

# ANNUAL REPORT





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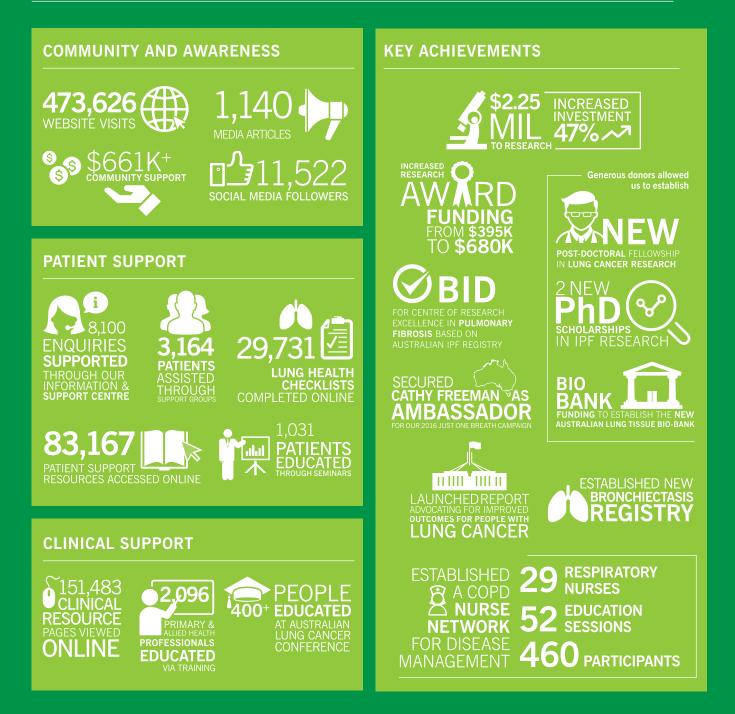
### We need your support

As little as \$10 a month can help make a difference to the lives of millions of Australians affected by lung disease. Your regular donation will help us provide ongoing support, education, resources and advocacy on behalf of those living with lung disease and their families. Please call **1800 654 301** or visit our website **www.lungfoundation.com.au** to set up your monthly donation.

### Lung Foundation Australia

PO Box 1949 Milton, Queensland, 4064 1800 654 301 enquiries@lungfoundation.com.au www.lungfoundation.com.au

# Making an impact



# Message from the Chair and CEO

It has been another busy and successful year for Lung Foundation Australia, as we continue to expand the breadth of our services, increase our funding support for research, set our strategic direction for the next four years and build on our fundraising program.

Lung disease, including thoracic cancers and chronic respiratory diseases, remains the second leading cause of death in Australia after ischaemic heart disease<sup>1</sup>. It affects approximately one in four Australians<sup>2</sup> and is responsible for more than 10% of Australia's overall health burden<sup>3</sup>.

Despite this, publicity, empathy, research and funding for lung diseases in Australia remain extremely low. Lung disease has never been a simple issue and it is our belief that widespread negative attitudes and social stigma surrounding those with lung disease is a significant barrier to improving outcomes. This continues to be one of the biggest challenges that Lung Foundation Australia is working to remove. This stigma contributes to disparate policies and inadequate funding, which have a staggering impact on patient mental health and access to care and support. Our conversations with government and key stakeholders are ongoing and aimed at ensuring that people affected by lung disease receive the equitable care and support they need and deserve.



Throughout the year, we continued to focus on improving the outcome and quality of life for those living with lung disease through the provision of evidence-based services and support.

### **Highlights**

**Research:** Lung disease struggles to attract the same level of research funding received by other disease areas. Lung Foundation Australia works tirelessly to help fill this gap, with support for research remaining one of our critical priorities. In 2016, we are pleased to report we significantly increased our funding support for research by 47%. Read more on page 10.

**Advocacy:** We campaigned consistently to be a courageous voice for Australians with a lung disease, and to influence the policies and approaches necessary to drive equitable evidence-based treatment. This included discussions with government to achieve Medicare reimbursement for pulmonary rehabilitation, and the development and release of a report *Improving Outcomes for Australians with Lung Cancer*, which advocates for the government to make lung cancer a priority. Read more on page 12.

**Fundraising:** We would like to give a vote of thanks to the Lung Foundation Australia community for their generosity last year. Our fundraising efforts including our Just One Breath Gala Dinner in Sydney, our inaugural Love Your Lungs Fun Run and Walk in Melbourne, our inaugural Corporate Cycle Challenge in Brisbane and our Shine a Light on lung cancer fundraising appeal were all very successful. These valued contributions allow us to continue our vital patient support and research initiatives. Read more on page 14.

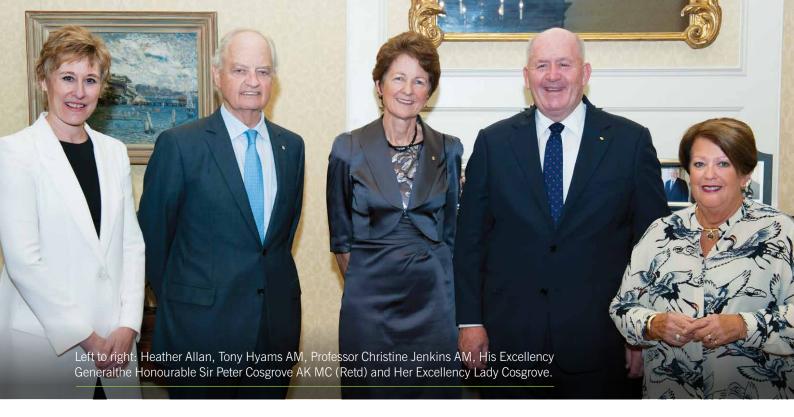
**Patient support:** We grew the breadth of our services to better address the needs of those living with lung disease. This included increasing the number of Patient Seminars and Lungs in Action exercise programs delivered, as well as the number of patients supported by our dedicated Lung Cancer Nurse. Read more on page 6.

