# Impact Report 2018

# *Hope* in Every Breath



Lung Foundation Australia

# Driving Quality Research

#### \$2.077 million

invested to support advances in lung disease research

#### \$787.600

invested in cutting-edge research awards supporting the best and brightest researchers

#### 24 research awards, 8 of these are new awards

focusing on prevention, early diagnosis, management or a cure

# F

facilitate Australia's first National Strategic Action Plan

#### 11 government submissions

Making Lung Cancer A Fair Fight: A Blueprint for Reform launched - a first-of-its-kind impact report highlighting the true burden of lung cancer in Australia

of government to adopt lives of people living with



#### Support services accessed 7.145+ times. That's almost 29 interactions a day.

919,000+ website visits providing information, resources and support for patients, carers and health professionals

#### 19 seminars and 3.320+

webinars accessed by 2,285 patients, carers and health professionals

#### health professionals engaged via online and face-to-face training

30,200+ 16,350+ Lung Health Checklists

completed

2,385+ media articles with 192.8 million people reached

\$790.600+ raised through



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Freddy, five years old, lives with bronchiectasis.

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# No one deserves lung cancer: smoker, non-smoker or never smoker. It shouldn't matter.

"I am a loved wife, mother of four beautiful daughters and a Japanese language high school teacher. I was diagnosed with stage IV lung cancer the week of Mother's Day in 2018.

I didn't think it was possible for me to get lung cancer. I had never smoked and my exposure to passive smoke was minimal. Yet in 2018, the impossible became possible. All I ever had was a dry cough. If you have lungs you can get lung cancer.

I went to the doctor many times and had an initial clear chest X-ray, but the cough continued until I was diagnosed in May 2018. When I heard the three words that would change my life forever, I felt shocked, powerless, angry and in denial, but also hopeful.

There are so many different types of lung cancer. I have the type that is commonly seen in young, female, non-smokers who are often Asian (well, I did live in Japan for two years!). The standard of care these days is not chemotherapy or immunotherapy, it is a targeted therapy. This drug can extend my life by shrinking the tumours – awesome. But the rub is that it doesn't work forever.

What happens when this targeted therapy stops working? Hopefully I should qualify for a clinical trial. But then without money going into lung cancer research what options will I have?

For lung cancer, there is no cure. There is no remission. At best there is progression free survival. And yet I am hopeful. The lung cancer landscape has the potential for change."

- Carolyn, lives with lung cancer.



"When mum was diagnosed I felt really helpless. I took it upon myself to find something that would help with research into her type of cancer. The Sydney Blackmores Run - the half marathon - was a few months away. I thought, this is it, this is what I want to do."

Brittany raised over \$7,000 for research into lung cancer.

The trusted source of guidance and support for patients at every stage of their journey.

Lung Foundation Australia is the only charity and leading peak body of its kind in Australia that delivers lifechanging research and programs to support and provide hope to people of all ages with a lung disease, and their families, at every stage of their journey.

Our aim is to ensure lung health is a priority for all - from promoting lung health and early diagnosis, to supporting people with lung disease and championing equitable access to treatment and care.

Our work is centred on the needs of those living with lung disease, and underpinned by the values of compassion, respect and collaboration.

I am proud to have been part of the strong team culture at Lung Foundation Australia for the past 14 years. Working in the Information and Support Centre, I saw first-hand the positive impact the service has on the lives of people living with a lung disease. I am also fortunate to work with a dedicated team of expert clinicians on evidence-based guidelines which inform best-practice management and care for people living with a lung disease.

Juliet, Chronic Obstructive Pulmonary Disease (COPD) Project and Guidelines Manager.

#### Our Mission

To improve lung health and reduce the impact of lung disease for all Australians through five key areas:



#### Research

Driving world-class research into the causes, treatment and cure for lung diseases.



#### Advocacy

Being a loud and passionate voice for people with lung disease and their needs.



#### Support

Providing high quality information and support services that help people with lung disease achieve better health outcomes and improve their quality of life.



#### Awareness

Raising community awareness of lung health, lung disease and the symptoms to look out for.



#### Education

Providing evidence-based training and programs to support health professionals in the delivery of best-practice clinical care.

#### Our Values



#### **Evidence-based**



#### **Patient-centred**



#### Compassion







Lung Foundation Australia Impact Report 2018

# Working to promote lung health and improve outcomes for those living with a lung disease.

On behalf of the Board of Directors and staff, we are delighted to present Lung Foundation Australia's Impact Report for the year ending 31 December, 2018.

The year in review has demonstrated substantial growth in services and demand for awareness and influence; as well as research investment and collaborations. Over the last 28 years, people with lung disease and their families have come to Lung Foundation Australia, as a trusted charity, seeking support, information and reassurance when they are often at their most vulnerable. Lung Foundation Australia continues to achieve its dual purpose of promoting lung health for all and working to ensure improved health outcomes for people living with a lung disease.

Along with those of many of our clinical and research partners, Lung Foundation Australia's efforts to address the lack of investment in lung health research this year yielded immediate dividends. Lung Foundation Australia's advocacy and awareness strategy has seen several significant milestones achieved. They include recognition of the inadequate funding and the burden of lung disease by the Australian Government, with Lung Foundation Australia funded by the Department of Health to facilitate Australia's first National Strategic Action Plan for Lung Conditions.

Our ability to shine a light on the need, aspirations and circumstances of all Australians living with or impacted by lung disease was again highlighted in the release of *Making Lung Cancer A Fair Fight: A Blueprint for Reform* at Parliament House in Canberra in November, 2018. This report attracted significant media attention and again awaits a response from federal and state governments to address the gaps in services that are preventing people with lung cancer from gaining access to equitable treatment.

Whilst there is cause for celebration, Lung Foundation Australia



continues to address a range of challenges including raising enough funds to keep pace with the demand for services and to address the lack of investment by government in research. In an increasingly competitive donor and charity landscape, in 2018 Lung Foundation Australia committed more resources to:

- Building community awareness of lung disease
- Fighting the stigma of lung cancer and other lung diseases
- Repositioning lung health as a cause worthy of community, corporate and government support.

