reduce its impact as the nation's second leading cause of death. The submission outlined six high-priority and cost-effective actions that will transform the lives of those affected by lung disease.

## Pharmaceutical Benefits Scheme listings

Lung Foundation Australia continued to play a role in advocating for affordable access to new and proven medications for people living with a lung disease, such as lung cancer, Chronic Obstructive Pulmonary Disease (COPD) and Idiopathic Pulmonary Fibrosis (IPF).

## Pulmonary rehabilitation MBS listing

Lung Foundation Australia invited key federal Members of Parliament to visit their local pulmonary rehabilitation class to see first-hand the benefits patients receive from participating in this program. This formed part of our advocacy work supporting our application to the Medical Services Advisory Committee (MSAC) for pulmonary rehabilitation programs to be subsidised on the Medicare Benefits Scheme (MBS), submitted in December 2014. An outcome is expected in late 2018.

# Fundraising

Diversifying our revenue to continually grow and enhance the level of information, resources, advocacy and support services we provide.



## Cycle Challenge

**104 riders**  
collectively raising  
**\$90,000**

In July 2017, Lung Foundation Australia supporters and keen cyclists joined us for our second Cycle Challenge in Brisbane to help raise awareness and funds to support research into lung disease.

The event would not have been possible without the support of our event sponsor, Novartis.

Thanks also to the corporate teams who took part and raised funds including, ResMed, RSW Belting Supplies, Novartis, AstraZeneca, Philips Respironics, CURA Active, A. Menarini Australia, Peddle Thorpe, Fisher & Paykel Healthcare, Slater + Gordon, Air Liquide Healthcare and GlaxoSmithKline.



*Doug, Chronic Obstructive Pulmonary Disease patient with his Lungs in Action CURA active team and Lung Foundation Australia CEO Heather Allan.*

## SNAPSHOT

**\$1.85 million**

raised through community events, appeals, bequests and donations

community fundraisers

**200%**

increase in funds raised for lung cancer research

## Gala Dinner

**250 attendees**  
**\$143,000 raised**

In October 2017, guests joined us for our fourth Annual Gala Dinner at the Hyatt Regency in Sydney. Funds raised allow us to continue to support and advocate for people living with a lung disease, fund

vital research as well as provide information and education to patients and health professionals.

Special acknowledgments to our

### Premier Sponsors:

Pfizer and Boehringer Ingelheim.

### Table Sponsors:

Actelion, AstraZeneca, Bristol Myers Squibb, A. Menarini Australia, Merck Sharpe and Dohme, Philips Respironics, The Professionals - Padstow, Resmed, Sanofi, Slater+Gordon, TEVA Pharmaceuticals, and all guests for giving so generously.

## Appeals

**\$75,000 raised**

Our Winter and Christmas Appeals raise valuable funds to support our many programs and services such as help establish a new Respiratory Nurse Telephone Support Service available via our freecall number.

## Lasting legacies

Thank you to the generous individuals and families who have made significant donations. By making a legacy gift to Lung Foundation Australia you are leaving a lasting legacy that will help change the future for people with a lung disease.



*"For those who wish to donate or bequest money, I recommend Lung Foundation Australia as a professional organisation worthy of their support. As doctors, we are good at diagnosing lung conditions and there are treatments available for most conditions. However, a cure for many of the devastating conditions of the lungs needs much more research and many more dollars. Every contribution helps, and I encourage people to donate within their means."* - Dr James Markos.



## Recognising our supporters

In recognition of the contribution our major donors and corporate partners make, we held a special cocktail function in March, which was kindly hosted by His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd), Governor-General of the Commonwealth of Australia and Her Excellency Lady Cosgrove at Admiralty House.

## Where our funds go

We sincerely appreciate the support we receive from our community. Every donation goes a long way

toward making a difference to the lives of Australians living with lung disease. Your donations directly fund our services which include health programs, patient support, research, awareness and advocacy.

**Community fundraising**  
**\$197,230+**  
raised by  
**136** fundraisers

We extend our thanks to our community fundraisers who have been instrumental in helping us achieve many milestones in 2017.