**Clinical support:** Our evidence-based training, tools and resources supported an increased number of health professionals in the delivery of best-practice care for patients with lung disease. Read more on page 8.

Left to right: Lung Foundation Australia CEO Heather Allan and Chair Professor Christine Jenkins

ABS, Australia's Leading Causes of Death, 2015, http://www.abs.gov.au
 AIHW, 2016, http://www.aihw.gov.au/chronic-respiratory-conditions/
 Lung Disease in Australia, 2014, Woolcock Institute of Medical Research

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### **Our patron**

We were honoured and grateful to have His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd) confirm his patronage of Lung Foundation Australia in April 2016.

### Looking ahead: 2017 - 2020 Strategic Plan

During 2016, the Board and Executive Team worked to consolidate and strengthen our strategic focus on research, advocacy, patient and clinical support through development of the Lung Foundation Australia Strategic Plan 2017 - 2020. At our December 2016 Board meeting, the Directors signed-off on the Strategic Plan, and reaffirmed our mission and strategic goals.

### Mission

Lung Foundation Australia aims to improve lung health and reduce the impact of lung disease for all Australians through our strategic goals:

### Strategic goals



**Research:** Driving quality research.



Awareness: Promoting lung health and timely diagnosis of lung disease.



**Patients:** Supporting and being the voice for those with lung disease and their carers.



**Practice:** Providing evidence-based education and resources to health professionals.



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

A number of strategic investments over the coming four years will be necessary to support this work and these include:

• Increasing awareness, reach and influence by being the credible voice linking evidence to patient care and better lung health through our work with government and the media.

- Becoming the patient interface by supporting patient self-management and profiling our important role as the bridge between hospital and care in the community for patients.
- Connecting patients, families, health professionals, and the community to evidence-based support and each other through a targeted digital strategy.
- Working with government and other potential funders to deliver patient support and clinical education (particularly in primary and allied health).
- Continuing to grow our support for lung disease research.
- Diversifying our revenue streams to support our work.

### **Acknowledgments**

Lung Foundation Australia gratefully acknowledges the significant contributions of all Lung Foundation Australia National Council Members over the last 27 years. The National Council has played a key advisory role to the Board. Moving forward, to strengthen and support delivery of our Strategic Plan 2017 - 2020, the role of the National Council will be replaced through an annual meeting of all clinical advisory committee chairs with the Board.

We would also 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 2017.

Huallan

Professor Christine Jenkins

Heather Allan

### The facts

### Every day, on average, we take more than 22,000 breaths. For some people, just one breath is a challenge.

Lung disease doesn't discriminate. It affects men, women, children, smokers, ex-smokers and never-smokers.



- Lung disease overview
- There are over 30 types of lung disease
  1 in 4 Australians has a lung disease<sup>1</sup>
- Use the second secon
- $\int_{0}^{1}$  1 in 7 deaths is a result of lung disease<sup>2</sup>
- $\int$  Over 50% of Australian adults rarely think about their lung health<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>

### Idiopathic Pulmonary Fibrosis (IPF)

- IPF is a debilitating and fatal lung disease
- The prevalence of IPF is estimated at 1.25–63 out of 100,000<sup>6</sup>
- Lung cancer Australia's biggest cancer killer
- Lung cancer kills more Australians than breast, prostate and ovarian cancers combined<sup>7</sup>
- 25 people die each day from lung cancer<sup>7</sup>
- Approximately 12,500 people will be diagnosed with lung cancer in 2017<sup>8</sup>
- $\bigcirc$  1 in 3 women and 1 in 10 men diagnosed with lung cancer will have never smoked<sup>7</sup>

### Challenges

- O Publicity, empathy, research and funding for lung diseases in Australia remain extremely low
- $\bigcirc$  Of 15 nationalities, Australians have the least sympathy for people with lung cancer<sup>7</sup>
- Less than 5 cents of every cancer research dollar goes to lung cancer<sup>9</sup>

### Lung cancer doesn't discriminate

"In 2009, I was a newly-wed, 29 year old teacher, about to embark on a teacher's exchange program to Canada. I was having the required pre-trip medical tests, which identified a shadow in my lung. I was diagnosed with lung cancer in the left lung and less than two weeks later I was in hospital having my left lung removed."

Victoria Taber, six year survivor of lung cancer with husband Luke and two sons Archie and Lenny.

- <sup>1</sup> AIHW, 2016, http://www.aihw.gov.au/chronic-respiratory-condition <sup>2</sup> Lung Disease in Australia, 2014, Woolcock Institute of Medical Rese <sup>3</sup> Operating Description Line and Conduct Vietner <sup>3</sup> August 1997 (Vietner <sup>4</sup>).
- Galaxy Research Omnibus, January 2014 (wave 1)
  folde 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, Junter M, Crabox P, Southurell P, Vollmor W, Buite A, Marke C
- Respiratory symptoms and illness in older Australians: The Burden of

<sup>5</sup> Page A, Ambrose S, Glover J et al. Atlas of Avoidable Hospitalisatio in Australia: ambulatory care-sensitive conditions. Adelaide PHIDL University of Adelaide. 2007 6 Io HE Glasnola L Grainge C et al. Reseline characteristics of Io HE Glasnola L Grainge C et al. Reseline characteristics of

- idiopathic pulmonary fibrosis: analysis from the Australian Idio Pulmonary Fibrosis Registry. Eur Respir J 2017; 49:1601592
- [https://doi.org/10.1183/13993003.01592-2016]. <sup>7</sup> Lung Foundation Australia, Improving outcomes for Australians with

wp-content/uploads/2016/08/LFA-improving-outcomes-report 0816-proof10.pdf <sup>3</sup> Australian Institute of Health and Welfare 2017. Cancer in

- Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW.
- Cancer Australia, Cancer Research in Australia: an overview of funding to cancer research projects and research programs in Australia 2006 to 2011 (Sydney: Cancer Australia, 2014)

### Promoting lung health and supporting Australians living with lung disease.



# Who we are

# Lung Foundation Australia is the only national charity dedicated to supporting anyone with a lung disease.

Since 1990, we have been the national first point-of-call for patients, their families, carers, health professionals and the general community. Lung Foundation Australia works across all areas of lung disease, with a particular focus on Chronic Obstructive Pulmonary Disease (COPD), lung cancer and rare lung diseases including Idiopathic Pulmonary Fibrosis (IPF) and bronchiectasis.

