

2019 Impact Report



of research, support, advocacy and hope.



Campaigning for Change

Australia's first National Strategic Action initial \$4 million funding commitment from the Australian Government.

> The first national enquiry into a lung cancer screening program was announced by the Australian Government.

A National Dust Disease Taskforce was formed to tackle the emerging silicosis crisis.

government submissions were made by Lung Foundation Australia.



Driving Quality Research

\$5.29 million

invested to support advances in lung disease and lung cancer research.

\$437,800

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

LL research awards

focusing on prevention, detection, management or a cure.

new research awards introduced across Idiopathic Pulmonary Fibrosis and lung cancer.

Education and Support



3,554 health-related enquiries received via our Information and Support Centre.

802,800+ website visits providing information, resources and support for patients, carers and health professionals.

90% of lung cancer telephone support group participants reported a sense of reduced isolation.

> **88%** of people who engaged with our Respiratory Care Nurse service reported improvements in managing their condition.

2,310+ health professionals engaged via online and faceto-face training.



17,000+

Lung Health Checklist.

18,900+

\$1.1+ million

raised through donations, appeals, events, membership and sponsorship.

2,733 media articles with **261 million+** people reached.

3 national awards

received for our stigma and





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Lung Foundation Australia acknowledges the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

Lung Foundation Australia Impact Report 2019

30 years changing lives

In 2020, Lung Foundation Australia is celebrating an exciting milestone – three decades of service and commitment to people of all ages living with or impacted by lung disease and lung cancer.

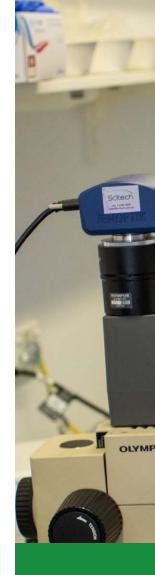
Since 1990, with your help, we have raised and invested over \$40 million in research that's changing the way we think about lung disease and lung cancer, accelerating advancements in the prevention, treatment and search for a cure. We have supported countless Australians, arming them with the confidence, skills and resources to navigate the health system and maximise opportunities in their treatment. We have championed change in lung disease and lung cancer policy, supported the inclusion of new treatments on the Pharmaceutical Benefits Scheme and recently led the development of Australia's first *National Strategic Action Plan for Lung Conditions*. Our evidence-based clinical training and internationally recognised guidelines continue to support the delivery of best-practice treatment and care for people living with lung disease.

Over the last three decades, Lung Foundation Australia has grown and evolved to become the leading trusted central source of information and support for lung disease and lung health in Australia.

This is all thanks to the ongoing support and generosity of our passionate and dedicated community.

Together we have made an undeniable impact on the future of lung disease and lung cancer. Particularly in recent years, advancement in treatments have seen an increase in survival rates and quality of life across a number of lung diseases – providing hope that has never existed before.

Now more than ever, we need to work together and build on the momentum we've created to drive real and lasting change. Change that will see all Australians impacted by lung disease and lung cancer receive the care, support and access to treatment they deserve. Change that will lower the number of people affected and increase survival rates. Change that will give hope for a cure. **This change starts with research.**







The gift of hope

The Lung Foundation Australia Diana Cox PhD Scholarship in Idiopathic Pulmonary Fibrosis (IPF) Research was founded in 2019 thanks to Diana's generosity. This award is supporting PhD student Doctor Laura Glenn (pictured) in her research to increase diagnostic accuracy in Interstitial Lung Diseases.

"It was an easy decision to make a gift to Lung Foundation Australia and it makes me feel, in a small way, as if I'm involved in IPF research and that I may see results of that research. It probably won't help me, but it will help other people in the future."

- Diana Cox, major donor, living with IPF.

The power of investing in research

Through her research project Novel diagnostic techniques in Interstitial Lung Disease (ILD), Doctor Laura Glenn is investigating previously unidentified or poorly understood pathobiologic pathways and biomarkers of ILD such as Idiopathic Pulmonary Fibrosis, which will have implications not only for diagnosis, but also for prognostication and treatment of ILD.

"I have seen first-hand the impact that current barriers to accurate and timely Interstitial Lung Disease diagnosis has on patients. I hope that my research will contribute to more easily accessible, accurate and safe diagnostic pathways for patients with ILD.

Your generosity is incredibly important in helping to understand lung disease and pathways that can be utilised to find better ways to help patients. In supporting early career researchers such as myself, you are directly contributing to the advancement of lung-focused research."

- Doctor Laura Glenn, recipient of the Lung Foundation Australia Diana Cox PhD Scholarship in Idiopathic Pulmonary Fibrosis Research.



Change starts with research.

Together we can change the future and give hope for a cure.

lungfoundation.com.au/donate



Australian Lung Foundation (now Lung Foundation Australia) established in partnership with the Thoracic Society of Australia and New Zealand (TSANZ).

- National research awards program launched. - Head office established in Brisbane by Dr Robert Edwards.

> o - Patient support program established including support groups and LungNet News (now called Inspired Living).

- LungBus introduced in New South Wales, screening people for lung disease and raising awareness about lung
- Multicentre Clinical Trials Network utilised for the first time in a respiratory clinical trial.

- National 1800 helpline established. - Specialist interest groups established, bringing together key clinicians across lung cancer, respiratory infectious diseases and Chronic Obstructive Pulmonary Disease (COPD).

> **ှ - COPD-X Guidelines first** published providing evidence-based recommendations for best-practice clinical

> > management.

Australasian Lung Cancer Clinical Trials Group (ALTG) established.

- Smoking bans rolled out

- **Kylie Johnston Lung Cancer** Network established (now the Lung Cancer Network).
- Television advertising for COPD awareness launched.
- **Respiratory Infectious Diseases** Case Statement published.
- COPD Patient Taskforce formed.
- Lung Cancer Awareness Month events launched.

- Economic Impact of COPD Report

launched.

o - Lungs in Action program established.

- **COPD** included in the Federal Government's Asthma Management Program legislation.
- Australia and **New Zealand Lung Cancer Nurses Forum** established.
- Lung Health Checklist launched.
- Lung Health Awareness Month launched.

Lung Foundation Australia Impact Report 2019

- Commemorative Tree Planting Day established.
- **Primary Care Respiratory Toolkit** launched.

 - o **Australia** becomes the first country in the world to enforce **plain** packaging for cigarettes.
 - Lung Cancer Telephone **Support Group** established.
 - Shine a Light on Lung Cancer vigils launched.
 - Show us Your Lungs awareness campaign launched.
- First primary care online **training** course launched.
- The Australian Lung Foundation becomes
- Lung Foundation Australia.
- First of its kind Australian Registry for patients with Idiopathic Pulmonary Fibrosis (IPF) launched.
- First **Interstitial Lung** Disease (ILD) Symposium held.
- First Australian Rare Lung Disease Short Course held.



- Australasian Interstitial Lung Disease Registry established.
- **Australian IPF Registry** linked **Biobank** established.
- Check in With Your Lungs awareness campaign launched.

- o Australian **Bronchiectasis Registry** established.
 - **Lung Cancer Nurse** telephone support service established.
 - Thoracic Alliance for Cancer Trials (TACT) established.
- First immunotherapy for lung cancer approved in the US.
- Annual COPD Exacerbations campaign launched.
- Inaugural ALTG **Lung Cancer Preceptorship** established.
- Australian Lung Tissue Biobank established.
- **World Conference** on Lung Cancer held in Sydney
- Inaugural ALTG **Lung Cancer** Symposium held.



- First ever Australia and New Zealand
- Pulmonary Rehabilitation Guidelines launched.
- **Pulmonary** Fibrosis Peer Connect service introduced.
- Young Lung **Cancer Telephone Support Group** introduced.
- Anti-fibrotic medications for IPF added to Pharmaceutical Benefits Scheme (PBS).
- Immuno-oncology therapy (nivolumab) added to the PBS.
- National stigma survey and awareness campaign launched for lung cancer.

- o Pulmonary Fibrosis Australasian Clinical Trials Network (PACT) established.
 - Making Lung Cancer a Fair Fight: A Blueprint for **Reform** report and stigma campaign launched.
 - Two Respirology Australian **Guidelines** for IPF and ILD supported and developed.
 - Home-based pulmonary rehabilitation program established in a rural setting.



- National lung cancer **screening** program enquiry announced.
 - Respiratory Care Nurse service established.
 - First National Strategic Action Plan for Lung Conditions endorsed by the Australian Government.
 - Bronchiectasis Action Plan developed.
 - First **Bronchiectasis** Stepwise Management Plan developed.
 - Four major lung cancer stigma campaigns launched.
 - Two national 2019 **PRIME Awards** received for our stigma campaigns.

Lung Foundation Australia is the only charity and leading peak body of its kind in Australia that funds life-changing research and delivers support services that give hope to those affected.