Looking forward, our efforts will focus on the quality assurance of programs to ensure they are evidence-based and more closely aligned with health consumer needs. It is crucial that we improve the brand awareness of Lung Foundation Australia as well as lung health and lung disease specifically, so that we are competitive for corporate and lung community donations.

This Impact Report highlights the significant amount of work completed by our dedicated team of staff, volunteers and supporters. On behalf of the Board, we extend our sincerest thanks to all those who give their time and resources to help Lung Foundation Australia achieve its purpose. We particularly want to acknowledge the tremendous



contribution of Heather Allan, who stepped down as Chief Executive Officer in July 2018, and to thank her personally for her dedication to lung health. Equally we acknowledge retiring Directors Professor Peter Frith and Dr Briony Scott, for their stewardship as Board Members and for their passion for Chronic Obstructive Pulmonary Disease (COPD) and lung cancer respectively. All three will be greatly missed.

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 2018.

The future looks bright with significant opportunity on the horizon for Lung Foundation Australia to continue to make progress within the lung health space and improve the lives of people living with lung disease.

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Professor Christine Jenkins AM, Chairperson

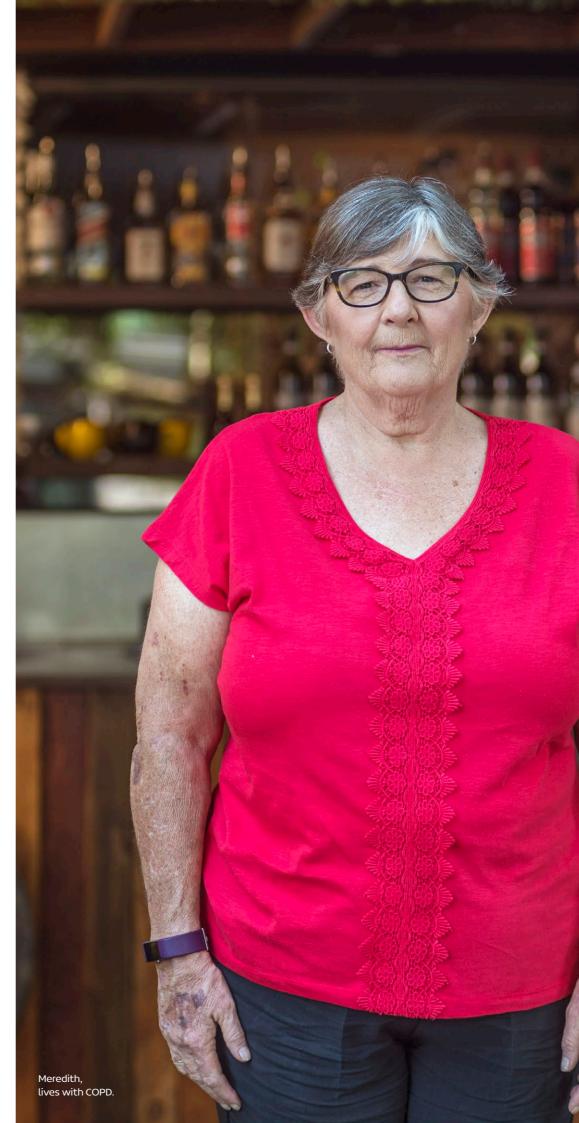
WRKrocke

Mark Brooke, Chief Executive Officer

D Lung Foundation Australia Impact Report 2018

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

Lung	- Lung disease impacts 7 million (almost 1 in 3) Australians.
Disease Overview	- Lung disease accounts for 10% of the total health burden in Australia.
	- Almost 50% of all Australians rarely or never think about the health of their lungs.
Chronic Obstructive Pulmonary	- COPD is the most common cause of potentially preventable hospitalisations.
Disease (COPD)	- 1 in 7 Australians over the age of 40 has COPD.
Lung Cancer	- In 2018, it is estimated over 12,740 Australians will be diagnosed with lung cancer in Australia. That's 34 people a day.
	- The economic burden of lung cancer for patients diagnosed in 2018 was estimated to reach \$283.7 million in direct costs, including treatment, out-of-hospital and out-of-pocket expenses.
	- Lung cancer has one of the lowest survival rates of any cancer in Australia with only 17% of Australians surviving 5 years after their diagnosis.
	- Lung cancer is Australia's biggest cancer killer: it kills more people than breast, prostate and ovarian cancers combined.
	- 1 in 3 women and 1 in 10 men diagnosed with lung cancer have no history of smoking.
Idiopathic Pulmonary	- The current survival rate of IPF is as low as some of the most devastating cancers.
Fibrosis (IPF)	- While 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.
Pulmonary	- PAH diagnosis is delayed on average 3.9 years.
Arterial Hypertension (PAH)	- On average it takes 5 General Practitioner visits before a specialist referral is given.
Bronchiectasis	- Bronchiectasis is a common lung disease caused by chronic infection damaging the lungs.
	- The prevalence of bronchiectasis continues to increase worldwide, disproportionality affecting Australian Indigenous children.
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.



#### Lung Health 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'.

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.

Lung Foundation Australia Impact Report

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### 2020 OBJECTIVE

stakeholders.

2020 TARGETS

The go-to resource for lung 15% of those diagnosed health and lung disease.

with lung diseases 'are actively engaged' with Lung Foundation Australia.

> PROGRESS Partially achieved, on target

and continuing as a priority.

A valued hub for all

Partially achieved and strengthening.

26%

31%

20%

# Becoming the patient interface.

#### Partners in your health journey

Lung Foundation Australia's Information and Support Centre team and Lung Cancer Support Nurse continued to provide telehealth support, face-to-face education and peer support groups. Our multifaceted program aims to increase the confidence, skills and capacity of consumers and their families to navigate the health system and maximise opportunities in their treatment. A 1% cornerstone of our work is providing consumers and their families with 10% the knowledge and expertise to 7% work with health professionals and make informed decisions about their health care and treatment.