### Our Mission

Our Mission is to improve lung health and reduce the impact of lung disease for all Australians by:

• Supporting those with lung disease, their families and carers.

- Driving world class research.
- Promoting lung health and timely diagnosis of lung disease.
- Providing clinical support and education.
- Promoting equitable access to evidence-based care.

We rely on the generosity of the community through donations, membership, bequests, grants, and support from business and industry.





# Patient and community support

As the only national charity dedicated to supporting anyone with a lung disease and their carers, we provide a first point-of-call linking patients to important information and services within the community.

### Lungs in Action

Lungs in Action is a community-based exercise program empowering people with stable chronic lung conditions to improve their quality of life. The program equips patients with the exercise steps and knowledge required to better manage their symptoms and maintain improvements OF 20 WEEKLY gained through pulmonary rehabilitation. There are currently classes in 75 locations across Australia, this is an additional eight locations offering 20 classes per week.

### Information and Support Centre and Lung Cancer Support Nurse

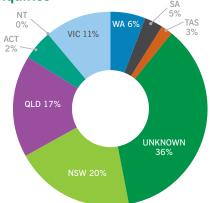
Our passionate and dedicated Lung Cancer Nurse and Information and Support Centre Team provide trusted advice, information, guidance and support to a growing number of patients, carers and health professionals. Our Lung Cancer Support Nurse also provides expert support and information to patients at all stages of their lung cancer journey.

### 2016 enquiries

CLASSES

CLASSES

- AN INCREASE



- " I used to walk for two minutes and now I walk for 10 minutes. The social interaction of being in a group of people going through the same thing is terrific. *Everyone looks after everybody else and understands* what you are dealing with.'
- Margaret Catlin, Lungs in Action participant at Colac's Blue Water Fitness Centre



### **Patient Seminars**

Patient Seminars provide patients and carers the latest evidence-based information and practical tips to help them to live better, stay out of hospital and improve their

overall guality of life. In 2016, our Patient Seminar Program expanded from 10 to 12 seminars.

"A very informative day and I took away many ideas and helpful hints." - Patient Seminar attendee, Camden, NSW

### Idiopathic Pulmonary Fibrosis (IPF) Peer to Peer Support Group

This telephone support group model provides patients the unique opportunity to share experiences and knowledge, connect with other IPF patients, offer support to one another and access information. In 2016 the group continued to grow with 31 participants supported by 7 mentors via monthly telephone calls, and in some cases, face-to-face meetings.

8,100

and Support Centre

enquiries to our Information



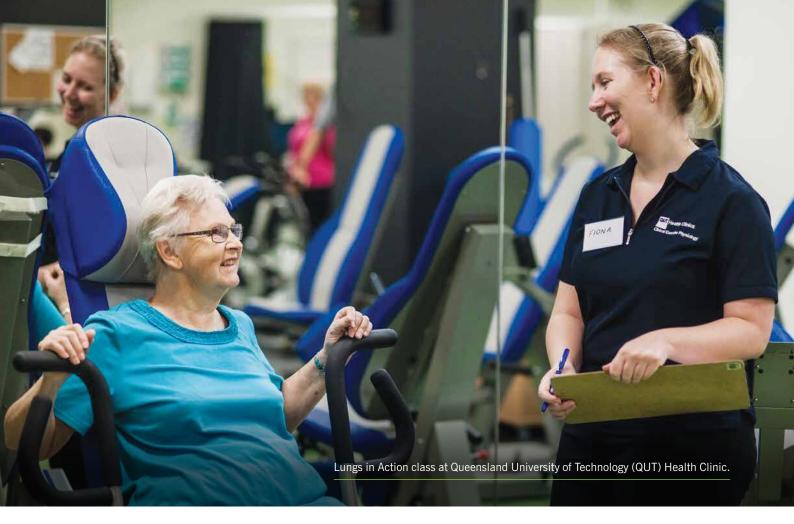
260+ Supported by our Lung Cancer Nurse, 50% of enquiries from regional and rural Australia

18,500 🛲

LungNet News recipients







# Better Living with Lung Cancer Consumer Forum

The Better Living with Lung Cancer Consumer Forum held at the 6th Australian Lung Cancer Conference provided both patients and carers the latest information in the lung cancer field. Presentations focused on important topics like scanxiety and the psychosocial challenges patients may face when living with lung cancer, the physical symptoms, managing side effects of treatments and the integral role of clinical trials. 40 patients and carers attended from all around Australia.

"I found the consumer forum very beneficial. In particular, it felt like a light bulb moment going off hearing other patients talk about their experiences and realising they were going through the same scanxiety as me. It was wonderful to be involved in a forum where we were asked questions about our anxiety. Best conference, well-done to all involved." – Sandy Sampson, six year lung cancer survivor

### 600 'LOVE YOUR LUNGS' CLUB MEMBERS

### New 'Love Your Lungs' club

In September, Lung Foundation Australia launched a new and exciting 'Love Your Lungs' membership program to provide a community for our patients, families and friends to keep up-to-date with the latest in respiratory news. The club offers a suite of benefits including a mailed copy of our popular quarterly LungNet News.

### New resources: keeping our community up-to-date

### Lung Cancer Care Pathway

This best-practice tool helps empower patients to be better informed and actively participate in their care. It helps patients improve their quality of life, dialogue with health professionals and, most importantly, their health outcomes.