Since 1990, we have been working to ensure lung health is a priority for all, from promoting lung health and early diagnosis, advocating for policy change and research investment, raising awareness about the symptoms and prevalence of lung disease and championing equitable access to treatment and care.

Our Vision

Lung Foundation Australia enables life-saving lung health and lung cancer research, and champions programs so that Australians with lung disease and lung cancer can live their best life.

Our Mission

By 2030, Lung Foundation Australia will be recognised as one of the world's most innovative and effective lung health charities and a fearless leader of lung health and lung cancer policy, programs and research.

Our Values

BE FAIR

- **B** old | be proactive and take risks that achieve our Mission.
- **E ntrepreneurial** | be focused on outcomes.
- **F** air | be equitable and work in the interests of all our stakeholders, particularly patients and their carers.
- A gile | create positive change.
- **I nnovative** | be inventive to achieve our Mission.
- **R espectful** | be honest and work hard every day in every way we are funded by the community, they should expect nothing less.

Strategic Pillars

- Healthy lungs for all
- Australia's lung health research funding incubator
- Impactful and meaningful lung disease programs and support
- Valuing our people
- Purposeful leadership and ethical governance.

Priorities 2020-2025

Programs

Support patients and generate knowledge.

Drive evidence-based and scientifically rigorous policy and programs for chronic lung disease, rare lung disease and lung cancer.

Acknowledge the global and national importance of **climate change** and its impact on air quality and lung health and lung cancer.



Partnerships

Catalyse collaboration and close the gap.

Catalyse collaboration and consumer engagement in all programs and research to bring about lasting change and positive impact. Close the gap in lung disease and lung cancer which disproportionately affects First Nation Australians and commit to targeting our services to those in our community that need it the most.



Participation

Mobilise communities and shift the narrative.

Mobilise our communities so all Australians living with lung disease and lung cancer are afforded equitable, dignified and timely healthcare, and shifting the narrative so it is free from stigma.



Profile

Inform policy and influence funders.

Generate and share knowledge and inform lung and public health policy. **Influence funding** to change the gross disparity that exists in lung health and lung cancer research investment.



Productivity

Build capacity and sustain growth.

Raise, invest and ethically apply funds to advance our Mission.

Celebrate the passion and talents of our people and partners and the accountabilities placed on both staff and volunteers to be purposeful leaders.





On behalf of Lung Foundation Australia, we are delighted to present the 2019 Impact Report. This year has been transformative for Lung Foundation Australia as a considerable number of important, long-held strategic objectives were achieved.

The National Strategic Action Plan for Lung Conditions was released in February by The Hon. Greg Hunt MP, Minister for Health. The Federal Government accepted the 22 recommendations outlined in the plan and announced an initial investment of \$4 million to implement four of the recommendations.

We are pleased to announce that, at the time of writing, the first \$1 million grant has been awarded to Lung Foundation Australia.

Through government and community support, we will work towards funding the implementation of all report recommendations. We will continue to advocate on behalf of all people living with or impacted by lung disease and lung cancer and strive to secure funding for vital services and research.

Our role as the peak consumer body for lung disease and lung cancer in Australia continues to transform our strategy. Throughout the year, with the aid of consumers and health professionals, Lung Foundation Australia launched four major advocacy campaigns to address the stigma that surrounds lung cancer and negatively impacts on community empathy, investment in research and patient support. Whilst we do not seek accolades

for our work, we are pleased that our lung cancer stigma campaigns were awarded two prestigious PRIME Awards for *Best PR Campaign* and *Sustained Excellence in Bettering Patient Outcomes*.

The recommendations outlined in our Making Lung Cancer a Fair Fight: A Blueprint for Reform report will continue to be a priority, and with the support of our patient, industry and health professional partners, we will continue to advocate for a fair go for lung cancer. Our lung cancer stigma campaigns provided the foundation for our World Lung Cancer Day event at Parliament House where the enquiry by Cancer Australia into a national lung cancer screening program was announced. This is one of the most significant achievements in our history, built on the hard work of hundreds of patients and health professionals.

Consumers remain at the centre of all that we do and we have developed a meaningful Consumer Engagement Strategy to guide how the community can be involved in our work at all levels. Pleasingly, this approach has resulted in record numbers of people engaged in awareness and advocacy campaigns, community fundraising and in advisory committees. The committee structure was transformed and work in this area will continue into 2020.

Lung Foundation Australia is uniquely positioned to collaborate with patients and health professionals to achieve mutually beneficial goals. We thank the 320 health professionals who support our work, pro bono, on our advisory committees. Their inclusion of patients in a team approach was most evident at the Australasian Lung Cancer Trials Group (ATLG) Annual Scientific Meeting where patients were key participants and welcomed by all clinicians and researchers in lung cancer care. We commend the organising committee and the ALTG for their innovation and leadership in this regard. Similarly, the Australian Rare Lung Disease Short Course, delivered in a partnership with the Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) and the Thoracic Society of Australia and New Zealand (TSANZ), embraced patient centricity.

We are delighted to report that both major events doubled participation on prior years and received overwhelmingly positive feedback. We look forward to working more with ALTG and the CRE-PF into the future to attract greater community and government investment so that their respective research agendas can flourish even more.

In 2019, Lung Foundation Australia began to be noticed as a leading body and a trusted source of information.

Collectively throughout the year, our community awareness campaigns for lung health, lung disease and lung cancer achieved over 200 million media impressions and our Pneumonia Awareness Week campaign won the Public Relations Institute of Australia's Community Relations

Campaign Award. The team revamped our 1800 lung health service and immediately saw enhanced quality of life for people with lung disease and lung cancer and the continuing evaluation of this service's outcomes remains a priority. We are left without any doubt that our Consumer Engagement Strategy, coupled with our increasing profile and stronger advocacy voice contributed to the substantial growth in community support and fundraising efforts.

We sincerely thank the tireless volunteers, community advocates, research participants, fundraisers and supporters for all your hard work and we hope that in reading this Impact Report you can see the fruits of your labour. We are proud of you and equally, we hope that you are proud of Lung Foundation Australia.

The growth in community fundraising can also be attributed to the Board's strategy to invest in our fundraising capabilities. The 2019 Hope in Every Breath Gala Ball was the most successful to-date, doubling previous attendance and our investment in lung cancer research. Again, the power of our Vision and the research partnerships to which we commit were proudly on display.

We acknowledge the continuing support from the Queensland Department of Health who confirmed a further five years of funding \$1.5 million, and the Australian Government Department of Health who have confirmed four years of support funding \$1 million. This funding is a good starting point to launch our 2030 Vision and we encourage

other State and Territory Health Departments and Ministers to also increase funding to further extend our reach.

Our investment in research topped \$5.29 million this year and we continue to press the Australian and State and Territory Governments to address the disproportionate level of investment in lung disease and lung cancer research. The inequitable level of funding will continue to be an issue for which we advocate until policy makers proportionately fund the health, social and financial burden of lung disease and lung cancer.

The emergence of accelerated silicosis and dust diseases more generally, together with the fact that lung cancer and Chronic Obstructive Pulmonary Disease remain two of the top five causes of death in Australia highlights the need for a dedicated Medical Research Future Fund Lung Health Research Mission, akin to what our cardiovascular research colleagues have achieved. This will be a major campaign focus in the years ahead.

We also acknowledge the tremendous strength and resilience of Lung Foundation Australia's staff. During 2019, a comprehensive corporate restructure was completed to ready the organisation for our 2030 Strategy. Any restructure is toughest on people working in the organisation and their dedication and hard work does not go unnoticed. The restructure allowed us to open offices in Sydney and Melbourne.

In 2020, Lung Foundation Australia will celebrate its 30th anniversary. We acknowledge those past and present Board, committee members, volunteers, and supporters. Your hard work and commitment have paved the way for present day success and are fondly remembered and appreciated.

Throughout 2020, we will celebrate our community, be transparent about the challenges that lie ahead and deliver a bold new vision for Lung Foundation Australia and lung health. In launching our 2030 Vision at this Annual General Meeting, we will aim to increase our research investment to \$50 million and importantly deliver change for the better for all Australians impacted by lung disease and lung cancer.

You can be proud of Lung Foundation Australia as a progressive charity that is both impactful and ready to embrace change into the future. There is Hope in Every Breath.

Professor Christine Jenkins AM Chairperson

Chustingen

Mark Brooke
Chief Executive Officer



At just 21 years of age, Cobey was diagnosed with a rare and incurable lung disease - Pulmonary Arterial Hypertension (PAH).

"I went from being a very active individual to not being able to walk my dog because of shortness of breath. I would fall asleep at 7pm because of fatigue. When I saw the GP for my racing heart, they diagnosed me with anxiety, but I wasn't sent for any tests despite my shortness of breath.

In July 2018 at an annual check-up I was told that the right side of my heart had doubled in size since 2017 and my pulmonary pressures had gone from normal to high. I spent five days in the hospital undergoing tests which led to the diagnosis of Idiopathic PAH.