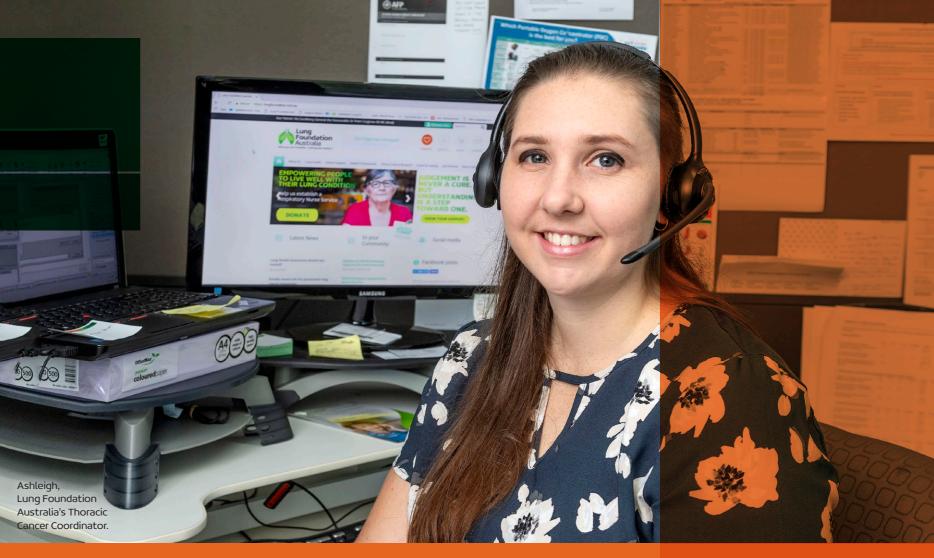
Thanks to our generous donors in the 2017 Christmas Appeal, Lung Foundation Australia employed a Respiratory Care Nurse who is providing telephone support to patients and carers across the country. This includes practical suggestions about their lung disease, personal care and management, as well as referral to local support services where necessary.

#### **Education seminars**

Last year, 12 Education Seminars were delivered all around Australia by clinical and consumer experts. The program provided practical tips and advice to highlight the important role of living well and self-management. Popular topics included understanding the emotional impact of lung disease, supportive care in advanced lung disease, tips for breathlessness and exercise and nutrition.

"I was very impressed with the presentations. The speakers were extremely informative and answered a lot of questions."

- Andrew, Adelaide Education Seminar.



#### Support groups

Lung Foundation Australia hosted telephone and face-to-face support groups, facilitated by our Lung Cancer Support Nurse and specially trained staff, which connected people living with a lung disease with others in a similar situation. Those who joined were provided with a safe, friendly and open environment to discuss the challenges they face living with lung cancer, share their experiences and gain valuable insights into living with their disease.

Almost 100% of surveyed joined the Telephone Support Groups to talk to others who understand what they are going others from the comfort of their own home.

#### Webinars Rare lung disease

To support Australians living in rural and remote Australia, Lung Foundation Australia introduced two new webinar series in the rare lung disease space, focusing on Idiopathic Pulmonary Fibrosis and Pulmonary Arterial Hypertension. Five webinars were held in 2018 providing the latest information to over 700 patients, carers and health professionals. The key topics included exercise, medications, selfmanagement and living well.

#### Lung Cancer Connect

In 2018, two Lung Cancer Connect webinars supported 186 patients, their families and carers, as well as health professionals, by providing information, advice and support about immunotherapy and living well with lung cancer. People were able to join the webinar from the comfort of their home and ask questions from

the expert presenters around the challenges experienced when 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

Lungs in Action is a safe and enjoyable ongoing community exercise maintenance program empowering people with a lung disease to improve their quality of life through exercise. There are now 87 unique locations running a combined total of 153 weekly classes across almost all of the nation's states and territories. The classes equip patients with the skills and knowledge to better manage their symptoms and maintain the improvements gained through pulmonary rehabilitation.



Guided by evidence and best-practice.



25% increase in health professional engagement with Lung Foundation Australia.

PROGRESS Partially achieved, on target and continuing as a priority.

A successful collaborator.

Achieved, strengthening and continuing as a priority.

# Supporting early diagnosis and best-practice clinical management.

#### Online and face-to-face training

This year, Lung Foundation Australia delivered its first face-to-face practical pulmonary rehabilitation workshops in Brisbane, Sydney and Melbourne. The workshops upskilled almost 50 nursing and allied health professionals on the key theoretical and practical elements needed to effectively deliver best-practice pulmonary rehabilitation programs in the community. These programs allow people living with chronic lung disease to do regular exercise which helps them to live well and maintain their physical fitness.

Our suite of online training continued to upskill clinicians, nurses, pharmacists and exercise professionals to ensure they have access to the most up-to-date education. Almost 450 training courses were completed with popular training including Chronic Obstructive Pulmonary Disease (COPD) Nurse online training, Pulmonary Rehabilitation online training and the COPD Medicines short module.

#### **Evidence-based quidelines**

Lung Foundation Australia's internationally recognised guidelines, The COPD-X Plan: Australian and New Zealand Guidelines for the management of COPD, as well as the Pulmonary Rehabilitation Guidelines, continued to deliver world-class expert recommendations to support health professionals in the clinical management of their patients. The COPD-X guidelines are reviewed quarterly, making them one of the most frequently updated guidelines in the world with more than 8,500 health professionals subscribed to receive notification of the updates.

#### Partnering to improve patient outcomes

Lung Foundation Australia continued to partner with Primary Health Networks (PHNs) across Australia to upskill health professionals and undertake health systems improvement initiatives, mainly in the area of COPD. Face-to-face education workshops were delivered to over 230 PHN staff to improve clinical knowledge, skills and confidence in identifying and diagnosing people with COPD, developing evidence-based treatment plans and preventing exacerbation and disease deterioration.



Lung Foundation Australia also partnered with PHNs and clinical excellence bodies to deliver larger, multi-year projects. These include:

#### - Murray PHN Project

Lung Foundation Australia and Murray Primary Health Network (PHN) partnered to deliver a multifaceted project aimed at improving management of people with COPD in the Murray PHN region. In 2018, this project:

- Provided a region-wide education program to support 560 health professionals improve their knowledge and confidence through best-practice care for people with COPD through online and face-to-face education.
- Improved local service capacity by upskilling 20 spirometry and 40 pulmonary rehabilitation providers as well as training

- 30 new Lungs in Action instructors and 40 health interviewing.
- Established a HomeBased 20 people living with a lung
- Practitioners.