### MediKidz: A comic to explain COPD

Lung Foundation Australia partnered with Novartis and MediKidz to develop a unique resource to educate children (aged 8 to 12 years), who have family members recently diagnosed with COPD. It tells the real-life story of Andrew and Hannah whose grandmother has COPD and the MediKidz superhero characters take the children on an adventure through the human body to learn about the disease.

### Better Living with COPD: A Patient Guide (third edition)

The Better Living With COPD Guide empowers people with COPD to improve their quality of life by better understanding and managing their condition. The guide is also useful for families, carers and health professionals who are supporting their patients in self-management. This valued resource was updated from the previous 2012 edition and includes new and revised information on medicines, inhaler devices, exacerbations and pulmonary rehabilitation.

### Better Living with Pulmonary Arterial Hypertension

The Pulmonary Hypertension Subcommittee began development of the first Better Living with Pulmonary Arterial Hypertension (PAH) educational resource, which will be released in early 2017. The resource will provide evidence-based information for people living with PAH and ways to better manage their condition.

# **Clinical support**

We continued to support health professionals by holding conferences, events and developing and maintaining best-practice resources including online training and support tools.

MDT ACCESSED 894 TIMES ONLINE IN THE 6 MONTHS SINCE ITS LAUNCH

### Lung cancer Multidisciplinary Team Directory

Australian lung cancer guidelines highlight the need for rapid referral of patients with suspected or proven lung cancer to a hospital and specialist linked with a lung cancer Multidisciplinary Team (MDT) service. Hospitals utilising MDT-based care provide best-practice treatment and deliver optimal treatment plans, which also address the psychological and physical needs of patients.

Lung Foundation Australia developed a database of all MDTs in Australia allowing users to search available MDTs by location or state. It also provides details about each MDT location, their diagnostic and treatment options, team composition and referral pathway.



### **6th Australian Lung Cancer Conference** *Aiming high for lung cancer - emphasising quality and value*

Lung Foundation Australia hosted the 6th Australian Lung Cancer Conference, which highlighted the latest advancements in lung cancer and mesothelioma. The conference theme encouraged delegates to aim high for their lung cancer patients. Key topics covered at the conference included immunotherapies, targeted therapies and lung cancer screening.

Delegates at the 6th Australian Lung Cancer Conference, Melbourne.

### 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 2016. This evidenced-based clinical resource for health professionals assists in the management of patients with COPD and is one of the most regularly updated COPD Guidelines in the world.



2016 SNAPSHOT

**First national directory** with 64 lung cancer Multidisciplinary Teams listed





**400 T** Health professionals educated at 6th Australian Lung Cancer Conference

101,200+ people accessed best-practice COPD-X Guidelines, an increase of 48% from 2015

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### General practitioner COPD Active Learning Modules

Lung Foundation Australia is committed to providing training and resources that support general practitioners keep abreast of the latest information about COPD. In 2016, we provided four Active Learning Modules for general practitioners to increase their knowledge, confidence and skills in the diagnosis and management of patients with COPD.

"It was so practical and really good information for general practice. One important message for me was that I must do more spirometry. Also the use of the inhaler devices and actually having them to take home was invaluable. I will take a lot of information back to my fellow general practitioners." – Active Learning Module participant.

1,200 HEALTH PROFESSIONALS EDUCATED, 50% INCREASE FROM 2015

### Have the CHAT COPD awareness campaign

Our Have the CHAT campaign raises awareness of COPD exacerbations amongst health professionals, patients and carers. In 2016, the initiative helped patients recognise early symptoms of a COPD exacerbation to reduce the chance of hospitalisation, and encouraged them to 'Have the CHAT' with their doctor. It also provided evidence-based resources and education for health professionals focusing on the COPD-X guidelines including the identification, diagnosis and management of COPD.

### **Online training**

Lung Foundation Australia offers a number of online training programs for nurses, pharmacists, clinicians and exercise professionals to ensure they have access to the most up-to-date and best-practice education. These continued to be popular during 2016 and all training modules were updated and relocated to a new web platform in our continued quest to ensure the best learning experience for our users. New features include accessibility on portable devices as well as automated payment, enrollment and generation of certificates of completion.

### Pulmonary rehabilitation advocacy

Pulmonary rehabilitation is an exercise and education program provided by specially trained health professionals such as physiotherapists and accredited exercise physiologists that teaches people with lung disease the skills they need to manage their breathlessness, to stay well and out of hospital.

Lung Foundation Australia applied to the Medical Services Advisory Committee (MSAC) for pulmonary rehabilitation programs to be subsidised on the Medicare Benefits Scheme (MBS) in December 2014. The protocol is currently under assessment with an outcome expected in November 2017. If approved, this means more programs will be available in the community, especially in rural and remote areas, and patients will have the knowledge and power to be able to regain some control over their lung condition.

# Research

Research offers hope and undisputed benefits for improving outcomes in lung diseases. Funding for research into lung disease is low relative to its burden, attracting a mere 5.5% of NHMRC funding.

In 2016, we increased our investment in research from approximately 25% to almost 30% of our total expenditure. This included funding to support researchers through our awards program and funding for research platforms, including our lung cancer clinical trials groups and our Idiopathic Pulmonary Fibrosis (IPF) and bronchiectasis registries.

Lung Foundation Australia joined forces with the Thoracic Society of Australia and New Zealand

to establish Lungs for Life, an initiative to attract more research funding into lung disease.





### Lung cancer clinical trials groups

Australasian Lung Cancer Trials Group The Australasain Lung Cancer Trials Group

(ALTG) held its second preceptorship in lung cancer, providing an intensive learning program for early career researchers. Attendees participated in critically reviewing clinical trials that have significantly contributed to the management of lung cancer.

TRIALS FOR<br/>ING CANCERIn November, the inaugural ALTG Lung Cancer<br/>Symposium had 116 registered participants from<br/>Australia, New Zealand and China. This annual<br/>event will be a key educational activity to help<br/>ensure research is translated into clinical practice.