I was totally devastated when I was diagnosed. It turned my life upside down. At 21, you don't expect to be told you have a life-threatening disease with no cure. Not when you think you have the rest of your life ahead of you. Every day is a mental and physical battle, but I refuse to let it beat me."

Since the diagnosis, Cobey's condition has forced her to reconsider her future plans, like starting a family. She knows at some point the medication she is on may stop working. Thankfully, Cobey has other options through further medication, however at some point a lung transplant will be a likely necessity.

"Since I've been diagnosed and put on medication, my life has improved. Medical advances have come a long way and I'm hopeful of what the future holds with more research.

It is my hope that more medications for PAH will be covered by the Pharmaceutical Benefits Scheme so that people don't have to stress about compassionate access to their second or third medications, and we need to see more funding for research to help find a cure."

- Cobey, lives with Idiopathic PAH.





Anyone can get lung disease.

There are currently almost 7 million Australians impacted by lung disease, yet it receives little research funding and support. Together with the support of the community, government, health professionals and industry, we are working to change these statistics.

Overview

- Almost 1 in 3 Australians has a lung disease.1
- Lung disease, including chronic respiratory conditions and thoracic cancers, is Australia's second leading cause of death.²
- Lung disease accounts for 10% of the total health burden in Australia.3
- Despite its heavy impact, lung disease and lung cancer receive very little research funding.

Chronic Obstructive Pulmonary Disease (COPD)

- 1 in 7 Australians over the age of 40 has COPD.4
- COPD is the leading cause of preventable hospital admissions.5

Lung Cancer

- In 2019, it is estimated that 12,817 Australians were diagnosed with lung cancer. That's 35 people a day.⁶
- Lung cancer is our nation's biggest cancer killer 25 Australians die each day.⁷
- The economic burden of lung cancer for patients diagnosed is estimated at \$297.2 million.8
- Lung cancer has one of the lowest survival rates of any cancer in Australia, with just 17% of people alive five years after their diagnosis.⁹
- 1 in 5 people living with lung cancer are life-long non-smokers.¹⁰

Idiopathic Pulmonary Fibrosis (IPF)

- The cause of IPF is unknown, hence the term 'idiopathic'.
- The current survival rate of IPF is as low as some of the most devastating cancers.
- While it's 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 Arterial Hypertension (PAH)

- PAH is a chronic condition that is caused by the narrowing or blockage of the blood vessels that carry blood to the heart.
- Early diagnosis is essential to ensure timely treatment that can improve symptoms and quality of life, yet on average it takes up to five GP visits before a specialist referral is given.¹¹
- Diagnosis for PAH is delayed on average 3.9 years.¹²

Bronchiectasis

- Bronchiectasis is a common lung disease caused by chronic infection that damages the lungs.¹³
- The prevalence of bronchiectasis continues to increase worldwide and the Australian Indigenous population are more frequently affected.¹⁴
- To date, little research has been undertaken to improve self-management in bronchiectasis in comparison to other chronic conditions.¹⁵

Rare Lung Disease in Children

- There is currently very limited information, support, treatment and research available for children diagnosed with rare lung disease in Australia.





"Lung cancer patients need the same investment in research and access to treatment and support as any other cancer. Seeing the positive changes being made through Lung Foundation Australia's advocacy and awareness initiatives, and supporting these in any way I can, gives me hope for the future."

- Michel, lives with lung cancer.



The conversation is changing

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

A 2019 survey revealed the number of people who would first ask if someone recently diagnosed with lung cancer was a smoker has fallen from 40% to 27% - a sizeable reduction in perception from just two years of strong campaigning from Lung Foundation Australia. We will continue campaigning until the conversation has shifted completely for lung cancer and lung disease.

2020 OBJECTIVE The go-to resource for lung health and lung disease.
A valued hub for all

2020 TARGETS

15% of those diagnosed with lung diseases 'are actively engaged' with Lung Foundation Australia.

8%



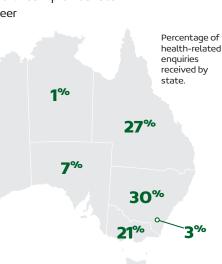
Achieved, on target and continuing as a priority.

stakeholders.

Partially achieved and strengthening.

Supporting consumers through every step of their journey.

Lung Foundation Australia's Information and Support Team provide faceto-face education, 1800 telehealth services and peer support programs that build the skills, confidence and capacity of consumers nationally, to manage their condition and navigate the often-challenging health system. Our team equips consumers with the knowledge and expertise to work with health professionals and make informed decisions about personal treatment and care, leading to better health



Respiratory Care Nurse

outcomes and quality of life.

Our Respiratory Care Nurse provides telephone-based information 3% and support for those living with Chronic Obstructive Pulmonary Disease (COPD) and bronchiectasis. The Respiratory Care Nurse interacts with participants across a four-month period, providing personal care, management, disease information and practical suggestions. There are currently 123 COPD and 26 bronchiectasis patients supported through this service. Current data from the COPD participants shows improvement in the uptake of key health indicators including:

Key health care indicator	At initial interaction with nurse	At final interaction with nurse
Action Plan ownership	22%	48%
Delivery device technique check	34%	72%
Referral to Pulmonary Rehabilitation	44%	77%
Current pneumonia vaccination	60%	88%

This service was made possible through fundraising by Bill Van Nierop, community fundraising and philanthropic grants.

"I found the service was just great, amazing. Felt more safe and secure having someone to talk to."

- Hazel, COPD patient.

Lung Foundation Australia's Respiratory Care Nurse.





Lung Cancer Nurse

Our Lung Cancer Support Nurse provides a telephone-based information and support service to those living with lung cancer, as well as their families and carers. The service expanded in 2019 to offer nurse-initiated calls to help address unmet supportive care needs. Early data from this service demonstrates improvement in patient confidence in using strategies to cope with their cancer.

"You were really the only one I could pour out my problems to.
You understood how I felt and you were my greatest support through a horrible time."

- Maxine, lung cancer patient.

Supporting consumer wellbeing

Lung Foundation Australia continued to facilitate regular telephone support groups for lung cancer and supported face-to-face support groups for people living with lung disease and lung cancer, their carers and families. These groups connected consumers to others facing similar situations, providing a safe, open environment for discussions about day-to-day challenges and experiences.

90% of lung cancer telephone support group participants reported a sense of connection, reduced isolation and felt they were provided a safe environment to express themselves.

Peer Connect, our one-on-one peer matching program for Pulmonary Fibrosis and Idiopathic Pulmonary Fibrosis connected people across the country to share experiences and knowledge through telephone interactions.

"I have found Peer Connect a great way to connect with someone in a similar situation to me which has helped me cope with my health condition. It's great to speak with someone who understands what I'm going through."

- Peter, Pulmonary Fibrosis Peer Connect participant.



Enhancing consumer partnerships

Lung Foundation Australia is committed to enhancing our partnerships with consumers, carers and families to ensure they are at the heart of everything we do. In 2019, a Consumer Engagement Strategy was developed to give consumers an active role in the planning, implementation and improvement of our services.

In developing the strategy, consumers were engaged to gain insight into their needs and the strengths, risks, and opportunities they face. Results demonstrated that consumers are seeking quality information, treatment updates, advocacy and awareness from Lung Foundation Australia. Long and short-term goals were developed with our consumer groups across our key work areas. The Consumer Engagement Strategy will form part of our new ten-year corporate strategy launching in 2020.

Empowering consumers with information

Lung Foundation Australia hosted a series of webinars providing the latest information and advice on Pulmonary Fibrosis and Pulmonary Arterial Hypertension to over 340 patients, carers and health professionals. A survey of webinar participants showed 89% of respondents felt they gained knowledge about managing their condition and 72% felt more confident to discuss topics with their healthcare team.

A series of education seminars was also delivered across Australia by clinical and consumer experts. These seminars provided practical tips and advice to support almost 400 consumers on their journey and help them live their best life.

Improving quality of life - Lungs in Action

Lungs in Action is a safe and enjoyable community-based exercise maintenance program empowering people with a lung disease to improve their quality of life. There are now 94 Lungs in Action locations across Australia running collectively almost 160 classes each week. This program equips participants with the skills and knowledge to keep up their physical fitness and maintain improvements gained through pulmonary rehabilitation.



2020 OBJECTIVE

The Hon. Greg Hunt MP, Minister for Health at the launch of the National Strategic Action Plan for Lung Conditions.

A leading advocate for lung health.

2020 TARGETS

Government increases the relative priority it places on lung disease.

PROGRESS

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

Campaigning for a brighter future.

National Strategic Action Plan

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.