## Long Walk for Lungs

**\$100K** raised

Despite being diagnosed with a debilitating and fatal lung condition, In September 2017, 63 year old Bill Van Nierop embarked on the Long Walk for Lungs - a 15 day, 697km journey across New South Wales, supported by his employer AgnVet Services. Bill raised awareness and \$100,000 for Idiopathic Pulmonary Fibrosis (IPF) research and support. This is an enormous feat for anyone let alone someone with IPF, a progressive and incurable lung disease that causes scarring of the lungs, making it difficult to breathe.

The money raised supported a new IPF PhD Research Award, Lung Foundation Australia's Pulmonary Fibrosis (PF) Peer Connect service, which connects people living with PF with others in a similar situation, and the future establishment of our Respiratory Nurse telephone service.

**Bill Van Nierop, husband, father and grandfather diagnosed with Idiopathic Pulmonary Fibrosis in March 2015.**



Lungs of Light at a Brisbane Shine a Light on Lung Cancer event.

## Shine a Light on Lung Cancer fundraising

**\$150,000+**  
raised

Our Shine a Light on Lung Cancer community events continued

to bring together patients, their family and friends, health professionals and researchers as one voice in support of more research funding and earlier diagnosis of lung cancer. Funds raised are dedicated to fund life-changing lung cancer research through research awards.

# Thank you

We would like to acknowledge the following individuals and organisations for their valued support in 2017. Every gift is greatly appreciated.

## Significant and major donors

Glenys Oxlee  
Elizabeth Frost  
Joan Whyte  
Rabia Manchanda  
The David Wilson Family

## Donors

Chantelle Asmar  
Anita Bartsch  
Helen Bogiatzis  
Michelle Books  
Katarina Buzanin  
Jonathan Christie  
Elaine Clarke  
Rod Cramer  
Peter Curtis  
Jill Dearing  
Brent and Vicki Emmett  
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Beverley McIlwain  
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Therese Underwood  
Ian and Pamela Wall  
Debbie Walsh  
Elaine Walters OAM  
Adam Wechsler  
David and Maree Whiting  
Lance Wright  
Lynn Yager

## Community fundraisers

Katarina Buzanin  
Chris Callaghan  
Carol Cook  
Virginia Craney  
Bronwyn Daniel  
Mellisa Eichmann  
Joju Family  
Sheridan Gaudry  
Soo Fong and Jeff Hamilton  
Richard and Helen Irving

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Margaret Morton  
Marilyn Nelson  
Bill Van Nierop  
Kate Norton  
Adam Pawsey  
Judy Powell  
Samantha Priddey  
Jo Robson  
Julie Rowen  
John and Lenette Ruttle  
Sandy Sampson  
Francisca Satya  
Jo Silva  
Greg Swindon  
Etienne Veschambre  
Justin Weight  
Bev White  
Claudia Wood

## Community groups

Macedon Ranges Shire  
Plenty Parklands Primary School  
NEGS School  
Bribie Island State High School  
Moggill State School  
Henley High School  
Huffers and Puffers - St George  
Love and Light Lung Cancer Support Group  
Nepean Puffers and Wheezers  
Huffin Puffin  
Windjammers  
Live To Breathe Support Group  
Breathe Easy Support Group  
Millicent Respiratory Support Group

## Estates

Estate of the late Joan Barry  
Estate of the late Laurence Peter Gordon  
Estate of the late Susie Whittington  
Estate of the late Ursula Heller  
Estate of the late Maureen Omiros  
Estate of the late Carmen Peiry

## Grants, trusts and foundations

Brass Holdings Pty Ltd  
Grenet Foundation  
Scobie and Claire Mackinnon Trust  
Bluesand Foundation  
John Laing Charitable Trust  
Lord Mayor's Charitable Foundation  
Brisbane City Council

## Corporate donors

Hal Leonard Australia Pty Ltd  
Klinge and Co Pty Ltd  
Odeum Fresh Corp  
Flight Centre  
Sumitomo Australia Melbourne  
National Australia Bank  
Art Hide Pty Ltd  
Capital Chemist Charnwood  
Ag World  
Syngenta  
Monsanto  
Bayer Crop Science  
Albany Regent Cinemas Partnership  
FMC Australia Pty Ltd

Disclaimer: Many of our donors wish to remain anonymous. Every effort has been made to ensure we have acknowledged everyone else. We sincerely apologise if your name does not appear. If you wish to have your name acknowledged in future please contact Mary Bishop on (02) 9222 6204 or maryb@lungfoundation.com.au Please note: Donations of \$1,000 and above during the 2017 financial year.