#### Integrated Care Innovation Fund COPD Project

Lung Foundation Australia partnered with Metro North Hospital and Health Service (MNHHS) and



Tegan, nurse who lives with Pulmonary Arterial Hypertension.

professionals in motivational

pulmonary rehabilitation pilot, in partnership with Bendigo Health, which has improved access for disease to-date who wouldn't have previously been able to access this best-practice care.

• Developed a software solution, in partnership with Medical Director, to improve the accessibility of the COPD Action Plan for General

the Brisbane North Primary Health Network (BNPHN) to upskill 112 General Practitioners (GPs) and nurses across the Metro North Hospital Health Service. It aimed to improve early detection and bestpractice treatment of COPD patients in primary care.

#### Adelaide Respiratory Health Project

Lung Foundation Australia and Asthma Australia continued to undertake the Adelaide Respiratory Health Project, which began in November 2017, funded by the Adelaide PHN. The project, due for completion in 2019, works to improve outcomes for people living with COPD and asthma by upskilling GPs and pharmacists through faceto-face inhaler device workshops, online COPD training modules, clinical guidelines and resources.



A leading advocate for lung health.

2020 TARGETS Government increases the relative priority it places on lung disease.



Achieved, on target and continuing as a very high priority.

# Campaigning for change.

#### National lung health strategy

Lung Foundation Australia successfully advocated for a national lung health strategy to ensure all people with lung disease have access to the same level of care and support as those with other chronic diseases.

Throughout 2018, Lung Foundation Australia led and facilitated one of the most important policy discussions in our organisation's history, culminating with the presentation of Australia's first National Strategic Action Plan for Lung Conditions to the Australian Government Department of Health in February 2019. This national plan, will help change the future of lung disease in Australia by defining tangible and practical actions that we can take to begin to make a difference to the lives of those millions of Australians.

#### The key priority areas and objectives include:

- Prevent lung conditions and reduce the risk of lung disease
- Raise awareness about lung conditions and reduce stigma, discrimination and social isolation
- Translate science into quality diagnosis, management and care of lung conditions
- Support people with lung conditions to participate in shared decision making and self-management
- Ensure equitable and timely access to evidence-based diagnosis and management of lung conditions
- Increase research capacity to redress under resourcing of research into highly prevalent lung conditions.

#### Improving outcomes for Australians with lung cancer

Lung Foundation Australia commissioned and released a new report Making Lung Cancer a Fair Fight: A Blueprint for Reform – a first-of-its-kind report addressing the social, economic and mental health issues of Australians living with lung cancer.

The report provides a clear indication of the true burden of lung cancer in Australia, now and over the next decade, as well as the confronting challenges facing those living with lung cancer. Importantly, it outlines solutions to improve outcomes for the many thousands of people living with lung cancer.

It is our hope that this research will continue to be used to inform decision makers to adopt key reforms and address the disjointed care, mental health and stigma that Australians with lung cancer face - and make lung cancer a fair fight.



#### **Pharmaceutical Benefits** Scheme (PBS)

Lung Foundation Australia continued to play a role in advocating for affordable access to new medications for people living with a lung disease, with three submissions made to the Pharmaceutical Benefits Advisory Committee (PBAC) for innovative lung cancer treatments, including both immunotherapies and targeted therapies. All three treatments were recommended for PBS listing by the PBAC.

Lung Foundation Australia also made a submission in Post-Market Review of COPD Medicines, in partnership with the Thoracic Society of Australia and New Zealand. We advocated for a number of recommendations to support a timely and stepped approach to pharmacological management of COPD and improved outcomes for patients. One of the most significant outcomes was the PBAC's support of our recommendation in relation to LAMA

and LABA medicines. Lung Foundation Australia advocated to add clinical criteria to the current restrictions, allowing their use in patients who have not been previously stabilised on a combination of LAMA and LABA medicines, but who have failed to have their symptoms controlled by either.

to A-Flag (mark as brand equivalent) a generic COPD medicine (DuoResp Lung Foundation Australia lobbied the government to direct the PBAC to to consider implications where the inhaler device of a generic medicine,

such as DuoResp Spiromax, was different to that of the comparator or brand-equivalent medicine. The Health Minister responded to our submission and requested the PBAC review its decision in relation to A-Flagging, however the decision was upheld at

Following a recommendation from PBAC Spiromax - budesonide and formoterol) remove the A-Flagging status attached to DuoResp Spiromax. Lung Foundation Australia highlighted the need for PBAC

the PBAC March 2018 meeting. Lung Foundation Australia continues to advocate for education in relation to A-Flagging and the importance of inhaler device technique training for both health professionals and patients.

#### Occupational lung disease

Lung Foundation Australia and The Thoracic Society of Australia and New Zealand lodged a submission to the Senate enquiry on coal workers pneumoconiosis (black lung) which highlights the need for increased community awareness about the risks, symptoms and prevention of occupational lung disease. The enquiry will also establish a national register for occupationally acquired lung disease to determine the prevalence in Australia and the industries in which they occur, and allow targeting of prevention activities.

# 2020 OBJECTIVE

Driving trends and direction of research. 2020 TARGETS Lung Foundation Australia's annual support for research is \$5 million

per annum.

A valued hub for all stakeholders.

Strong collaboration with Thoracic Society of in 2018.

Australia and New Zealand.

Achieved, on target and a continuing high priority.

> PROGRESS

Achieved, on target and

continuing as a very high

priority with a total of \$6.928 million invested

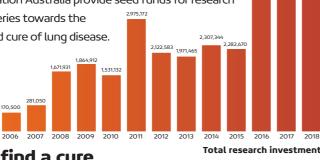
# Driving and funding research to ensure the best outcomes today whilst searching for tomorrow's cures.

#### Continuing to grow our research platforms

Research offers hope, whether for a cure or for an improvement in quality of life. With money raised through the generosity of organisations and the community, Lung Foundation Australia provide seed funds for research projects that support discoveries towards the

prevention, management and cure of lung disease.