In February, the Australian Government adopted our *National Strategic Action Plan for Lung Conditions* (NSAPLC), providing the nation's first roadmap of tangible and practical actions that will make a difference to the lives of millions of Australians affected by lung disease. This significant endorsement of our policies and priorities was backed with an initial investment of \$4 million to implement four priority recommendations. Lung Foundation Australia was awarded \$1 million to address stigma, discrimination and social isolation associated with lung conditions, increase symptom awareness and develop tools and support services to help people impacted by lung disease. We will monitor implementation of the NSAPLC and advocate for timely action to achieve lasting outcomes for our community.

Priorities at a glance

Within the Action Plan each priority, outlined below, has a number of recommended actions informed by evidence. To read the full Action Plan visit lungfoundation.com.au.

- 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.
- Ensure equitable and timely access to evidence-based diagnosis and management.
- Increase research capacity to redress under-resourcing of research into highly prevalent lung conditions.

"Lung conditions affect everyday Australians, and in sizeable numbers - yet, historically, they have attracted only a fraction of the funding needed to address prevention, gaps in care, equitable access to treatment and vital research dollars. It is my hope that implementation of this Plan will help to redress the current inequity in the care and management of those living with a lung disease. Facts can change. Let this Action Plan be a catalyst for that change."

 Professor Christine Jenkins AM, Chairperson of Lung Foundation Australia.



Improving lung health for all

Occupational lung disease

In May 2019, a National Dust Disease Taskforce was established by the Australian Government to lead a national approach to the prevention, early identification, control and management of occupational dust diseases in Australia. The Government committed \$5 million to support the work of the Taskforce, including funding for new research to better understand, prevent and treat occupational lung diseases.

Lung Foundation Australia was pleased to see our recommendations echoed by the Taskforce in their list of recommendations, which included:

- 1. Developing a targeted education and communication campaign to raise awareness of the risks of working with engineered stone.
- 2. Ongoing staged development of a national dust diseases registry, with specific data requirements recommended by the Taskforce.
- 3. Targeted investment in key research activities, to improve understanding of prevention, diagnosis and treatment.
- 4. Developing national guidance on screening workers working with engineered stone.
- 5. Development of a national approach to identify occupational silica dust exposure and other future occupational lung diseases.

In early 2020, the Australian Government accepted all five recommendations from the interim advice of the National Dust Disease Taskforce. Lung Foundation Australia will continue conversations with all levels of government to ensure the recommendations are implemented.

Tobacco products

As the Australian Government commenced a review of its National Tobacco Strategy, Lung Foundation Australia engaged with existing and new partners to strengthen Australian policy and regulatory settings for nicotine and non-nicotine flavoured products. This engagement has set the foundation for further advocacy efforts in 2020 aimed at increasing regulation of vaping products, opposing the introduction of new tobacco products in Australia and maintaining existing measures on smoking products and activities. We demonstrated our commitment to a nicotine-free generation by supporting a private member's bill in Tasmania to increase the age to purchase tobacco products to 21.

Clean air

In partnership with key environmental and health agencies, Lung Foundation Australia called on governments to implement stronger and better ambient air quality standards. Setting lower allowable levels of pollutants - such as ozone, nitrogen dioxide and sulfur dioxide - in the air will minimise the risk of adverse health impacts on individuals and protect the natural environment. This advocacy will continue in 2020 and include measures to address concerns arising from the 2019/2020 summer bushfires.

Access to treatment and management

Pharmaceutical Benefits Scheme (PBS)

A record number of new medicines, and dual use approvals, for use with lung conditions were listed on the PBS during 2019. This is a direct result of 42 Lung Foundation Australia led submissions and numerous individual submissions from the lung health community. These listings enable equitable access to much needed treatment for thousands of Australians living with lung disease and lung cancer.

Medicare Benefits Scheme (MBS)

Unfortunately, Lung Foundation Australia's submission to the Medical Services Advisory Committee (MSAC) for subsidised pulmonary rehabilitation services was unsuccessful. We will continue to advocate for a pulmonary rehabilitation MBS item number for people with chronic lung disease.

treatment and care for people living with lung cancer.

Campaign to the public

Strategy: Launched Fair Go for Lung Cancer campaign (February 2019).

• 11 loved ones of Australians living with lung cancer shared their story to call out and quell the stigma that continues to shroud the disease.

Partner with lung cancer health professionals

Strategy: Launched FFS! We're Losing Our Patients campaign (March 2019).

• Eight clinicians stood up for lung cancer by saying 'enough is enough' to stigma. The campaign called for funding of an additional 25 lung cancer specialist nurses.

Take the patient voice to **Parliament**

Strategy: Rallied patients to campaign directly to government on World Lung Cancer Day (August 2019).

• 12 Australians living with lung cancer shared their personal stories to call on the Federal Government to act on the gaps in treatment. care and empathy.

Empower the community voice

Strategy: Mobilised our consumer and clinical community through a grassroots advocacy campaign.

• Facilitated training to upskill patients and health professionals to engage with Members of Parliament and policy makers.

Champion for equity

Strategy: Launched Walk In My Shoes campaign and National Lung Cancer Scorecard (November 2019)

- First-of-its-kind short film, aired online and in cinemas across Australia, depicting the reality of a lung cancer diagnosis.
- Scorecard exposed disparity in research, treatment and support for lung cancer against other commonly diagnosed cancers.

Outcomes

- Federal Government committed \$1 million per year in response.
- 30+ million media and social media impressions.

Outcomes

- Australian Labor Party committed \$15 million to fund 20 new lung cancer **nurses**, if the party was successful at the Federal Election in May 2019.
- 21+ million media and social media impressions.

Outcomes

- Minister for Health announced the first enquiry into a national lung cancer screening program.
- 20.9+ million media and social media impressions.

Outcomes

- **50 people** trained as professional advocates.
- 76 meetings held between advocates and Members of Parliament and Senators.
- Advocates supported our 2020/2021 Federal **Budget Submission** for 100 specialist lung cancer nurses.

Outcomes

- \$5 million in Medical Research Future Fund funding announced for ground-breaking genomic profiling study.
- 24.4+ million media and social media impressions.

The conversation around lung cancer is changing.

In 2019, a National survey revealed the number of people who would first ask if someone recently diagnosed with lung cancer was a smoker had fallen from 40% to 27% - a sizeable reduction in perception in just two years of strong campaigning.



Driving trends and direction of research.



Lung Foundation
Australia's annual support
for research is \$5 million
per annum.



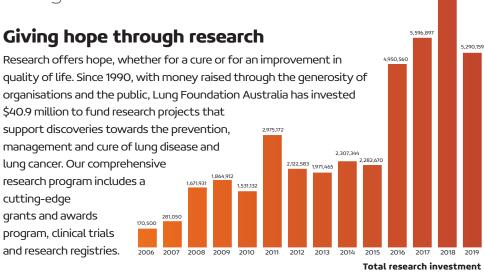
Achieved, tracking ahead of target.

A valued hub for all stakeholders.

Strong collaboration with Thoracic Society of Australia and New Zealand. On target and continuing high priority.

6,928,413

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



Ms Tylah Miles working to discover potential novel therapeutic targets for IPF.

Grants and Awards Program

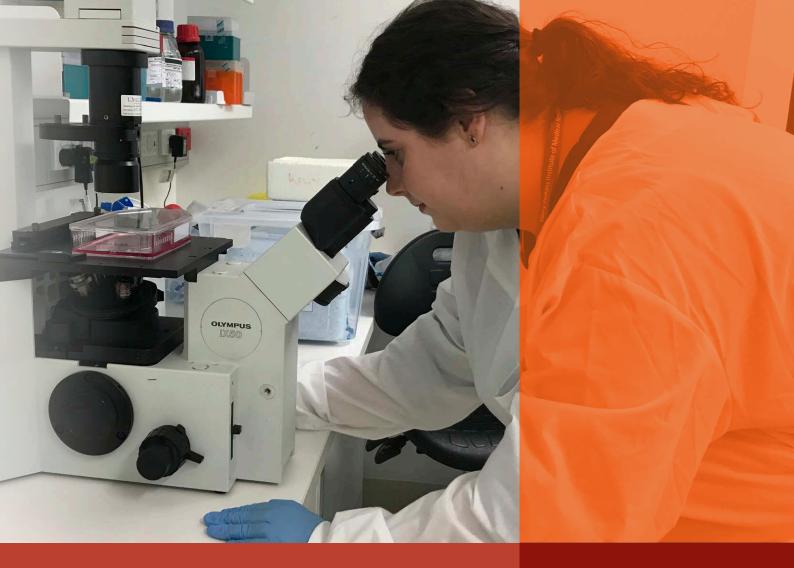
Collaborating to find a cure

In collaboration with the Thoracic Society of Australia and New Zealand, Lung Foundation Australia funds cutting-edge research projects through a competitive, peer-reviewed awards and grants program. The program funds early- and mid-career researchers and senior leaders in research who have the potential to make significant advances in the field of lung disease and lung cancer research. It provides opportunities for researchers to further develop their skills and become champions in their fields.