# Corporate partners

## Foundation partners

Boehringer Ingelheim  
AstraZeneca Australia  
Novartis  
Pfizer  
A. Menarini Australia  
Thoracic Society of Australia and New Zealand

## Principal partners

Merck Sharp & Dohme Pty Ltd  
Actelion Pharmaceuticals Ltd  
GlaxoSmithKline  
Roche Products Ptd Ltd  
BioCSL

## Supporting/project partners

Bayer Healthcare  
Insmed  
ResMed  
Bristol-Myers Squibb  
Maurice Blackburn  
Sanofi Pasteur

Oxygen Solutions  
Air Liquide Healthcare  
Breath-A-Tech

## Government/granting bodies

Queensland Government  
Cancer Australia

We acknowledge the generosity of the Thoracic Society of Australia and New Zealand, Alfred Health Solutions, Institute for Respiratory Health Western Australia, Royal Prince Alfred Hospital and Royal Adelaide Hospital for the provision of office space.

# Celebrating our people



The strength of Lung Foundation Australia comes from our professional team including our dedicated staff, volunteers, our Board and committees. Together we are working toward a world where people with lung disease matter and everyone is empowered to breathe well and live well.

## A motivated and caring workforce

Motivated, caring and passionate staff are fundamental to the work of Lung Foundation Australia. In 2017, we conducted a staff survey to gain an understanding of any gaps in the working environment of employees, as well as to improve the experience for our staff at work.

Respect, trust, quality and making a difference were key positives highlighted in the survey with 100% of the staff satisfied working for the Lung Foundation.

## Volunteers

**9,250**  
volunteers hours

**300**  
volunteers

We are extremely proud and grateful to our many clinical and community volunteers who generously donate their time and energy to make a meaningful difference by supporting us to deliver our vital programs.



● 21 Full-time ● 4 Part-time

## Community volunteer profiles



### Maureen Smith

In January 2017, long-term LungNet News volunteer Mrs Maureen Smith retired after 18 years of service. Maureen began

volunteering in 1998 as a result of her husband Neville's lung disease diagnosis. Following Neville's passing, Maureen continued her commitment to volunteering as she enjoyed the friendship and camaraderie of the volunteer team. Maureen has been an integral part of the Lung Foundation Australia team and we thank her for the many hours dedicated to distributing the newsletter.



Lung Foundation Australia CEO Heather Allan, Myrna Wakeling and Glenda Colburn.

### Myrna Wakeling

In October 2017, Myrna Wakeling retired after 19 years of volunteering across many different roles at Lung Foundation Australia. Myrna helped out with LungNet News mail-outs, represented the Lung Foundation at conferences and events and undertook media work as a face of

lung disease. Myrna attended almost every Brisbane Education Seminar and co-hosted the event for many years. She also established and was President of the Talk Lung Care Support Group which provided friendship and support to people affected with lung disease in the Ashgrove area of Brisbane. In May 2015, Myrna was presented with a Lung Foundation Australia Lifetime Achievement Award in recognition of her major contribution to the Lung Foundation and the community. We sincerely thank Myrna for her years of commitment and we wish her a very happy retirement.



# Meet our leaders

Our dedicated Senior Leadership Team has the experience and determination to deliver on the Lung Foundation Australia strategy.

## **Heather Allan,** Chief Executive Officer

Heather Allan was appointed as CEO in July 2014. Heather joined Lung Foundation Australia in 2005 initially as Director of the COPD National Program, then as Director of Marketing and Health Strategy. Heather has a background in coordinating public health policy. Before joining Lung Foundation Australia, Heather worked in various senior roles in public health in New Zealand, served for four years as Executive Director of the Canadian Chamber of Commerce in Hong Kong and ran her own communications and strategic planning consultancy. She holds a Bachelor of Arts (Economics).