Since 1990, Lung Foundation Australia has invested \$17.6 million into its research program.



#### Collaborating to find a cure

Lung Foundation Australia funded cutting-edge research awards through a competitive, peer-reviewed awards and grants program. In collaboration with the Thoracic Society of Australia and New Zealand, Lung Foundation Australia provided opportunities for individual researchers through fellowships and PhD scholarships, project grants, grants-in-aid and travel grants. These opportunities allow researchers to join forces and showcase their work nationally and internationally. In 2018, Lung Foundation Australia raised and invested \$787,600, into this program funding a total of 24 awards, with eight of these being new awards.

Congratulations to the 2019 Research Award recipients. For a full list please refer to the Research Impact Report 2018 or visit lungfoundation.com.au

#### Finding breakthroughs through clinical trials

We initiated and facilitated clinical trials in lung cancer and Idiopathic Pulmonary Fibrosis (IPF) to help find new advances in the diagnosis, treatments and management of these lung diseases.

#### Lung cancer: looking for a cure

In 2018, Lung Foundation Australia's Australasian Lung Cancer Trials Group (ALTG) initiated and continued funding one new trial, STIMULI, involving 325 participants globally. The trial works to assess the effectiveness of using two immunotherapies - nivolumab and ipilimumab - after having

Dr Clare W Walter and Eliza In of Medical Researc

> standard treatment of chemotherapy/ radiotherapy in people living with limited-stage Small Cell Lung Cancer and increase their overall survival rate.

#### **Idiopathic Pulmonary Fibrosis: Searching for** cutting-edge treatments

Pulmonary Fibrosis Australasian Clinical Trials Network (PACT) was developed to unite leading clinicians and researchers from across Australia and New Zealand to design, conduct and analyse clinical trials that will help find new advances in the diagnosis, treatments and management of pulmonary fibrosis. A Pulmonary Fibrosis clinical trials network is a priority in 2019 following the successful ALTG model.

#### Understanding lung disease through research registries

Lung Foundation Australia continued to lead two national disease registries that provide researchers

#### with a platform of rich longitudinal data for IPF and bronchiectasis.

#### Australian Idiopathic **Pulmonary Fibrosis Registry**

The Australian IPF Registry is a unique research platform that collects information on more than 765 patients living with IPF to better understand this rare and complex disease. This central source of rich data can be used to undertake and inform a wide range of research projects in both national and international studies, abstract presentations and publications to inform clinical practice and answer important research questions.

#### Australian Bronchiectasis Registry

The Australian Bronchiectasis Registry, which has over 1,200 participants involved to-date, works to identify and collect data on people living with bronchiectasis to facilitate national and international research, improve clinical management practices and





maximise opportunities for patients to participate in clinical trials.

#### Your donations in action

The 2018 Christmas Appeal raised valuable funds to support people living with bronchiectasis and fund lifechanging research. The appeal theme, It's not only superheroes who wear masks, told the story of five-year-old Freddy who, in the eyes of those who know him, is a true superhero. Freddy has bronchiectasis, which means he often has to wear a mask - and not a typical superhero mask - a mask to help him breathe.

The appeal rallied behind families like Freddy's who feel the impact of the lack of research and support for bronchiectasis. With the help of corporate supporter Insmed, all money raised during the Christmas Appeal supported our Australian Bronchiectasis Registry.

# Awareness

# 2020 OBJECTIVE

Driving trends and direction of research.

2020 TARGETS

Lung Foundation Australia's

annual support for research

is \$5 million per annum.



Partially achieved, on target and continuing as a very high priority with a total of \$6.928 million invested in 2018.

# Breaking down the stigma associated with lung disease and raising awareness about its symptoms, prevalence and impact on Australians.

#### Lung Health Awareness Month

In 2018, Lung Health Awareness Month was held in May for the first time. The month worked to raise awareness amongst the community about the importance of lung health and how to recognise and act upon the symptoms of lung disease. Over 17,000 people checked in with their lung health online. The key message from the campaign, *anyone can get lung disease*, aimed to get the community thinking about their own lung health whilst breaking down the stigma surrounding lung disease.

#### World COPD Day

World COPD Day on November 21 focused on raising awareness about the symptoms, risks and treatment of Chronic Obstructive Pulmonary Disease (COPD). Patients and health professionals were encouraged and supported to host and attend community awareness events, with 260 held nationally. A post-event survey revealed 35% of respondents undertook lung function screening to promote early diagnosis in the community as part of their event with 184 tests completed. Patients were empowered to take control of their lung condition through the campaign theme, *don't let shortness of breath stop you from living your dreams.* Tips encouraged people living with COPD to live well and stay out of hospital and to improve and maintain a good quality of life.

#### Shine a Light on Lung Cancer

Lung cancer has a devastating impact on the lives of millions of Australians, with one of the lowest survival rates of all cancers, and least funded, when compared to commonly diagnosed cancers. Our Shine a Light on Lung Cancer campaign 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. \$100,000 was raised to fund lifechanging lung cancer research.

#### New website and digital strategy

In 2018, Lung Foundation Australia launched a new website. The site was developed in consultation with consumers and key stakeholders and provides a central source of information and resources to support people of all ages living with lung disease, as well as health professionals, researchers and the community.



Bill is a 65-year-old husband, father of three and grandfather to five. He was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in March 2015. Since then, and despite having just 53% lung capacity, Bill has taken on two gruelling physical and mental challenges of a lifetime, sharing his inspiring story with communities along the way. In 2018, he completed The Long Kayak for Lungs - a 42-day, 2,200-kilometre kayaking journey along the Murray River which raised over \$94,000 to support Australians living with lung

Thank you, Bill, for your endurance and continued support of Lung Foundation Australia.

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# 2020 OBJECTIVE



Annual community fundraising revenue growth.

\$1.5 million per annum.

> PROGRESS

Achieved, on target and continuing as a very high priority.

Collaborating partners

generosity of the Alfred

for Respiratory Health

Royal Adelaide Hospital

and Roval Prince Alfred

Hospital, and Thoracic

Society of Australia and

Long Kayak for Lungs

Boehringer Ingelheim,

donors for supporting

Bill van Nierop to raise

over \$94,000 during his

incredible Long Kayak for

and the following major

Thanks to major sponsor,

Western Australia,

New Zealand.