Opportunities include fellowships and PhD scholarships, project grants and grants-in-aid, as well as travel grants which allow researchers to collaborate and showcase their work nationally and internationally. In 2019, over \$430,000 was raised and invested into this program, funding 22 research projects dedicated to making advancements in the prevention, early diagnosis, treatment and potential cures for lung disease and lung cancer.

2019 Award Winners

Congratulations to the 2019 Research Award recipients. To find out who was awarded, please refer to the Lung Foundation Australia Research Impact Report 2019 or visit **lungfoundation.com.au.**



Understanding lung disease through registries

Australian Bronchiectasis Registry

Lung Foundation Australia's Australian Bronchiectasis Registry provides a critical source of rich patient data to facilitate national and international research, improve clinical management practices and maximise opportunities for patients to participate in clinical trials. Through the registry, we collaborate closely with key European and North American researchers to build on the existing evidence base and explore novel treatments through state-of-the-art methodology. In 2019, registry participation continued to grow with over 1,380 adult and paediatric patients across 27 sites.

Australian Idiopathic Pulmonary Fibrosis (IPF) Registry

Our Australian IPF Registry is a unique research platform that collects information on more than 845 patients living with IPF to better understand this rare and complex disease. The registry provides a central source of rich data used in both national and international studies to better understand the incidence and prevalence of IPF, and search for advancements in diagnosis and treatment.

The Australasian Interstitial Lung Disease (ILD) Registry

Supported by Lung Foundation Australia, the Australasian ILD Registry provides a comprehensive secure platform to facilitate prospective data collection of clinical and demographic information of ILD patients. Established in 2016 in its first phase, the registry is a central source of rich data, that guides clinical practice, underpins standardisation of care, and supports research collaboration both in Australia and internationally. There are currently 1,352 patients entered in the ILD registry with prospective data captured across 13 different ILD diagnoses.

For more information about our Research Program and 2019 highlights, please refer to the Lung Foundation Australia Research Impact Report 2019 or visit lungfoundation.com.au.

"I dream of a world where there is equity in the way medical research is prioritised, where the journey is eased through new processes and support, where new discoveries and breakthroughs give people like me more valuable time with our loved ones.

With a huge number of Australians impacted, we desperately need to increase funding into lung disease. I am not giving up. If you are truly passionate about something, you can achieve the extraordinary."

- Bill Van Nierop, living with Idiopathic Pulmonary Fibrosis. Through Bill's incredible fundraising efforts the Lung Foundation Australia/Bill Van Nierop PhD Scholarship in Idiopathic Pulmonary Fibrosis Research award was established and is currently supporting Tylah Miles (pictured) to undertake research into the immune regulation of IPF.



Australasian Lung Cancer Trials Group (ALTG)

Lung Foundation Australia is pleased to partner with ALTG to drive better outcomes for people living with lung cancer through clinical trials.

In 2019, the ALTG celebrated its 15th year. Since its inception, membership has grown from 70 founding members to over 850, representing the full range of professional disciplines involved in caring for patients with lung cancer and mesothelioma, clinical trial professionals and consumer representatives.

The ALTG unites leading lung cancer experts in the design, development and conduct of clinical trials. Concepts are presented to ALTG members to gain feedback on their relevance, importance and practicality. In 2019, nine clinical trial concepts were reviewed. These trials encompass recent advances in lung cancer research and ultimately aim to determine the best care for patients.

2019 Highlights

Slowing treatment resistance: In some lung cancers, a mutation in the cells drives cancer growth. The discovery of these 'driver mutations' has led to the development of drugs that specifically target the mutation and limit cancer growth. Targeted therapies are one of the recent advances that have enabled better treatment for advanced lung cancer. Sadly, some lung cancers will eventually become resistant to the targeted therapy. In 2019, the ALKTERNATE clinical trial opened to investigate the effectiveness of alternating targeted therapy treatments. The study alternates a newer drug, lorlatinib, and an established drug, crizotinib. It is hoped that alternating drug cycles will delay emergence of resistance to the drugs.

Harnessing the body's immune system: Many cancers have developed effective ways to 'hide' or put the 'brakes' on the body's natural immune system that would normally eliminate some of the cancerous cells. In 2019, ALTG opened the clinical trial ILLUMINATE, offering immunotherapies that both release these 'brakes' and help in making cancerous cells visible to the body's own immune system. The immunotherapies are given together with chemotherapy, currently the best-known treatment for these patients. Patients will be recruited from 10 hospitals in Australia and the trial will run simultaneously in Taiwan and China as part of ALTG's international collaboration. This clinical trial offers hope for patients where earlier treatment is no longer effective.

"There's a really strong buzz around the group with new drug developments in targeted therapy and immunotherapy, making it an exciting time to be involved. There continues to be such a large unmet need in lung cancer and the group attracts like-minded people, determined to change outcomes for the better."

 Associate Professor Nick Pavlakis, ALTG President.

For more ALTG highlights in 2019, please refer to the Lung Foundation Australia Research Impact Report 2019 or visit lungfoundation.com.au.



Pulmonary Fibrosis Australasian Clinical Trials Network (PACT)

PACT unites dedicated and passionate leading clinicians and researchers to search for cutting-edge treatments that will improve quality of life and outcomes for people living with Pulmonary Fibrosis (PF). Together, these experts design and deliver high quality clinical trials and studies.

Proudly supported by Lung Foundation Australia, the development of PACT was a key objective of the Centre of Research Excellence in Pulmonary Fibrosis to increase engagement and involvement of patients in their research decision-making. In 2019, PACT processed more than 60 patient enquiries. Thanks to the incredible work happening through initiatives like PACT, the outlook for PF is changing.

2019 Highlights

COLDICE study for Interstitial Lung Disease (ILD): Often patients with ILD, an umbrella term for a group of lung diseases including PF, are too unwell to undergo a surgical biopsy so their diagnosis remains uncertain, impacting on treatment decisions and outcomes. A safer, reliable way to make a diagnosis is needed. The COLDICE trial is investigating the accuracy and reliability of taking small samples of lung tissue through the airways against traditional surgical lung biopsy for ILD diagnosis. Preliminary results show that in ILD patients, this alternative method was consistent with more invasive surgical processes.

PFOX study for PF: People with PF often have low oxygen levels during exercise, however there are no studies to show whether 'correcting' this makes people feel and function better. The PFOX trial is investigating whether portable oxygen concentrators can help people with PF to be more active in daily life and reduce symptoms such as breathlessness and fatigue. Physiotherapist and lead researcher Professor Anne Holland, together with a team of experts, conducted smaller studies to gather convincing data around patient needs and the potential of oxygen therapy. This data supported funding applications for the PFOX trial, and the team were fortunate to receive National Health and Medical Research Council funding in 2018. It is hoped the trial will provide a clear answer on the benefits and the costs of portable oxygen concentrators for people living with PF.

"I think we can make big inroads into not only survival but quality of life which will make a huge difference for patients and of course their families and carers."

- Professor Dan Chambers, Chair of PACT.

For more PACT highlights in 2019, please refer to the Lung Foundation Australia Research Impact Report 2019 or visit lungfoundation.com.au.



Guided by evidence and best-practice.



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



Partially achieved, on target and continuing as a priority.

A successful collaborator.

Achieved, strengthening and continuing as a priority.

Working with health services and clinicians to build workforce capacity and deliver best-practice care to patients living with lung disease.

Capacity building

Lung Foundation Australia facilitates a range of active learning programs to upskill health professionals including conferences, workshops, face-to-face and online training.

In 2019, a new case-based online training module was launched called "Does Curt Have Bronchiectasis?". The training develops clinical skills in identifying and managing bronchiectasis in primary care. Preliminary feedback of the module demonstrates an 86% increase in participant confidence in identifying patients at risk of bronchiectasis.

Our face-to-face training program for Chronic Obstructive Pulmonary Disease (COPD) trained over 780 primary health care and allied health professionals in inhaler device techniques and managing exacerbations in primary care. This training is based upon the evidence within the COPD-X Guidelines to upskill trainees in identifying, diagnosing and correctly managing patients with COPD.

In addition, our online training courses were completed more than 520 times. These courses utilise the latest evidence-based information to upskill nurses, pharmacists and exercise professionals.

Australian Rare Lung Disease Short Course

The Australian Rare Lung Disease Short Course provided 290 researchers, clinicians and consumers access to the most up-to-date advances in the treatment and management of rare lung diseases. Through the Identifying Research Priorities for Pulmonary Fibrosis Workshop, an innovation in the 2019 program, consumers provided unique and invaluable insights that will be fundamental to quiding the direction of future research.