### **Thoracic Alliance for Cancer Trials**

The Thoracic Alliance for Cancer Trials (TACT) is a unique collaboration of lung cancer research groups enabling lung cancer researchers worldwide to work together to run clinical trials. By the end of 2016, the collaboration had 13 member groups from across the USA, Europe and Australasia and four international companies supporting the group.

FIRST OF ITS KIND BRONCHIECTASIS RESEARCH PROJECT

ONGOING DATA

COLLECTED ON

PATIENTS

### Registries

### Australian Bronchiectasis Registry

The Australian Bronchiectasis Registry works to collect data together with linked Medicare and Pharmaceutical Benefits Scheme data. This helps researchers and health professionals understand and improve clinical management practices, raise awareness in the community and advocate for improving the lives of all Australians with bronchiectasis. The registry was initiated at 14 sites in 2016.

### Australian Idiopathic Pulmonary Fibrosis (IPF) Registry

Our IPF Registry provides a unique research platform that collects information on patients throughout the country. Researchers use this information to help us better understand this serious and complex disease.

This unique and rich dataset is already being used in both national and international studies.

LONG-TERM SNAPSHOT





additional research funding generated by Australasian Lung Cancer Trials Group (ALTG) **since established in 2004**  \$3.4MIL generated by investigators linked to Idiopathic Pulmonary Fibrosis Registry since the beginning of data collection in 2012



### Lung Foundation Australia Research Awards

Through our annual Research Awards Program, Lung Foundation Australia raises funds to support medical research into the cause, treatment and cure of lung conditions. This funding is awarded by an expert panel of judges to universities, graduates, PhD students, and health professionals wanting to pursue research in lung disease.



Left to right: Dr Atiqur Rahman, award recipient, and Ms Rabia Manchanda. Lung Foundation Australia received a very generous donation from the Manchanda family after Mr Deep Manchanda passed away from lung cancer. The funds will be used to support postdoctoral fellows in lung cancer for the coming 16 years.

### Congratulations to our 2016 winners

Lung Foundation Australia funded awards

Award name	2016 recipient	Total award funding
Lung Foundation Australia/Boehringer Ingelheim COPD Research Fellowship	Dr Christian Osadnik, Monash University	\$160,000
Lung Foundation Australia/Boehringer Ingelheim COPD Research Top-Up Grant	Dr Sabine Zimmermann and Dr Vanessa McDonald	\$20,000 each
Grant-in-Aid in Lung Cancer Research	Dr Pei Ding	\$10,000
Lung Foundation Australia/A. Menarini Australia COPD Travel Grants - American Thoracic Society	Dr Annemarie Lee and Dr Kristin Carson	\$3,000 each
Lung Foundation Australia/A. Menarini Australia COPD Travel Grants - European Respiratory Society	Dr Christian Osadnik and Dr Natasha Smallwood	\$3,000 each
Lung Foundation Australia/A. Menarini Australia COPD Travel Grants - Asian Pacific Society of Respirology	Alicia Mitchell and Leanne Ross	\$3,000 each
Lung Foundation Australia/Ivan Cash Research Grant-in-Aid Award	Dr Helen Jo	\$5,000
Lung Foundation Australia/Lizotte Family Research Award	Gang Liu	\$5,000
Lung Foundation Australia/ Ludwig Engel Grant-in-Aid for Physiological Research	A/Prof Alex Larcombe, A/Prof Sandra Orgeig and Dr Emma Parkinson-Lawrence	\$5,000
Lung Foundation Australia/Australian Cochrane Airways Group Scholarship	Anke Lenferink	\$2,500
Lung Foundation Australia Cochrane Airways Australian Satellite	Harshani Jayasinghe	\$2,000
New award: David Serisier Memorial Award for Translational Research in Bronchiectasis	Dr Greg Fox	\$1,000

### Lung Foundation Australia funded awards with matched funding from our research partners

Award name	2016 recipient	Total award funding	Our award funding contribution	Leveraged award funding (minimum contribution)
New award: Deep Manchanda/Lung	Dr Atiqur Rahman,	\$520,000	\$160,000	\$360,000 over two years
Foundation Australia co-funded Fellowship	University of Newcastle	over two years	over two years	from University of Newcastle
Co-funded Lung Cancer Research PhD Scholarship	Casey Ah-Cann, Walter and Eliza Hall Institute	\$90,000 over three years	\$45,000 over three years	\$45,000 over three years from Walter and Eliza Hall Institute of Medical Research
Co-funded Lung Cancer Research	Priyanka Sahu,	\$90,000	\$45,000	\$45,000 over three years from University of Newcastle
PhD Scholarship	University of Newcastle	over three years	over three years	
Co-funded Lung Cancer Research	Katharine See,	\$90,000	\$45,000	\$45,000 over three years from University of Melbourne
PhD Scholarship	University of Melbourne	over three years	over three years	
New award: The David Wilson PhD	David Waters,	\$90,000	\$45,000	\$45,000 over three years from University of Newcastle
Scholarship in Idiopathic Pulmonary Fibrosis	University of Sydney	over three years	over three years	
New award: The David Wilson PhD	Adelle Jee,	\$90,000	\$45,000	\$45,000 over three years
Scholarship in Idiopathic Pulmonary Fibrosis	University of Sydney	over three years	over three years	from University of Sydney





2016 SNAPSHOT

## Advocacy and awareness

We work to raise the profile of lung disease and the importance of lung health, reduce the stigma associated with lung disease, and advocate to make lung disease a government priority.

# Improving outcomes for Australians with lung cancer – A call to action

Lung Foundation Australia released a report *Improving outcomes for Australians with lung cancer - A Call to Action* advocating for the government to make lung cancer a priority. The report identifies the following four priority areas:

- Raising the profile and reducing the stigma of lung cancer.
- O Prioritising early detection efforts where cure is most likely to be achieved, including identifying and implementing an effective national screening strategy.
- Improving access to best-practice care for people with lung cancer, whoever they are and wherever they live.
- Increasing research funding targeted to lung cancer to improve health outcomes.