Lungs in 2018.

Agribusiness

Agworld

Elders

Recruitment

BarkerGroup

HIB Insurance

IR Department

Pharmaxis Ltd

RSM Australia

• The Lucas Group

Tryden Investments

Ruralco

Sipcam

Trust

II Lawson

Club

Leon Serry

• Hillis Motor group

Adama

• AdAlta Limited

• AGnVET Services

Agrijobs Australia

Ashborn Industries

Dave and Ann Robertson

• MD Altschwager & Sons

• Ray White Redland Bay

Renmark Rotary Club

Murray Bridge Rotary

Health Solutions, Institute

We acknowledge the

#### 2020 OBJECTIVE Financially healthy



\$1.5 million per annum.

\$5 million per annum.

As a charitable institution and Company Limited by

community and corporate goodwill to achieve its goals.

The Lung Foundation Australia Board consists of eight

help improve lung health and reduce the impact of lung

directors who volunteer their expertise and time to

The Board's role is to ensure a range of strategies that

support people impacted by lung disease are achieved.

To undertake this role, the Board is responsible for the

• Approving and monitoring financial performance

· Establishing and monitoring the achievement of

The Board delegates responsibility for the operation

and administration of the organisation to the Chief

Executive Officer. Responsibilities are delineated by

The Board adopted a four-year Strategic Plan in 2017.

This outlines our mission, purpose, values, goals and

and are measured by clearly defined Key Performance

strategies. These strategies are outcome-focused

• An annual business plan and budget relating to the

framework, from the Board to the CEO and staff,

built around a performance culture measured by a

Lung Foundation Australia has a formal process to induct

and educate new and continuing Directors about the

nature of the organisation, health and medical issues,

performance and conduct of Board Members.

the corporate strategy and the expectations concerning

• Ensuring the integrity of internal control and

management information systems.

• Appointing, removing and creating policies

overall corporate governance of the organisation.

• Formulating its strategic direction

Setting executive remuneration

organisational goals

formal authority delegations.

Our Strategic Plan includes:

• A reporting framework against KPIs

performance appraisal process

**Board of Directors education** 

A risk management plan.

• Delegated authorities, recorded in a policy

Indicators (KPIs).

Strategic Plan

Board planning framework

disease for all Australians.

This includes:

Guarantee Lung Foundation Australia relies upon

Lung Foundation Australia's

annual support for research is

# Thanks to our supporters. Every gift is greatly appreciated.

Thank you to everyone who supported Lung Foundation Australia in 2018. Our mission to improve the lives of all Australians living with lung disease would not be possible without you. We would like to acknowledge the following individuals and organisations for their contribution this year.

Kathryn Galloway

lynley Bear-Norton

• Michael Zammit

Paul & Dolli Taylor

Rhiannon Carpenter

Corporate partners

Foundation partners

Boehringer Ingelheim

• Menarini Australia

Principal partners

GlaxoSmithKline

• Seqirus Australia

community groups

• Bristol-Myers Squibb

• Lions Club Of Taylors

• Lugarno Lions Club

Oxygen Solutions

• Phillips Healthcare

Teva Pharmaceutical

Seasonal Supplies Pty Ltd

• South Grafton District

Ex-Servicemen's Club

• Taree Lungnet Support

Pdmedical

Industries

• Sanofi

Group

• Order Of The Eastern Star

Redcliffe Chapter No. 85

• Air Liquide

Breath-A-Tech

• District Gazett

Bayer

Insmed

Lakes

Merck Sharpe Dohme

Supporting partners and

• Samantha Priddey

• Nina Munro

Rvan Markev

Susana Jarufe

• Tom Powell

AstraZeneca

Novartis

Actelion

Roche

• Pfizer

Zoe Karst

- Government funding
- Cancer Australia
- Oueensland Health

#### Estates

- Estate of Albert Robertson
- Estate of Carmen Joan Piery
- Estate of Carol Anita Maddan
- Estate of Susan Bradshaw Whitington

#### Major donors

- Brent And Vicki Emmett
- Brian Eaton Family
- Christine Jenkins
- Christine O'Keefe
- David Sprat
- The David Wilson Family
- Elaine Walters OAM
- Elizabeth Frost Elizabeth Magee
- Elizabeth Yates
- The Greenwood Family
- Ivan Cash
- lack Rust
- Joan Whyte
- Joshua Ritterman
- Kane Morris
- Leon Serry
- Rabia Manchanda
- Rehle Cheney
- Sherene Guy
- Teck Ming Tang William Moulds

#### Donors

- Agnes Varcoe Barbara Shears
- Belinda Cochrane
- Beverley Hewett
- Brett Lamond
- Bruce Kirkham
- Clare Ashen
- Darren Simpson
- Douglas Osborn
- Elise Elliott
- Elizabeth Melbourne
- Frank Elliott
- Gary Catley
- Georgiadis Family

- Ian & Pamela Wall Katie O'Malley Kirsten Mooney
- Indravadan Patel
- Iohn Gaidzkar
- John Lungren
- Ken Sweeney

Helen Bogiatzis

- Lal Pardasani
- Lois E Cox
- Lorraine Hughes
- Malcolm Stewart
- Margaret Kinnell
- Margaret Morgan
- Martin Phillips Miriam Mcgoldrick
- Neville Marriott
- Pamela Lumb
- Peter Garbutt
- Prue Ffelan
- Richard Ramsav
- Rosemary Taylor
- Thomas Dawson
- Tonia Krause

#### Grants, trusts and

- Foundations
- Brass Holdings Pty Ltd Better Breathing
- Foundation
- Blue Sand Foundation
- Chain Reaction Challenge Foundation
- Dry July
- Investment Corp
- Property Trust
- Jelena Hahan
- Perpetual Trustees
- Scobie And Claire
- Mackinnon Trust
- Community fundraising
- partners • Angus & Mary Bishop
- Belinda Prideaux
- Bev White
- Bill Lange
- Brittany Riordan
- Chanelle Price
- Denise Lindsell
- Donna Long Ella Tuckey

Gary Blom

Evangeline Lim

Helen & Richard Irving

#### > PROGRESS

Achieved, on target and continuing as a very high priority.