Murray PHN Project

For over 18 months we have partnered with the Murray PHN to improve clinical care for people living with Chronic Obstructive Pulmonary Disease (COPD) in the region. The outcomes for 2019 include:

- Equipped approximately 300 GPs with the COPD Action Plan, resulting in an estimated prevention of five hospitalisations and \$29,000 in health care costs.
- Trained 673 health professionals, resulting in an increase in workforce capacity for spirometry, motivational interviewing and Lungs in Action exercise programs.
- Establishment of home-based pulmonary rehabilitation programs and three Lungs in Action programs.
 Patients who participated in the programs reported significant improvements in exercise capacity and quality of life.

Nurse network

Established by Lung Foundation
Australia, the Australia and New Zealand
Lung Cancer Nurses Forum (ANZ-LCNF)
is a group of passionate nurses with a
common focus on improving the care
and outcomes for patients. In 2019,
the ANZ-LCNF played a critical role in
our lung cancer stigma and advocacy
campaigns, which focused on rallying
government funding for specialist lung
cancer nurses.

Evidence-based guidelines

Lung Foundation Australia manages two internationally recognised guidelines that were developed in partnership with the Thoracic Society of Australia and New Zealand:

- The COPD-X Plan Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease
- The Australian and New Zealand Pulmonary Rehabilitation Guidelines.

In 2019, these guidelines continued to deliver world-class and evidence-based recommendations to support almost 10,000 health professionals in the clinical management of their patients. The COPD-X Guidelines were ranked second highest in a review of 10 Australian guidelines which examined the strength of evidence used in the development of recommendations.

Partnerships

Lung Foundation Australia is proud to partner with state respiratory networks, Primary Health Networks (PHNs) and peak body organisations to deliver evidence-based training and quality improvement support to health professionals working in the field of lung health. Our current and new projects have delivered meaningful outcomes in 2019 with several initiatives now in their second phase of delivery.

Adelaide Respiratory Health Project

This project was delivered in collaboration with Asthma Australia and Adelaide PHN, to address the high rates of avoidable asthma and COPD hospitalisation. Outcomes include an increase in device technique checks, labelling of primary containers, priming inhalers before dispensing and improved confidence performing spirometry.

North Coast PHN Pulmonary Rehabilitation Project

Through this first-time partnership with North Coast PHN and Entag (The Diary), Lung Foundation Australia co-designed and delivered a bespoke pulmonary rehabilitation training program to meet the specific needs of the local health service environment. This project, which will conclude in June 2020, is building workforce capacity and increasing access to pulmonary rehabilitation services as part of a larger, multi-year project.



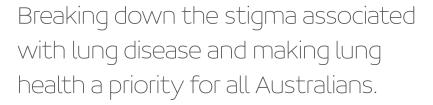
Driving trends and direction of research.



Lung Foundation Australia's annual support for research is \$5 million per annum.



Achieved, tracking ahead of target.



Lung Health Awareness Month

During Lung Health Awareness Month in May, Lung Foundation Australia's campaign *Know, Plan, Act* encouraged the community to identify the signs and symptoms of lung disease, visit their doctor and be proactive about their lung health, especially during the winter season. Throughout the campaign, 4,285 people completed our online Lung Health Checklist. During the month, our annual Pneumonia Awareness Week campaign was released, encouraging those most at risk of pneumonia infection to protect themselves through vaccination. The campaign was mentioned in 678 media pieces, reaching 40 million+ people. This success resulted in the campaign receiving a Public Relations Institute of Australia (PRIA) Award for *Best Community Relations Campaign*.

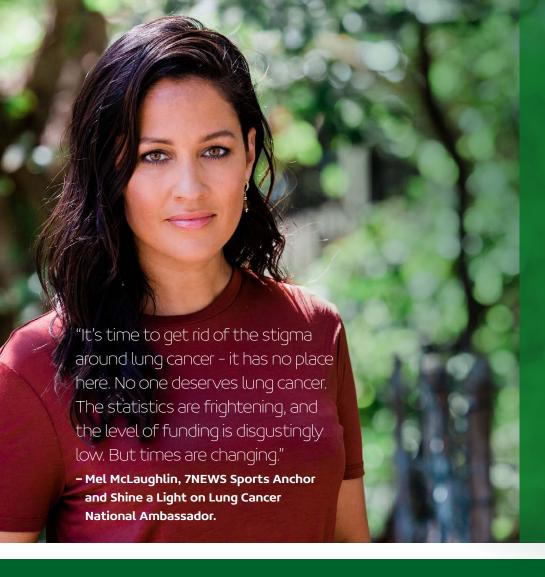
Stigma campaigns

The stigma that surrounds lung cancer and lung disease acts as a roadblock to research, treatment and care. In 2019, Lung Foundation Australia released a suite of stigma campaigns to change the conversation around lung cancer and champion equitable funding and care. The campaigns played a pivotal role in the announcement of the government's enquiry into the nation's first lung cancer screening program. The campaigns also laid the foundation to support continued conversations with key decision makers regarding equitable access to care and helped raise awareness, collectively reaching more than 96.3 million people. Three of our stigma campaigns were recognised in the 2019 PRIME Awards for *Sustained Excellence in Bettering Patient Outcomes* and *Best PR Campaign*. For more information, please refer to the Advocacy section of this report.

National health campaigns

Our suite of national lung disease awareness campaigns, including Pulmonary Fibrosis Awareness Month, Pulmonary Hypertension Awareness Month and World COPD Day, educated the community on the signs and symptoms associated with lung disease and the importance of early detection. The campaigns linked over 13,000 people to information and support via our website, encouraged connection to our free educational webinars, Peer Connect support services, face-to-face support groups, education seminars and online resources.





Shine a Light on Lung Cancer

Every year, our Shine a Light on Lung Cancer campaign brings together a community of patients, their family and friends, health professionals and researchers as one voice to raise funds for lifechanging research and support services. 2019 was a record year for the campaign, with over 55 community fundraisers banding together with us to raise over \$360,000, including the funds raised through our annual gala ball. In addition, Lung Foundation Australia was pleased to welcome 7NEWS Sports Anchor Mel McLaughlin, who lost her sister to lung cancer in 2015, as a National Ambassador for the campaign.

Community Champions

Our community of supporters and fundraisers are a critical and valued part of our community, and we thank everyone who supported us throughout the year, no matter how big or small. Your donation and support are helping to change the future for people living with lung disease and lung cancer.

In 2019, 134 community supporters raised over \$189,000 for research, advocacy and support services.

Snapshot of supporter highlights

Sandy Sampson, John Porter & Tamara Lindsay

\$53,600+ raised for lung cancer research and support.

Sandy and John, who live with lung cancer, and Tamara, hosted a high tea fundraiser.

Matthew Britton

\$48,000+ raised for a lung bus to encourage earlier detection of lung disease. Matthew coordinated and participated in the annual Trail to Triumph 250-kilometre ultra-marathon in memory of his father, Tony.

Peter Hewett

\$29,000+ raised for lung cancer research and support.

Peter and three of his mates completed the inaugural Vapor Trail - cycling 3,200 kilometres across Japan.

Carolyn Riordan

\$21,500+ raised for lung cancer research and support.

Carolyn, who lives with lung cancer, trekked the 1,000km Bibbulmun Track in Western Australia.

Evangeline Lim

\$8,000+ raised for lung cancer research and support.

Evangeline, who lives with lung cancer, hosted a gala charity dinner.

Wayne Declase

\$7,000+ raised for lung cancer research and support.
Wayne created a tribute film 'Goodnight Sweetheart' to honour his late sister Cassy.

Russell Winwood

\$7,000+ raised to support pulmonary rehabilitation programs.

Russell, who lives with Chronic

Obstructive Pulmonary Disease,
competed in the Cairns Ironman with
just 30% lung capacity.

Denise Clarke

\$2,300+ raised for lung disease research.

Denise, who lives with asthma and bronchiectasis, swam 50-kilometres across the English Channel.





PROGRESS

Annual community fundraising revenue growth.

\$1.5 million per annum.

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

Thanks to our supporters. Every gift is greatly appreciated.

Thank you to everyone who supported Lung Foundation Australia in 2019. Our mission to improve the lives of all Australians living with lung disease and lung cancer would not be possible without you. We acknowledge the following individuals and organisations for their contribution this year.