We will continue to utilise the report to advocate for more funding into lung cancer research in 2017.



### Just One Breath

Lung Foundation Australia's lung health promotion campaign, Just One Breath, celebrated positive health and wellbeing while encouraging everyone to think about the importance of healthy lungs. The campaign featured patient stories and achieved significant media coverage. We also enlisted the support of iconic Australian, Cathy Freeman, to put a face to lung disease in Australia. Cathy took part in a regional NSW visit to educate the local Indigenous community and school of Albury Wodonga. In addition, Cathy was the front of six patient video stories profiling Australians living with a lung disease, promoting early diagnosis through the Lung Foundation Australia's Lung Health Checklist.



Cathy Freeman, 2016 Just One Breath Ambassador.

"Before I was diagnosed with COPD I was a fairly busy person, I guess sickness was for those 'other guys'. When I found myself unable to walk up hills as easily as I used to – I was saying I must be getting older, I mustn't be as fit as I was. My goal when I joined the Lung Foundation initially was that if I could help prevent one case of lung disease from my advocacy or by my advice, my time was well spent." – Ian Venamore, Just One Breath COPD patient ambassador

2016 SNAPSHOT





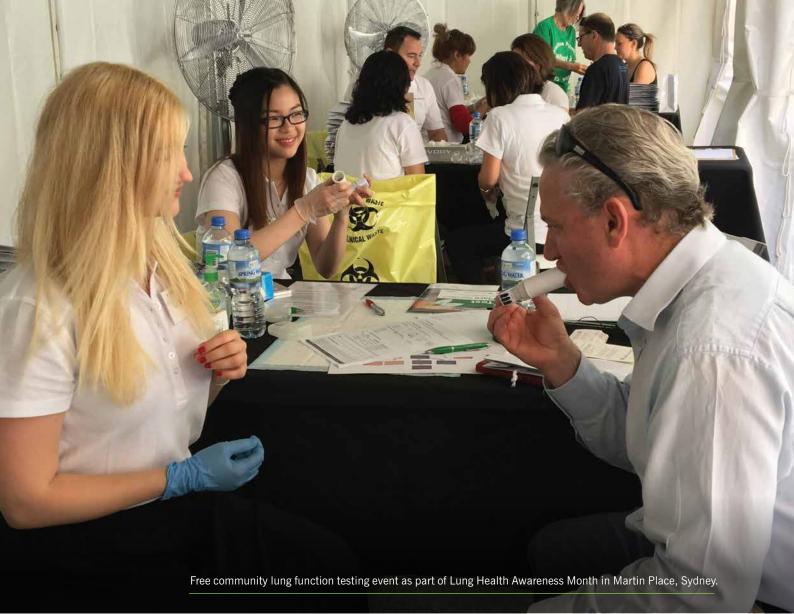
### New report

launched advocating for the Government to help improve the outcomes for Australians living with lung cancer

### Advocating

for the Government to establish a Medicare

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PIECES

### Pneumonia Awareness Week

Each year, Lung Foundation Australia runs Pneumonia Awareness Week to educate Australians about the health risks associated with pneumonia, especially with increasing age, and raise awareness about the preventative measures that can be taken.



### Quit4october

Our QUIT4october campaign focused on providing support for people starting their quit smoking journey, whether it was their first or their 50th attempt.



### Lung Health Awareness Month

### Sydney lung function testing

Lung Foundation Australia partnered with Woolcock Insititue of Medical Research to hold a free community lung testing event in the Sydney CBD. The event helped to raise awareness about the importance of lung health and looking after our lungs, with one test completed every 39 seconds.

### Shine a Light on lung cancer

Our Shine a Light on lung cancer events bring together survivors, patients, their family and friends, health professionals, clinicians, and researchers as one voice in support of more research funding for lung cancer. In 2016, 40 Shine a Light on lung cancer events were held.



### World COPD Day

World COPD Day in November encourages all Australians to recognise the symptoms of COPD - breathlessness and cough - and ask their health professional for a lung health check. In 2016, Lung Foundation Australia launched a

new webinar education initiative, 'Managing COPD,' which was hosted in partnership with AstraZeneca for general practitioners.

Lung Foundation Australia also provided resources and materials to support 250 events across the country working towards raising awareness of COPD.

# Fundraising

# During 2016, individuals, families, businesses and industry generously supported Lung Foundation Australia.

We rely on and are deeply appreciative of this generosity. To increase our support for research, patients and advocacy, it is critical we continue to build our capacity to raise further funds in the community.

### Lung Foundation Australia events

Throughout the year, we continued to build on our fundraising program by introducing new events. These events grew our supporter base and raised awareness of Lung Foundation Australia and the work we do in the community.

### Just One Breath Cycle Challenge

In August, cycling enthusiasts came together in Brisbane to help raise awareness and much needed funds to support research at our first ever Just One Breath Cycle Challenge.



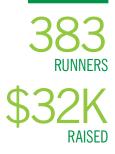
### Just One Breath Gala Dinner

We hosted our third Just One Breath Gala Dinner at the Museum of Contemporary Art Foundation Hall. James Morrison and his Motown Band took to the stage with a performance that had the dance floor at capacity until the end.

Special acknowledgments to our Premier Sponsor Boehringer Ingelheim, Major Sponsors, Pfizer and Sanofi, Table Sponsors, Novartis, Actelion, Slater+Gordon, AstraZeneca, A. Menarini Australia and all guests for giving so generously.







### Love Your Lungs Fun Run and Walk

To mark the end of Lung Health Awareness Month, Lung Foundation Australia held its inaugural Love Your Lungs Fun Run and Walk in Melbourne. The event was supported by Collingwood Football Club who generously provided the Glasshouse Venue and iconic Olympic Oval for the event.