Partially achieved, on target and continuing as a very high priority with a total of \$6.928 million invested in 2018.

#### Role of the Board of Directors

The Board is skills-based and is broadly representative of the lung health and disease stakeholders.

#### Critical risk and mitigations impacting Lung Foundation Australia

The strategic risks being actively managed by the Board and leadership team include:

The ongoing sustainability of the organisation through increased, and a greater diversity of, fundraising, impact and research. This is monitored monthly to ensure the company have enough reserves to meet short and long-term liabilities.

Increasing awareness of lung health within government and the broader community, including the stigma of lung disease and cancer to attract increased funding and investment. The Board has approved an advocacy strategy starting with the National Strategic Action Plan for Lung Conditions and is actively engaging State and Federal Governments to fund core service priorities.

Attracting and retaining talented staff and volunteers. The Board recognises the transformation underway within the organisation to develop existing staff skills to meet the challenges of fundraising and service delivery. A plan is now in place to upskill staff and identify gaps in skills with pro bono support via skilled volunteers as a core activity.

#### Funding from pharmaceutical companies

Lung Foundation Australia recognises the importance of working in partnership with all stakeholders who have an interest in lung disease. This includes the pharmaceutical, biotechnology, diagnostic and device industries. Funding from these industries assists Lung Foundation Australia to achieve its mission and to deliver better outcomes for patients living with a lung disease.

Lung Foundation Australia accepts funding from pharmaceutical companies in line with our Working with Industry Policy, which requires absolute transparency, and complies with the Medicines Australia Guidelines for patient organisations working with pharmaceutical companies.

This policy ensures that we retain full independence in considering all proposals and clearly document contracts that specify our independence. We offer no exclusive arrangements with industry partners. Our Working with Industry Policy can be read in full at lunafoundation.com.au

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.

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. Professor Jenkins plays a major role in advocacy and leadership for lung health in Australia, has over 200 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 Respiratory Physician, who previously worked at Sir Charles Gairdner Hospital, a tertiary institute in Perth, attached to the University of Western Australia, where he was a Clinical Professor. He

relocated to Sydney in 2018 and now practices at Macquarie University Hospital and is an Honorary Clinical Professor at Macquarie University. He has had research interests in asthma, COPD, lung cancer and interventional pulmonology. Professor Phillips has served on a number of state and national bodies, including the Royal Australasian College of Physicians and the Thoracic Society of Australia and New Zealand, as well as international organisations such as the World Association of Bronchology and Interventional Pulmonology.

#### Professor Peter Frith

Board Member since March 2013 (retired October 2018)



Professor Peter Frith is a respiratory physician who has specialised in chronic disease management for COPD, pulmonary rehabilitation, selftreatment 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 Lung Foundation Australia's COPD National Program, 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 the Scientific Committee of the Global COPD Initiative (GOLD).

#### **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 (Kathy) 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. Kathy maintains an active interest in the changing shape of retail banking through attendance at conferences and various consulting assignments to the finance industry on emerging business models 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 200 peer-reviewed publications and is a Fellow of the American Thoracic Society.

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



Mr Tony Hyams is experienced in banking, finance and investment. He was previously Head of Credit Suisse in Australia and later an 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, Deputy Chairman of the Australian Maritime Safety Authority and Director of the Melbourne Airport amongst others. He has degrees in Law and Commerce, has been a participant at the World Economic Forum and is 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 (resigned October 2018)



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 with the media on education, leadership, and parenting. She has specialised in motivational theory, technology, and gender equity.

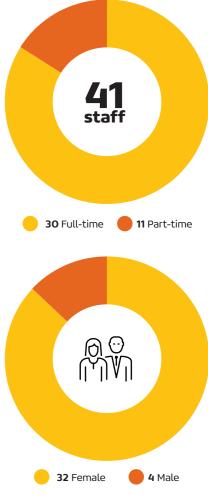


Our professional team and motivated staff, volunteers, and our Board and committees form the strength of Lung Foundation Australia. Lung Foundation Australia's team is built on dedicated and motivated staff and volunteers. A second staff survey was conducted in 2018 to gain insight into any gaps for improvement in the working environment of employees, as well as to improve the experience for staff at work.

The survey achieved an excellent participation rate, with 100% responding to part one, and 97% responding to parts two, three and four. Respondents appreciated the friendly and supportive team environment, their quality of work, and making a difference in the lives of people living with a lung disease. They also acknowledged the opportunities they were provided at work, with 96% of respondents proud to say to colleagues, family and friends they work at Lung Foundation Australia.

In July 2018 Ms Heather Allan resigned as Chief Executive Officer (CEO) of Lung Foundation Australia and in September 2018 Mr Mark Brooke was appointed CEO.

**5** Lung Foundation Australia



Lung Foundation Australia Impact Report 20

# Summary financial statements for the year ended 31 December 2018

The unaudited summary financial statement has been prepared for presentation in the 2018 Impact Report of Lung Foundation Australia for the year ended 31 December 2018. 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 2018, 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 2018. Members of Lung Foundation Australia are able to obtain a full financial report, directors report and auditors report by visiting the Lung Foundation Australia website lungfoundation.com.au or by visiting the ACNC website acnc.gov.au

#### Lung Foundation Australia statement of profit or loss and other comprehensive income

#### For the year ended 31 december 2018

	<b>2018</b> [\$]	<b>2017</b> [\$]
Continuing operations		
Revenue from projects	4,881,736	4,230,150
Donations and bequests	692,629	1,194,771
Revenue from fundraising and events	520,954	515,361
Revenue from specifically designated funds	338,828	253,136
Other income	230,813	193,671
Total revenue and other income from continuing operations	6,664,960	6,387,089
Project expenses	(4,881,736)	(4,230,150)
Specifically designated fund expenses	(338,828)	(253,136)
Other expenses	(1,444,409)	(1,808,639)
Surplus / (deficit) from continuing operations before finance	(13)	95,164
income		
Finance income	39,932	33,540
Net surplus / (deficit)	39,919	128,704
Other comprehensive income		
Items that may be reclassified subsequently to profit or loss:		
Fair value gains/(losses) on Equity FVOCI financial assets	(126,497)	74,956
Total comprehensive income / (loss)	(86,578)	203,660
Net surplus / (deficit) for the year is attributable to:		
Members	39,919	128,704
	39,919	128,704
Total comprehensive income / (loss) for the year is attributable to:	:	
Members	(86,578)	203,660
	(86,578)	203,660