Government funding

- Cancer Australia
- Queensland Health
- Murray PHN
- North Coast PHN
- · Department of Health
- Adelaide PHN

Estates

- Susie Bradshaw Whitington
- Maurice Coomber
- Isabelle Mary Fabris
- William Arthur Shipperlee
- Guy Dobson
- Carol Madden
- Elizabeth Joy Marston
- Rodney Noel Grey
- Eleanor Marie Finn
- Lucy McVicar
- John McHugh
- · Robin Denise Davidson
- Shirley Rae Mosman
- Audrey Nancarrow
- Marcus James Quinlivan
- David and Maree Whiting
- John Gerard Farrell

Major donors \$5k+

- Andrew Sypkes
- Brent and Vicki **Emmett**
- Carmel Murphy
- Christine O'Keefe
- Diana Cox
- Elizabeth Magee
- Joan Whyte
- Julie Rowen
- Lynn Yager

Grants, Trusts and **Foundations**

- Australian Executor Trustees
- Australian Philanthropic Services
- Brass Holdings Pty
- Better Breathing Foundation
- Bluesand Foundation
- Eva and Tom Breuer Foundation
- Gambling Community Benefit Fund
- Jeanetta Winkless Foundation
- · Lord Mayor's Charitable Foundation
- Scobie and Claire Mackinnon Trust
- Scottish Masonic Charitable Foundation WA

Community fundraising partners

- Alison Bolton
- Anita McGrath
- Amy Van Rooye
- Amy O'Toole
- · Beverly White
- Lachlan Mullen
- Carolyn Riordan
- Evangeline Lim
- Fiona Telfer
- John Porter
- Sandy Sampson
- Tamara Lindsey

- Russell Winwood
- Alexandra Utting
- Denise Clarke
- The Vapor Trail
- Trail to Triumph

Corporate partners

- Actelion
- · Air Liquide
- AstraZeneca
- Bayer
- Boehringer Ingelheim
- Bristol-Myers Squibb
- Galapagos NV
- GlaxoSmithKline
- Insmed
- Maurice Blackburn Lawyers
- Medical Developments International
- A Menarini Australia
- Merck Sharpe Dohme
- Novartis
- Pfizer
- Phillips Healthcare
- Roche
- Sanofi
- Segirus Australia
- Shine Lawyers
- Slater & Gordon Lawyers
- Takeda
- Pharmaceuticals Australia

Supporting partners

- Aesir Health
- Arnhem Physiotherapy
- Australian Blouza Association Inc.
- Avalyn Pharma Pty Ltd
- BOC Healthcare
- District Gazette
- Downer EDI
- GS Building
- Janssen-Cilag
- · Lions Club of Pittsworth
- · Lions Club of Taylors Lakes
- · Lugarno Lions Club
- Order of The Eastern Star Redcliffe Chapter No. 85
- Quota International of Narooma Inc
- ResMed
- South Grafton District Ex-
- The Royal Australian College of General Practitioners -Queensland Faculty

Servicemen's Club

USG Boral



Financially healthy.



\$1.5 million per annum.

Lung Foundation Australia's annual support for research is \$5 million per annum.



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

Achieved, tracking ahead of target.

As a charitable institution and Company Limited by Guarantee Lung Foundation Australia relies upon community and corporate goodwill to achieve its goals.

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

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 overall corporate governance of the organisation. This includes:

- Formulating its strategic direction
- Approving and monitoring financial performance
- Setting executive remuneration
- Appointing, removing and creating policies
- Establishing and monitoring the achievement of organisational goals
- Ensuring the integrity of internal control and management information systems.

The Board delegates responsibility for the operation and administration of the organisation to the Chief Executive Officer. Responsibilities are delineated by formal authority delegations.

Board planning framework

The Board adopted a five-year Corporate Plan in 2020. This outlines our mission, purpose, values, goals and strategies. These strategies are outcome-focused and are measured by clearly defined Key Performance Indicators (KPIs).

Our Strategic Plan includes:

- An annual business plan and budget relating to the Corporate Plan
- A reporting framework against KPIs
- Delegated authorities, recorded in a policy framework, from the Board to the CEO and staff, built around a performance culture measured by a performance appraisal process
- A risk management plan.

Board of Directors education

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, the corporate strategy and the expectations concerning performance and conduct of Board Members.

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 has 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 lung 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 Australian 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 lungfoundation.com.au.

The Lung Foundation Australia Board consists of ten 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 AM, 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 AM 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 the University of New South Wales

Sydney, Clinical Professor at the University of Sydney, and a Thoracic Physician at Concord Hospital. She also heads the Respiratory Group at The George Institute for Global Health, Sydney, Australia. Professor Jenkins has played major roles in advocacy and leadership for lung health in Australia, has over 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 notfor-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 Phillips is a Respiratory Physician practising at Macquarie University Hospital and is an Hon Clinical Professor at Macquarie University. His clinical interests are in Interventional Pulmonology, lung cancer, asthma, emphysema and Interstitial Lung Disease.

He has served on several committees for the Royal Australasian College of Physicians and the Thoracic Society of Australia and New Zealand, and chaired Special Interest Groups in Interventional Pulmonology and Lung Cancer. He was previously a Clinical Professor at the University of Western Australia and Consultant Respiratory Physician at Sir Charles Gairdner Hospital in Perth, where he had been Head of the Department of Respiratory Medicine and Director of Lung Cancer and Interventional Pulmonology Services.

Doctor David Michail

Board Member since March 2013



Doctor 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. Doctor Michail also chairs Lung Foundation Australia's Pulmonary Arterial Hypertension Committee.

Ms Kathleen Cummings Board Member since April 2014



Ms Kathleen Cummings has 30 years of experience in the banking and finance industry and in January this year joined BOQ as a General Manager in Retail Banking. 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, Ms Cummings 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. Ms Cummings 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. He is Stevenson Chair and Head of Department of Paediatrics at the University of Melbourne and currently the Director of Respiratory and Sleep Medicine at the Royal Children's Hospital

in Melbourne. Professor Ranganathan is 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. He has published more than 200 peer-reviewed papers and raised over \$35 million in research funding.

Ms Angela Ratcliffe

Board Member since December 2018



Ms Angela Ratcliffe has over 25 years business experience specialising in Marketing, Sales and General Management working in Consumer, Industrial and Healthcare Sectors and has worked in Australia and the United Kingdom. She has been a member of ANZ Executive Leadership Teams for 3M, Staples and

Philips and is currently the Asia Pacific Business Leader for Philips Sleep and Respiratory Care. Ms Ratcliffe is an experienced director in both not-for-profit and commercial sectors and is passionate about lung health and improving the lives of those with Chronic Obstructive Pulmonary Disease.

Associate Professor Lucy Morgan

Board Member since September 2019



Associate Professor Lucy Morgan is a Respiratory Physician in Sydney with clinical roles at Concord Hospital, Nepean Hospital and Macquarie University Private Hospital. She has had a long history with Lung Foundation Australia having been awarded the Lung Foundation Australia Boehringer Ingelheim COPD Fellowship in 1998, chaired

the Lung Foundation Australia Palliative and Supportive Care Committee and the Respiratory Infectious Diseases Committee, been a member of the Australasian Lung Cancer Trials Group and COPD-X Committee, Lung Foundation Australia Clinical Council and more recently, Lead Clinician of Lung Foundation Australia's Australian Bronchiectasis Registry. She is a passionate advocate for equity of access to benchmark clinical care for all Australians with lung disease and for gender equity in research and clinical leadership.

Professor Paul Reynolds

Board Member since September 2019



Professor Paul Reynolds completed Medical School at the University of Adelaide, then Physician Training in Respiratory and Sleep Medicine at the Royal Adelaide Hospital (RAH) in 1992. He then undertook a PhD in the molecular biology of airways disease at The Hanson Institute/RAH/University of Adelaide, then a five-year Post-Doc / Research Assistant Professor position in the Division of Human Gene Therapy, University of Alabama in Birmingham. He returned to the RAH in 1992 to take up a position as Consultant Physician in the Department of Thoracic Medicine, and Director of the Lung Research Laboratory. Professor Reynolds has over 150 peer-reviewed publications. He also holds an Adjunct Professor position in University of South Australia and is a member of the Centre for Cancer Biology. He Chairs the RAH Research Committee and has overseen the distribution of many millions of dollars in funding to the RAH Research Community. Other local leadership roles have included Chair of the Medical Staff Society and Vice-President of South Australian Salaried Medical Officers Association. Professor Reynolds is currently Medical Lead of the Heart and Lung Program of the Central Adelaide Local Health Network (overseeing Thoracic and Sleep Medicine, Cardiology and Cardiothoracic Surgery), as well as the acting Director of RAH Thoracic and Sleep Medicine Department.

Ms Melissa Le Mesurier

Board Member since September 2019



With original training as a journalist, Ms Melissa Le Mesurier has 25 years experience as a senior corporate affairs executive with blue-chip organisations such as Medibank, Kraft/Cadbury, Foster's Group and Australian Airlines. She is currently the Principal of MLM Consulting which advises executives and boards on

strategy, reputation, cultural change and communications. Both professionally and personally, Ms Le Mesurier is passionate about medical research, consumer engagement and patient empowerment – something sparked when her (now adult) son was diagnosed with Cystic Fibrosis (CF) in 1996. She is a Graduate of the Australian Institute of Company Directors and a member of the Australian and New Zealand Urogenital and Prostate Cancer Trials Group Consumer Advisory Panel. She was previously a member of the Alfred Hospital's CF Consumer Advisory Panel and founding Chair of the Royal Children's Hospital Cystic Fibrosis Research Trust (1999-2009) which has raised more than \$3 million for research and funded about 20 clinical fellows.