A huge thanks to Collingwood Football Club, Ego Pharmaceuticals, Breath-A-Tech, Novartis, GlaxoSmithKline, Yarris, Credit Suisse, City of Melbourne Council, Swinburne University, and Goodlife Fitness for their support and sponsorship.



### **Appeals**

Each year, our tax appeal and our Christmas appeal raise valuable funds to support our programs and services.

### Where our funds go

We sincerely appreciate the support we receive from our community. Every donation goes a long way toward making lung disease a priority for all Australians. Your donations directly fund our services, which include Health Programs, Patient Support, Research and Awareness/Advocacy.

### **Lasting legacies**

Thank you to all of the generous families who have made significant bequest donations from the loss of a loved one to support and improve outcomes for the future generations of people living with lung disease.

### Generous donors and corporate partners

In recognition of the contribution our major donors and corporate partners make, we held a special thank you cocktail event 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.

### **Community fundraising**

We thank all our community fundraisers who have been instrumental in helping us achieve many milestones throughout 2016.



82% of our revenue went back into our services Remaining 18% supported administration (11%) and fundraising (7%) 2016 SNAPSHOT





## Celebrating our people

Our talented and committed team including staff, volunteers, our Board and committees work together, harnessing our skills, experience and dedication to help improve lung health and reduce the impact of lung disease for all Australians.

### 28 STAFF MEMBERS

### Staff

2016 was a milestone year for a number of Lung Foundation Australia staff who attained or surpassed 10 years of service. In November, CEO Heather Allan, Lung Cancer National Program Director Glenda Colburn, and Information and Support Centre Coordinators Juliet Brown and Jenny Hose were presented with awards in recognition of their commitment and loyalty to the Foundation.

### 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 and services. 9,250 VOLUNTEER HOURS 300 VOLUNTEERS

### Community volunteer profile

In 2016, Lung Foundation Australia's staff celebrated the 10 year anniversary of Eileen Perry who has generously volunteered her time in the Information and Support Centre since April 2006. Eileen has been an integral part of the growth and development of Lung Foundation Australia and her contribution is held in high regard by all those who have had the pleasure of coming into contact with her.





### **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).

### Glenda Colburn, General Manager Research

Glenda Colburn has over 25 years of experience in the health and clinical sectors. Glenda joined Lung Foundation Australia in 2005 as the Business Development Manager for the Multi-centre Clinical Trials Network. In 2006, she took on the organisation's lung cancer initiatives and in 2010 was appointed the Lung Cancer National Program Director. Glenda has recently been appointed the new position of General Manager for Research to strengthen the focus of facilitating and funding best-practice research into lung disease. Glenda holds a Diploma in Clinical Trials Management with Canberra University and recently completed her Executive Master of Business Administration (Executive MBA).

### 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's strong clinical background as a registered nurse and clinical nurse consultant will play a key role in making lung cancer a priority for all Australians. 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, HR and Treasury. He has also recently been appointed as the Company Secretary for Lung Foundation Australia. Chris holds a Bachelor of Commerce, is a qualified Chartered Accountant and a graduate of the Australian Institute of Company Directors.

### Mary Bishop, Fundraising Manager

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-forprofit sectors. Her strong marketing, corporate affairs, communications and stakeholder engagement credentials will play a key role in increasing awareness and support for lung disease, and in raising the profile of Lung Foundation Australia over the coming years. Danielle holds a Bachelor of Mass Communication, a Diploma in Events Management and a Certificate in Digital Marketing.

### Juliet Brown, Program Development Manager: Information and Support Centre, and Guidelines

Juliet Brown has over 20 years of experience in the information provision health industries. Juliet joined Lung Foundation Australia as an Information and Support Centre volunteer in 2004 and started full time work at the Foundation in 2005. Juliet is responsible for the leadership and strategic direction of the Information and Support Centre Team ensuring patients, carers and health professionals receive relevant and high quality information and support in a timely manner. Juliet holds a Bachelor of Arts (English and Sociology) and a Masters in Information and Library Studies.

### Meet our Board

### The corporate governance, strategic direction and performance of Lung Foundation Australia are the responsibility of our Board of Directors.

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.

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

### **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 Clinical Professor at the University of Sydney, Department of Thoracic Medicine, Concord Hospital, and Head of 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 160 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 September 2012

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 an experienced respiratory physician who specialises in chronic disease management – specifically Chronic Obstructive Pulmonary Disease (COPD), pulmonary rehabilitation, self-treatment for people with chronic diseases, and mental health comorbidities related to lung disease. He is currently a Professor in Respiratory Medicine at Flinders University. Professor Frith is also the past Chair of the Lung Foundation's COPD National Program and has served as convenor of the Thoracic Society of Australia and New Zealand's COPD Special Interest Group. He has published over 150 peer-reviewed papers throughout his career, serves on the Board of GOLD (the Global COPD Initiative), and remains active in research today.

### **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 key interest in ambulatory models of care for sleep disorders and their management in primary care. Dr Michail also chairs Lung Foundation Australia's national program on pulmonary arterial hypertension.

### **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 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.



### A/Professor Sarath Ranganathan Board member since April 2014

A/Professor Sarath Ranganathan is an experienced and internationally recognised paediatric respiratory physician and medical researcher. He is currently the Director of Respiratory Medicine at the Royal Children's Hospital in Melbourne and a leading authority on the role of infant pulmonary function testing in young children with cystic fibrosis. His areas of expertise include cystic fibrosis, paediatric asthma, allergy, paediatric bronchoscopy and tuberculosis, and lower respiratory tract infection. A/Professor Ranganathan has also published more than 150 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 is now 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.

...eight directors who volunteer their expertise and time to help improve lung health and reduce the impact of lung disease for all Australians.

# Thank you

We would like to acknowledge the following individuals and organisations for their valued support in 2016. We would also like to thank the many donors who asked to remain anonymous. Every gift is appreciated.