## **Janet Moore,** General Manager Research

Janet Moore joined Lung Foundation Australia in October 2017, bringing over 20 years of national and international healthcare and clinical research experience from the public, private and not-for-profit sectors. Her strong business acumen, healthcare management and clinical trials skillset will play a key role in elevating the research profile of the Lung Foundation Australia over the coming years. Through her 'warrior' spirit, Janet aims to make research matter for our key stakeholders, friends of the Foundation and community we serve. Janet holds a Master of Business Administration (MBA), Bachelor of Nursing and is a Graduate of Australian Institute of Company Directors (GAICD).

## **Kirsten Phillips,** General Manager COPD

Kirsten Phillips is a qualified occupational therapist and has worked across a variety of health services and organisations both in the UK and Australia. Kirsten joined Lung Foundation Australia in 2015 and brings a wealth of experience and unique perspective to her role as General Manager of the COPD National Program.

Kirsten is responsible for the strategic direction of the COPD Program and ensuring high quality, evidence-based resources and support information (including guidelines and online training) are available for patients, carers and health professionals. Kirsten holds a Bachelor of Occupational Therapy and also has a Masters in Health Science.

## **Jane Kerr,** General Manager Thoracic Cancers

Jane Kerr joined Lung Foundation Australia in January 2017 as General Manager Thoracic Cancers bringing over 20 years of marketing experience in the pharmaceutical industry where her primary area of focus was oncology and more recently in the rare lung disease area, Idiopathic Pulmonary Fibrosis (IPF). Jane also has a strong clinical background as a registered nurse and respiratory clinical nurse consultant. She is responsible for driving the Lung Cancer Program strategy including patient and consumer support, evidence-based patient information, advocacy and health professional training. Jane holds a Bachelor of Nursing.

## **Chris Emery,** General Manager Operations

Chris Emery is a qualified Chartered Accountant and has over 20 years of experience working in the not-for-profit sector. Chris joined Lung Foundation Australia in 2009 as the Director of Operations and is responsible for finance, IT, administration, Human Resources and Treasury. He was also appointed as the Company Secretary for Lung Foundation Australia in 2016. Chris holds a Bachelor of Commerce, is a qualified Chartered Accountant and a graduate of the Australian Institute of Company Directors.

## **Mary Bishop,** Senior Manager - Fundraising

Mary Bishop is an experienced marketing and fundraising professional with over 20 years of

experience working both nationally and internationally. Mary joined Lung Foundation Australia in 2015 as the Fundraising Manager and is responsible for building a robust team within the fundraising program to ensure we have sustainable revenue to support the work of the Foundation long into the future. Mary holds a Bachelor of Social Science (Psychology), Postgrad Diploma in Marketing and Business Management, and an Executive Certificate in Events Management.

## **Danielle Aami,** Senior Manager - Marketing and Communications

Danielle Aami joined Lung Foundation Australia in January 2017, bringing with her over 10 years of marketing and communications experience in private, public and not-for-profit sectors. She is responsible for the development and delivery of branding, media relations, marketing and communication strategies that will increase the profile of Lung Foundation Australia, and raise awareness of lung health and lung diseases. Danielle holds a Bachelor of Mass Communication, a Diploma in Events Management and a Certificate in Digital Marketing.

## **Sharon Gavioli,** Senior Manager - Information and Support and Rare Lung Disease

Sharon Gavioli joined Lung Foundation Australia in April 2017 and brings a wealth of experience working with a number of not-for-profit organisations, as well as her love of people, to her role. Sharon has a background in health as a Registered Nurse and Adult Educator and has a broad understanding of the impact of chronic disease on people. She is focused on delivering high quality, compassionate and evidence-based information, resources and support to empower people to live well with their lung disease via the Information and Support Centre.

# Meet our Board

The Lung Foundation Australia Board consists of nine directors who volunteer their expertise and time to help improve lung health and reduce the impact of lung disease for all Australians.

Led by Professor Christine Jenkins, our Board delegates responsibility for day-to-day operations to our CEO who, together with our Executive Team, is accountable to the Board.