Mr Tony Hyams AMBoard Member since November 2014 - resigned March 2019

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. Mr Hyams is currently a Governor of WWF Australia and has been named a Member of the Order of Australia.

In 2019, staff participated in an anonymous survey to gain insight into the organisation's performance and the steps that need to be taken to continuously improve.

Results showed that staff members rated their sense of loyalty, job satisfaction and pride in working for Lung Foundation Australia as high.

Staff scored Lung Foundation Australia high in the following areas:



Organisation direction



Safety



Results focus



Facilities



Mission and values



Learning and development



Ethics



Motivation and initiative



Role clarity



Talent



Teamwork



Work / life balance and flexibility

The top five areas identified for improvement included processes, rewards and recognition, cross-unit cooperation, technology, skills and wellness. As part of our commitment to continuous improvement a Staff Engagement Committee, comprised of staff members from each department, is now working to co-design and implement action plans to address the five priorities identified.







Staff training and professional development

In 2019, Lung Foundation Australia introduced a new performance appraisal process and committed to strengthening the team's personal and professional development through continuous learning and internal and external training.

External training

Internal (on-the-job) training

Professional development

16 opportunities

11 opportunities

\$500 allocation for every staff member

77 staff training sessions undertaken

111 staff training sessions undertaken

11 staff accessed their professional development fund

Staff Welfare

Lung Foundation Australia has an Employee Assistance Program which is freely available to all staff and their immediate families. This anonymous and independent service is offered to all staff as part of our commitment to self-care, mental health and wellbeing.



Volunteers

Lung Foundation Australia has a total of 320 clinical and research volunteers, the majority of whom are health professionals serving on various advisory committees. In addition, there are over 670 patient volunteers working across a number of areas including research committees, advisory committees, advocates, peer support and group leaders.

Expanding our footprint

In 2019, Lung Foundation
Australia opened offices in
Sydney and Melbourne allowing
the organisation to increase
stakeholder engagement and
grow its operational footprint. This
was made possible from savings
achieved through a corporate
restructure.

Summary financial statements for the year ended 31 December 2019

The unaudited summary financial statement has been prepared for preseantation in the 2019 Impact Report of Lung Foundation Australia for the year ended 31 December 2019. It has been prepared on an accruals basis 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 2019, which has been approved 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 2019. Members of Lung Foundation Australia are able to 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 2019

	2019 [\$]	2018 [\$]
Continuing operations		
Revenue from projects	4,491,795	4,881,736
Donations	768,945	383,175
Bequests	622,547	309,454
Revenue from fundraising and events	767,708	520,954
Revenue from specifically designated funds	293,837	338,828
Other income	282,970	230,813
Total revenue and other income from continuing operations	7,227,803	6,664,960
Project expenses	(4,491,795)	(4,881,736)
Specifically designated fund expenses	(293,837)	(338,828)
Other expenses	(2,173,712)	(1,444,409)
Surplus / (deficit) from continuing operations before finance	268,459	(13)
income		
Finance income	20,550	39,932
Net surplus / (deficit)	289,009	39,919
Other comprehensive income		
Items that may be reclassified subsequently to profit or loss:		
Fair value gains/(losses) on Equity FVOCI financial assets	160,623	(126,497)
Total comprehensive income / (loss)	449,632	(86,578)
Net surplus / (deficit) for the year is attributable to:		
Members	289,009	39,919
	289,009	39,919
Total comprehensive income / (loss) for the year is attributable to:		
Members	449,632	(86,578)
Total revenue and other income from continuing operations	449,632	(86,578)

In 2019, 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 Australians impacted by a diagnosis of lung disease. The changes included:

- 1. The opening of our new Sydney office in March 2019 to house our Fundraising and Development team.
- 2. The opening of our new Melbourne office in June 2019 to house our Clinical Research and Innovation team.
- 3. The delivery of two national reports the National Strategic Action Plan for Lung Conditions and the Making Lung Cancer a Fair Fight: A Blueprint for Reform. Both reports have raised the profile of Lung Foundation Australia at Federal and State Government levels creating a strong platform to deliver an effective advocacy campaign.

Lung Foundation Australia had a successful year by:

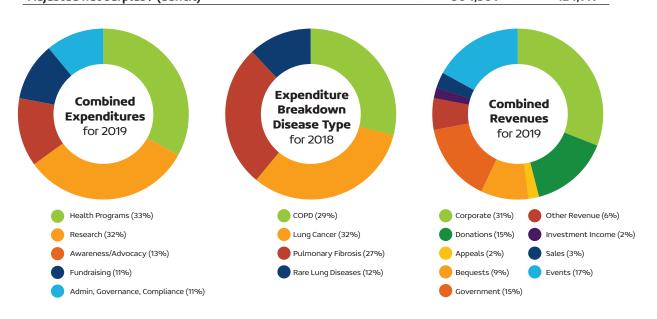
- 1. Increasing its total revenue by 8.44% from 2018.
- 2. Increasing its revenue from donations and fundraising events by 70% from 2018.
- 3. Maintaining the level of overall expenditure on lung disease projects and programs (including research). This included an increase in overall expenditure on research by 14%.
- 4. Generating a surplus of \$289,009 for the year.

Despite the existence of a volatile world equity market during 2019, the value of the investment portfolio was improved by an unrealised gain of \$160,623, which has been shown in the Statement of profit and loss and other comprehensive income.

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.

Adjusted net surplus / (deficit)	304 509	124 919
in prior years	15,500	85,000
Plus payments made with respect to Research Award income received		
comprehensive income	289,009	39,919
Net surplus / (deficit) per Statement of Profit or Loss and other		
	2019 [\$]	2018 [\$]



Lung Foundation Australia statement of financial position

As at 31 December, 2019

,	2019 [\$]	2018 [\$]
Current assets		
Cash and cash equivalents	1,776,409	1,571,654
Receivables	749,347	616,804
Financial assets - Research	295,353	336,871
Financial assets - Company	447,750	404,921
Total current assets	3,268,859	2,930,250
Non-current assets		
Financial assets - Research	480,417	621,918
Financial assets - Company	1,764,284	1,974,449
Property, plant and equipment	193,496	118,265
Right of Use Asset	711,431	-
Intangible assets	175,362	144,418
Total non-current assets	3,324,991	2,859,050
Total assets	6,593,850	5,789,300
Current liabilities		
Payables	219,094	201,881
Income in advance	1,631,596	2,004,555
Contract Liability	1,465,631	1,466,434
Lease liabilities	199,230	-
Employee benefits	122,323	98,227
Total current liabilities	3,637,874	3,771,097
Non-current liabilities		
Payables	-	32,193
Lease liabilities	545,353	
Employee benefits	37,885	64,666
Total non-current liabilities	583,238	96,859
Total liabilities	4,221,112	3,867,956
Net assets	2,372,738	1,921,344
Equity		
Retained earnings	2,309,786	2,020,777
Equity FVOCI financial assets reserve	62,952	(99,433)
Total equity	2,372,738	1,921,344

Lung Foundation Australia statement of cash flows

For the year ended 31 December, 2019

Totale year chaed of December, 2017	2019 [\$]	2018 [\$]
Cash flows from operating activities		
Receipts from operating activities	7,742,133	7,538,256
Payments for operating activities	(7,802,148)	(8,087,299)
Dividends received	126,612	128,558
Interest received	36,591	41,608
Interest paid	(45,954)	-
Net cash flows from operating activities	57,234	(378,877)
Cash flows from investing activities		
Proceeds from term deposits	451,205	596,899
Acquisition of securities and equities	(217,591)	(1,230,970)
Proceeds from sale of securities and equities	282,330	757,913
Acquisition of plant and equipment	(131,623)	(28,569)
Acquisition of intangible assets	(71,298)	(110,880)
Net cash flows used in investing activities	313,023	(15,607)
Cash flows from financing activities		
Payment of finance lease liabilities (principal)	(165,502)	
Net cash flows used in investing activities	33,152	0
Net increase/(decrease) in cash and cash equivalents held	204,755	(394,484)
Cash and cash equivalents at the beginning of the financial year	1,571,654	1,966,138
Cash and cash equivalents at the end of the financial year	1,776,409	1,571,654

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For all other references please visit lungfoundation.com.au

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How You Can Support Us

Invest in the



Help find a cure



Get involved



Philanthropy and partnerships



Community fundraising



Scientific breakthroughs can take years to accomplish. Invest in a future free from lung disease and lung cancer 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.

Your donation can help us understand the causes and future treatments of lung disease and lung cancer. 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.

More than ever, Australians are aware of the need to increase research funding to fight lung disease and lung cancer 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.

Lung Foundation Australia is proud to partner with philanthropists, companies, trusts and foundations to raise vital funds for lung disease and lung cancer 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 upto-date on progress. This is our promise.

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













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