In 2018, Lung Foundation Australia experienced a year of change, positioning the organisation to be ready for the next phase of growth and increased impact on the lives of those Australian impacted by a diagnosis of lung disease. The changes included:

- 1. The appointment of our new Chief Executive Officer, Mark Brooke
- 2. The implementation of an office restructure in readiness to commence with the new structure in 2019
- 3. The complete revamp of the Lung Foundation Australia's website, which provided a cleaner look, better navigation and aligned the website with our new branding.

Lung Foundation Australia had a successful year by:

- 1. Increasing its total revenue by 4.35% from 2017
- 2. Increasing its overall expenditure on lung disease projects and programs (including research) by 16.4% (which included an increase in overall expenditure on research by 21%)
- 3. Generating a small surplus of \$39,919 for the year.

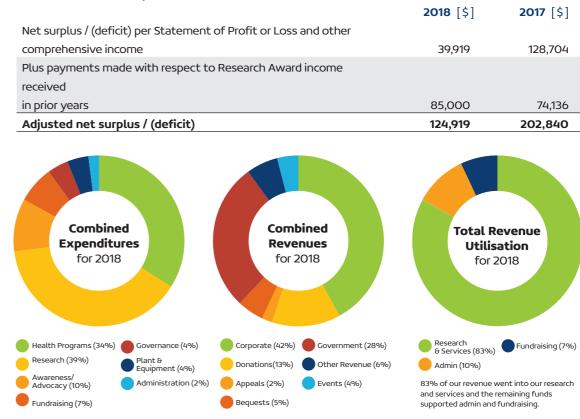
Due to a volatile world equity market during the last quarter of 2018, the value of the investment portfolio was impacted by an unrealised loss of \$126,497, which has been shown in the Statement of Profit or Loss and Other Comprehensive Income. By the end of January 2019, the value of investment portfolio had recovered approx. 1.4% (or \$50,000) of its value.

#### 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 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.

received



#### Lung Foundation Australia statement of financial position

As at 31 December. 2018

13 00 3 1 December, 2010	<b>2018</b> [\$]	<b>2017</b> [\$]
Current assets		
Cash and cash equivalents	1,571,654	1,966,138
Receivables	616,804	622,652
Inventories	-	13,694
Financial assets	741,792	1,294,232
Total current assets	2,930,250	3,896,716
Non-current assets		
Financial Assets	2,596,367	2,333,207
Property, plant and equipment	118,265	132,891
Intangible assets	144,418	47,732
Total non-current assets	2,859,050	2,513,830
Total assets	5,789,300	6,410,546
Current liabilities		
Payables	201,881	281,829
Income in advance	3,470,989	3,762,642
Employee benefits	98,227	212,541
Total current liabilities	3,771,097	4,257,012
Non-current liabilities		
Payables	32,193	48,992
Employee benefits	64,666	53,623
Total non-current liabilities	96,859	102,615
Total liabilities	3,867,956	4,359,627
Net assets	1,921,344	2,050,919
Equity		
Retained earnings	2,020,777	1,980,858
Equity FVOCI financial assets reserve	(99,433)	70,061
Total equity	1,921,344	2,050,919

#### Lung Foundation Australia statement of cash flows

For the vear ended 31 December. 2018

for the year chaed of beechiber, 2010	<b>2018</b> [\$]	<b>2017</b> [\$]
Cash flows from operating activities		
Receipts from operating activities	7,538,256	7,235,294
Payments for operating activities	(8,087,299)	(6,836,919)
Dividends received	128,558	80,490
Interest received	41,608	57,089
Net cash flows from operating activities	(378,877)	535,954
Cash flows from investing activities		
Investing in term deposits	-	-
Proceeds from term deposits	596,899	1,097,506
Acquisition of securities and equities	(1,230,970)	(1,305,290)
Proceeds from sale of securities and equities	757,913	176,549
Acquisition of plant and equipment	(28,569)	(30,635)
Acquisition of intangible assets	(110,880)	(4,700)
Net cash flows used in investing activities	(15,607)	(66,570)
Net increase/(decrease) in cash and cash equivalents held	(394,484)	469,384
Cash and cash equivalents at the beginning of the financial	1,966,138	1,496,754
year		
Cash and cash equivalents at the end of the financial year	1,571,654	1,966,138

Invest in the Ŝ future

Find a cure Your donation can help us understand the causes and future treatments of lung disease. Regular giving is our most precious source of revenue. It gives us certainty and continuity in an unpredictable funding environment and provides an independent source of funding. A donation of \$5.00 per week goes a long way. Put simply regular donations allow great science to flourish.

involve

Lung Foundation Australia is proud to partner with philanthropists, companies, trusts and foundations to raise vital funds for lung disease research. We focus on forming personalised connections with donors and supporters to achieve our mission. We are outcomes focused and ensure your investment is tracked against measurable goals. As with all our support, we keep you up-to-date on progress. This is our promise.

Community Fundraising

and

Philanthropy

Partnerships

fun run, cycle or hold an event.

References For references please visit lungfoundation.com.au Copyright
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Scientific breakthroughs can take years to accomplish. Invest in a future free from lung disease by leaving a bequest or gift as part of your Will. Leaving a bequest is a way of ensuring you can continue to support the causes that are special to you, even after you're gone. Equally, talking with your family about a Gift in Memoriam celebrates your life and gives hope to others.

More than ever, Australians are aware of the need to increase research funding to fight lung disease and give hope to their fellow Australians. Share your story, become a Lung Foundation Australia Ambassador or join workplace giving. There are many ways you can support Lung Foundation Australia and make a difference.

Celebrate hope and support your loved one, friend or work colleague by doing something you love. Join our team, take part in a





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