## Professor Christine Jenkins AM

**Chair, Board Member since September 2012**

Professor Christine Jenkins has a strong commitment to respiratory practice and clinical research, particularly in the management of asthma and Chronic Obstructive Pulmonary Disease (COPD). She is the Professor of Respiratory Medicine at UNSW Sydney, Clinical Professor at the University of Sydney, and a Thoracic Physician at Concord Hospital. She also heads the Respiratory Group at The George Institute for Global Health, Sydney, Australia. Professor Jenkins has played major roles in advocacy and leadership for lung health in Australia, has over 180 publications including three books, and has contributed to respiratory guidelines in Australia and internationally. She has made significant contributions to the community sector through senior leadership positions for government, health professional and not-for-profit organisations. She was awarded Member, Order of Australia in 2002 for Services to Respiratory Medicine, and was President of the Thoracic Society of Australia and New Zealand from 2007-2009.

## Mr Andrew Churchill

**Deputy Chair, Board Member since March 2010**

Mr Andrew Churchill is an experienced executive and director with a strong business background in the professional services, telecommunications and information technology sectors.

Mr Churchill has significant experience in strategy development and implementation, paired with strong financial management skills. He has provided a range of business management, mentoring, coaching and advisory services through his management services firm Churchill Associates, and has previously held CEO and Board positions in both private and public companies.

## Professor Martin Phillips

**Board Member since September 2012**

Professor Martin Phillips is a Clinical Professor at the University of Western Australia and a Respiratory Physician at Sir Charles Gairdner Hospital in Perth where he is the Director of the Lung Cancer Service and Interventional Pulmonology Service. He has served on several committees in the Thoracic Society of Australia and New Zealand and co-chaired Special Interest Groups in lung cancer and interventional pulmonology. His research interests include asthma, Chronic Obstructive Pulmonary Disease (COPD), lung cancer and interventional pulmonology. Professor Phillips also delivers practical training courses each year on interventional pulmonology and medical thoracoscopy.

## Professor Peter Frith

**Board Member since March 2013**

Professor Peter Frith is a respiratory physician who has specialised in chronic disease management for Chronic Obstructive Pulmonary Disease (COPD), pulmonary rehabilitation, self-treatment strategies, and mental health comorbidities related to lung disease. He is a Professor in Respiratory Medicine at Flinders University and Adjunct Professor at the University of South

Australia. Through long-standing involvements as Chair of the Lung Foundation's COPD National Program and a convenor of the Thoracic Society of Australia and New Zealand's COPD Special Interest Group, Professor Frith has made major contributions to practice guidelines for COPD and pulmonary rehabilitation. Although now retired from clinical practice he remains active in research, has published around 200 peer-reviewed papers, provides advisory and educational inputs to Non-Government Organisations, government and pharmaceutical industry groups, and serves on the Boards of the Global COPD Initiative (GOLD) and Lung Foundation Australia.

## Dr David Michail

**Board Member since March 2013**

Dr David Michail is a Consultant Respiratory and Sleep Physician working as a Senior Visiting Medical Officer at Westmead Hospital and with specialist services. He is the Clinical Lead of the Western Sydney Multidisciplinary Lung Cancer Group and is the Director of the Pulmonary Hypertension Service at Westmead Hospital, as well as a member of the Clinical Trials Program of the Ludwig Engel Centre for Respiratory Research. In addition to his roles in lung cancer and pulmonary hypertension, he has a key interest in ambulatory models of care for sleep disorders and their management in primary care. Dr Michail also chairs Lung Foundation Australia's Pulmonary Arterial Hypertension Committee.

## Ms Kathleen Cummings

**Board Member since April 2014**

Kathleen has 30 years of experience in the banking and finance industry. She is highly experienced in



*Clockwise from top left: Chris Emery, Lung Foundation Australia Company Secretary, Dr David Michail, Tony Hyams AM, Prof Martin Phillips, Prof Peter Frith, Prof Sarath Ranganathan, Andrew Churchill, Kathleen Cummings, Prof Christine Jenkins AM (Chairman), Heather Allan Lung Foundation Australia CEO and Dr Briony Scott.*

strategic planning, financial and risk management, and specialises in distribution and talent management. As an integral member of the Retail Banking Leadership Team, Kathy built CommBank's mortgage broker business from start-up to its current market dominance. She also played a key role in the evolution of the mortgage broking industry through her thought leadership and direct involvement with the predominant industry body, the Mortgage and Finance Association of Australia. More recently, Kathy has been consulting to the finance industry on an emerging business model in digital banking.