#### **Significant Donors**

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We acknowledge the generosity of the Thoracic Society of Australia and New Zealand, Alfred Health Solutions, Institute for Respiratory Health WA, University of Queensland Northside Clinical School, Concord Repatriation General Hospital, Royal Prince Alfred Hospital and Royal Adelaide Hospital

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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 \$1K and above during the 2016 financial year.

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# Collaboration

Lung Foundation Australia unites experts in lung disease from across the country through a number of specialised committees to foster collaboration and knowledge sharing. This ensures Lung Foundation Australia continues to deliver best-practice, innovative solutions and services to support the improvement of lung health and reduce the impact of lung disease in Australia. We would like to acknowledge the efforts and selfless dedication of these volunteer committee members.

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Australian IPF Registry

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A/Prof Stefan Heinze

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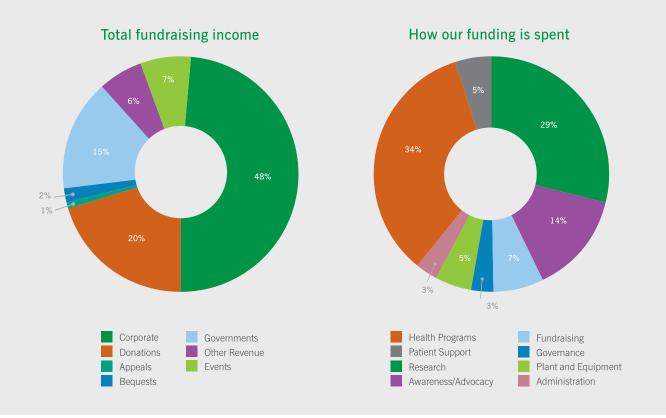
## **Summary Financial Statement**

For the year ended 31 December 2016

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Statement of Cash Flows	

The unaudited summary financial statement has been prepared for presentation in the 2016 Annual Report of Lung Foundation Australia for the year ended 31 December 2016. 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 2016, which has been prepared 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 2016. 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.



# **Financials**

### Statement of Profit or Loss and other Comprehensive Income

For the year ended 31 December 2016		
	2016 \$	2015 \$
Continuing operations		
Revenue from projects	4,321,636	3,555,004
Donations and bequests	478,170	724,634
Revenue from fundraising and events	472,861	420,499
Revenue from specifically designated funds	275,637	246,609
Other income	205,831	213,904
Total revenue and other income from continuing operations	5,754,135	5,160,650
Project expenses	(4,321,636)	(3,555,004)
Specifically designated fund expenses	(275,637)	(246,609)
Other expenses	(1,613,538)	(1,588,361)
Deficit from continuing operations before finance income	(456,676)	(229,324)
Finance income	45,649	63,406
Net deficit	(411,027)	(165,918)
Other comprehensive income		
Items that may be reclassified subsequently to profit or loss:		
Fair value gains/(losses) on available-for-sale financial assets	5,808	(42,403)
Total comprehensive loss	(405,219)	(208,321)
Net deficit for the year is attributable to:		
Non-controlling interest	-	-
Members	(411,027)	(165,918)
	(411,027)	(165,918)
Total comprehensive loss for the year is attributable to:		
Non-controlling interest		-
Members	(405,219)	(208,321)
	(405,219)	(208,321)

### 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.

	2016 \$	2015 \$
Impact of Investment in Research Awards from Reserves		
Net deficit per Statement of Profit or Loss and other comprehensive income	(411,027)	(165,918)
Less payments made with respect to Research Award income received in prior years	(207,136)	(99,136)
Adjusted net surplus / (deficit)	(203,891)	(66,782)

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### **Statement of Financial Position**

As at 31 December 2016

AS at 51 December 2010		
	2016 \$	2015 \$
Current assets		
Cash and cash equivalents	1,496,754	1,450,465
Receivables	590,650	496,856
Inventories	22,592	7,348
Financial assets	2,231,721	1,406,108
Total current assets	4,341,717	3,360,777
Non-current assets		
Financial Assets	1,291,692	1,178,729
Property, plant and equipment	145,324	159,467
Intangible assets	60,692	53,031
Total non-current assets	1,497,708	1,391,227
Total assets	5,839,425	4,752,004
Current liabilities		
Payables	348,947	225,891
Income in advance	3,315,205	1,946,003
Employee benefits	231,473	190,680
Total current liabilities	3,895,625	2,362,574
Non-current liabilities		
Payables	54,244	58,444
Employee benefits	38,944	65,208
Total non-current liabilities	93,188	123,652
Total liabilities	3,988,813	2,486,226
Net assets	1,850,612	2,265,778
Equity		
Retained earnings	1,852,154	2,263,181
Available-for-sale financial assets reserve	(1,542)	2,597
Total equity	1,850,612	2,265,778

### Statement of Cash Flows

For the year ended 31 December 2016		
	2016 \$	2015 \$
Cash flows from operating activities		
Receipts from operating activities	7,676,130	5,968,659
Payments for operating activities	(6,702,016)	(5,926,472)
Dividends received	85,969	60,696
Interest received	23,246	65,274
Net cash flows from operating activities	1,083,329	168,157
Cash flows from investing activities		
Investing in term deposits	(866,904)	-
Proceeds from term deposits	-	382,380
Acquisition of securities and equities	(210,687)	(609,595)
Proceeds from sale of securities and equities	124,257	-
Acquisition of plant and equipment	(23,762)	(17,000)
Acquisition of intangible assets	(59,944)	(10,500)
Net cash flows used in investing activities	(1,037,040)	(254,715)
Net increase/(decrease) in cash and cash equivalents held	46,289	(86,558)
Cash and cash equivalents at the beginning of the financial year	1,450,465	1,537,023
Cash and cash equivalents at the end of the financial year	1,496,754	1,450,465



### Lung Foundation Australia

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