**Professor Sarath Ranganathan**  
Board Member since April 2014

Professor Sarath Ranganathan is an experienced and internationally recognised Paediatric Respiratory Physician and medical researcher. He is currently the Director of Respiratory and Sleep Medicine at the Royal Children's Hospital in

Melbourne and a leading authority on lung disease in young children with cystic fibrosis. His areas of expertise include cystic fibrosis, paediatric asthma, allergy, paediatric bronchoscopy, tuberculosis and lower respiratory tract infection. Professor Ranganathan has also published more than 170 peer-reviewed publications.

**Mr Tony Hyams AM**  
Board Member since November 2014

Mr Tony Hyams is highly experienced in banking, finance and investment. He was previously Head of Credit Suisse in Australia and an Independent Adviser to the Credit Suisse Group. He has held numerous Board positions including inaugural Chairman of The Commonwealth Superannuation Corporation, Chairman of the Military Superannuation and Benefits Board, as well as Director of the Australian Government Employees Superannuation Trust. He has degrees in Law and Commerce, has been a participant at the World Economic

Forum and is also a member of the Law Institute of Victoria. Tony is currently a Governor of WWF Australia and has been named a Member of the Order of Australia.

**Dr Briony Scott**  
Board Member since July 2017

Dr Briony Scott is the Principal at Wenona School and, having been diagnosed with lung cancer in April 2015, is now a passionate and respected lung cancer advocate. Briony is focused on raising awareness around the lack of research, funding, treatment and support available for people living with lung cancer and other lung diseases. She is well-respected amongst networks within the community as well as with clinicians, which she channels through her role on the Lung Foundation Australia Board. Briony regularly engages in community forums, conferences, and the media on education, leadership, parenting and has specialised in motivational theory, technology, and gender equity.

# Summary Financial Statements

for the year ended 31 December 2017

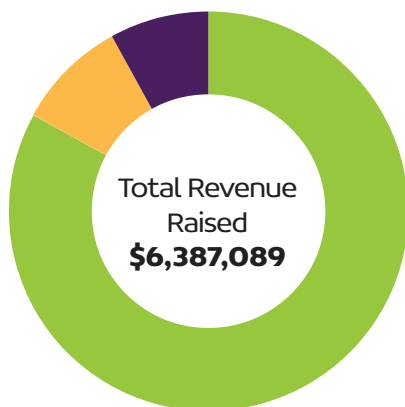
The unaudited summary financial statement has been prepared for presentation in the 2017 Annual Report of Lung Foundation Australia for the year ended 31 December 2017. It has been prepared on an accruals basis and is based on historical costs modified by the revaluation of financial assets and financial 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 2017, 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 2017. 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.

## Statement of profit or loss and other comprehensive income

For the year ended 31 December 2017

|   | 2017 \$          | 2016 \$          |
|---|------------------|------------------|
| <b>Continuing operations</b>  |                  |                  |
| Revenue from projects   | 4,230,150        | 4,321,636        |
| Donations and bequests  | 1,194,771        | 478,170          |
| Revenue from fundraising and events   | 515,361          | 472,861          |
| Revenue from specifically designated funds                                  | 253,136          | 275,637          |
| Other income  | 193,671          | 205,831          |
| <b>Total revenue and other income from continuing operations</b>            | <b>6,387,089</b> | <b>5,754,135</b> |
| Project expenses  | (4,230,150)      | (4,321,636)      |
| Specifically designated fund expenses                                       | (253,136)        | (275,637)        |
| Other expenses  | (1,808,639)      | (1,613,538)      |
| <b>Surplus / (deficit) from continuing operations before finance income</b> | <b>95,164</b>    | <b>(456,676)</b> |
| Finance income  | 33,540           | 45,649           |
| <b>Net surplus / (deficit)</b>  | <b>128,703</b>   | <b>(411,027)</b> |
| <b>Other comprehensive income</b>   |                  |                  |
| <b>Items that may be reclassified subsequently to profit or loss:</b>       |                  |                  |
| Fair value gains/(losses) on available-for-sale financial assets            | 74,956           | 5,808            |
| <b>Total comprehensive income / (loss)</b>                                  | <b>203,659</b>   | <b>(405,219)</b> |
| <b>Net surplus / (deficit) for the year is attributable to:</b>             |                  |                  |
| Members   | 128,703          | (411,027)        |
|   | <b>128,703</b>   | <b>(411,027)</b> |
| <b>Total comprehensive income / (loss) for the year is attributable to:</b> |                  |                  |
| Members   | 203,659          | (405,219)        |
|   | <b>203,659</b>   | <b>(405,219)</b> |

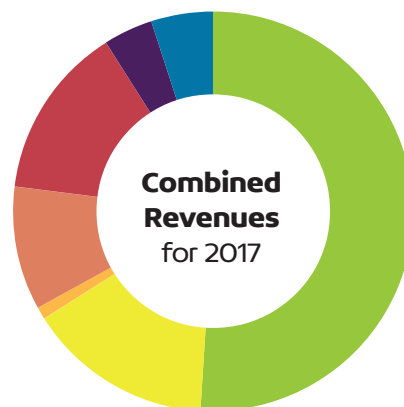


Research & Services (83%) Fundraising (8%)  
Admin (9%)

83% of our revenue went into our research and services and the remaining funds supported admin and fundraising.



Health Programs & Patient support (41%) Research (31%)  
Advocacy (11%) Fundraising (8%)  
Administration (2%) Plant & Equipment (5%)  
Governance (2%)



Corporate (51%) Donations (15%) Appeals (1%) Bequests (10%)  
Government (14%) Other Revenue (3%)  
Events (5%)

## Impact of Investment in Research Awards from Reserves

Prior to 31 December 2013, Lung Foundation Australia had a specifically designated reserve which represented funds that had been set aside from retained earnings for specific research award payments that would be made in future financial periods. Effective 1 January 2014, the balance of the specifically designated reserve was transferred into Opening Retained Earnings. For all future research award payments that are made from the funds that formed a part of the specifically designated reserve prior to 1 January 2014, the impact of these research award payments is not able to be offset by an allocation of the specifically designated reserve into revenue. Hence, revenue was recognised when it was received and expenditure related to these research rewards is only recognised when incurred, which may be in a subsequent financial year. The following reconciliation illustrates the impact these research award expenses have had on the financial results for the last two years.

|   | 2017 \$ | 2016 \$   |
|---|---------|-----------|
| <b>Net surplus / (deficit) per Statement of Profit or Loss and other comprehensive income</b> | 128,704 | (411,027) |
| <b>Plus payments made with respect to Research Award income received in prior years</b>       | 74,136  | 207,136   |
| <b>Adjusted net surplus / (deficit)</b>   | 202,840 | (203,891) |

## Investment in Research Awards

In the Annual Report 2017, we have reported a direct investment in research awards (not including leveraged research funds) of \$696,082. Due to the requirements of the Australian Accounting Standards, this direct investment in research awards is not immediately identifiable in the reporting included in the Financial Statements for the year ended 31 December 2017. The following reconciliation provides an analysis of where the direct investment in research awards is included in the Financial Statements:

|   | 2017 \$        | 2016 \$        |
|---|----------------|----------------|
| Specifically designated research fund expenses  | 253,136        | 275,637        |
| Other Expenses - Payment of Awards  | 76,636         | 169,136        |
| Other Expenses (Contribution to Lungs 4 Life research)                                | 31,967         | 30,000         |
| Project Expenses (IPF Genetics Research, Lung Cancer Fellowship, IPF PhD Scholarship) | 422,500        | 70,000         |
|   | <b>784,239</b> | <b>544,773</b> |
| Movement - IIA Accounts   | (88,157)       | (80,773)       |
| <b>Direct investment in research awards</b>   | <b>696,082</b> | <b>464,000</b> |

## STATEMENT OF FINANCIAL POSITION - As at 31 December 2017

|   | 2017 \$          | 2016 \$          |
|---|------------------|------------------|
| <b>Current assets</b>                       |                  |                  |
| Cash and cash equivalents                   | 1,966,138        | 1,496,754        |
| Receivables                                 | 622,652          | 590,650          |
| Inventories                                 | 13,694           | 22,592           |
| Financial assets                            | 1,294,232        | 2,231,721        |
| <b>Total current assets</b>                 | <b>3,896,716</b> | <b>4,341,717</b> |
| <b>Non-current assets</b>                   |                  |                  |
| Financial Assets                            | 2,333,207        | 1,291,692        |
| Property, plant and equipment               | 132,891          | 145,324          |
| Intangible assets                           | 47,732           | 60,692           |
| <b>Total non-current assets</b>             | <b>2,513,830</b> | <b>1,497,708</b> |
| <b>Total assets</b>                         | <b>6,410,546</b> | <b>5,839,425</b> |
| <b>Current liabilities</b>                  |                  |                  |
| Payables                                    | 281,829          | 348,947          |
| Income in advance                           | 3,762,642        | 3,315,205        |
| Employee benefits                           | 212,541          | 231,473          |
| <b>Total current liabilities</b>            | <b>4,257,012</b> | <b>3,895,625</b> |
| <b>Non-current liabilities</b>              |                  |                  |
| Payables                                    | 48,992           | 54,244           |
| Employee benefits                           | 53,623           | 38,944           |
| <b>Total non-current liabilities</b>        | <b>102,615</b>   | <b>93,188</b>    |
| <b>Total liabilities</b>                    | <b>4,359,627</b> | <b>3,988,813</b> |
| <b>Net assets</b>                           | <b>2,050,919</b> | <b>1,850,612</b> |
| <b>Equity</b>                               |                  |                  |
| Retained earnings                           | 1,980,858        | 1,852,154        |
| Available-for-sale financial assets reserve | 70,061           | (1,542)          |
| <b>Total equity</b>                         | <b>2,050,919</b> | <b>1,850,612</b> |

## Statement of cash flows for the year ended 31 December 2017

|   | 2017 \$          | 2016 \$            |
|---|------------------|--------------------|
| <b>Cash flows from operating activities</b>                             |                  |                    |
| Receipts from operating activities                                      | 7,235,294        | 7,676,130          |
| Payments for operating activities                                       | (6,836,919)      | (6,702,016)        |
| Dividends received  | 80,490           | 85,969             |
| Interest received   | 57,089           | 23,246             |
| <b>Net cash flows from operating activities</b>                         | <b>535,954</b>   | <b>1,083,329</b>   |
| <b>Cash flows from investing activities</b>                             |                  |                    |
| Investing in term deposits  | -                | (866,904)          |
| Proceeds from term deposits   | 1,097,506        | -                  |
| Acquisition of securities and equities                                  | (1,305,290)      | (210,687)          |
| Proceeds from sale of securities and equities                           | 176,549          | 124,257            |
| Acquisition of plant and equipment                                      | (30,635)         | (23,762)           |
| Acquisition of intangible assets  | (4,700)          | (59,944)           |
| <b>Net cash flows used in investing activities</b>                      | <b>(66,570)</b>  | <b>(1,037,040)</b> |
| <b>Net increase/(decrease) in cash and cash equivalents held</b>        | <b>469,384</b>   | <b>46,289</b>      |
| <b>Cash and cash equivalents at the beginning of the financial year</b> | <b>1,496,754</b> | <b>1,450,465</b>   |
| <b>Cash and cash equivalents at the end of the financial year</b>       | <b>1,966,138</b> | <b>1,496,754</b>   |

# UNDERSTANDING IS RARE, LUNG DISEASE IS NOT.

“For some reason the community just will not talk about lung disease and when they do, it’s mostly about it being a problem you brought on yourself. It’s been great working with Lung Foundation Australia to help raise awareness about lung disease and break down the stigma that it carries.

We don’t want people’s sympathy but we’d like their empathy and understanding - their understanding it’s not about the cause, it’s about what can be done to help people that are impacted. I’d like to see more corporate organisations and people within the community get behind this cause and help achieve equality in our access to research, treatment and support.”

**Bill Van Nierop, husband, father and grandfather diagnosed with Idiopathic Pulmonary Fibrosis in March 2015.**



**Lung  
Foundation  
Australia**

*when you can't breathe... nothing else matters®*

*When you can't breathe... nothing else matters®*

Level 2, 11 Finchley Street, Milton, QLD 4064

PO Box 1949, Milton, QLD 4064

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

[lungfoundation.com.au](http://lungfoundation.com.au)

1800 654 301



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