2019 Research Impact Report

Changing the future through research and giving hope for a cure.

Lung Foundation Australia

celebrating 30 years

Our 2019 Impact

$5.2m+
invested to support advances in lung disease and lung cancer research.

Awards program

22 research awards and grants for early- and mid-career researchers.

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

Over 100 applications received.

$2.5m+
additional funding secured by award winners.

Clinical trials

6 **lung cancer trials** open to recruitment through the Australasian Lung Cancer Trials Group.

10 **Pulmonary Fibrosis clinical trials** endorsed by the Pulmonary Fibrosis Australasian Clinical Trials Network.

2 trials completed recruitment

100+
patients recruited for participation in clinical trials.

12 publications in peer-reviewed journals.

10+ national and international conference presentations.

Collaborations

Collaborated with 12 institutions.

9 **Medical Research Future Fund** and **National Health and Medical Research Council** funding applications supported.

2 **were successful** resulting in

$4.5m+ in funding for bronchiectasis and Chronic Obstructive Pulmonary Disease.

$3.5m+
funding secured by researchers with our support.

Cover Image:
Dr Venessa Chin, Lung Foundation Australia Deep Manchanda Lung Cancer Fellowship recipient.

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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 past, present and emerging.

Celebrating

Giving hope through research

Lung disease, including thoracic cancers and chronic lower respiratory diseases, is our nation's second leading cause of death, yet the prioritisation and level of investment in lung related research in Australia remains disproportionately low[1].

Research improves care, produces better outcomes and transforms lives.

Since 1990, with your help, we have raised and invested over $40.9 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.

Together we have made an undeniable impact on the future of lung disease and lung cancer. Particularly in recent years, advancements 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.

Scientific breakthroughs can take years to accomplish so every dollar gifted to Lung Foundation Australia will help make inroads to real and lasting change.

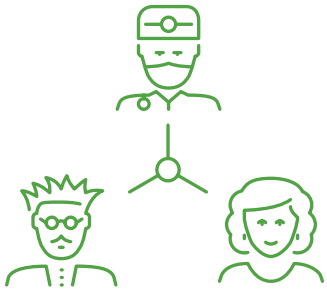
Together we can change the future and give hope for a cure.

30 YEARS OF RESEARCH SNAPSHOT

$40.9 million

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

31 clinical trials initiated to advance treatments and care in lung cancer and Pulmonary Fibrosis.



260+ awards and grants

to support the best and brightest researchers.

g 30 Years

The power of investing in research

For 30 years, we have been partnering with organisations to provide seed funds to support cutting-edge research projects. Boehringer Ingelheim Australia Managing Director, Wes Cook says, "for decades, we have proudly partnered with Lung Foundation Australia and we continue to share its mission to improve the lives of Australians living with lung disease and provide hope for future generations through research".

In 1999, Associate Professor Lucy Morgan was one of the first recipients of the *Lung Foundation Australia Boehringer Ingelheim COPD Research Fellowship*, an opportunity she considers sentinel in the path of her career. With the funding support, Associate Professor Morgan completed her PhD in mucociliary clearance and learnt critical skills in designing research, interpreting results and identifying key priorities in a space where there were so many unknowns. Today, Associate Professor Morgan is a respiratory physician and in 2019, joined the Lung Foundation Australia Board as a director.

"Medical research is all about puzzle solving on a shoestring and, to misquote Donald Rumsfeld, is the sorting out of the knowns from the unknowns. The greatest joy in medical research is finding a piece of the puzzle that helps to improve the lives of our patients," Associate Professor Morgan said.

"Every year, we see the hard work of researchers from the recent past come to fruition in the clinic room and bedside. It gives us hope that similar breakthrough therapies might be just around the corner for all our patients.

"As a researcher I worked with tissue samples, as a physician I work with individual patients. Now, joining the Lung Foundation Australia Board offers me the chance to make a difference to the lives of many more Australians by not only advocating loudly for increased funding for research, but by changing the attitudes of voters and policy makers to issues of lung health."

Without the support of our industry partners and community supporters, our awards program would not be possible. Thanks to your support, we're creating real and meaningful change.

"The greatest joy in medical research is finding a piece of the puzzle that helps to improve the lives of our patients."

Associate Professor Lucy Morgan.

Welcome

For 30 years lung disease and lung cancer research has been an important focus of Lung Foundation Australia's work. From very humble beginnings in 1990 Lung Foundation Australia, in partnership with thousands of national and international researchers, has raised and invested $40.9 million in lung disease and lung cancer research.

As well as raising funds for research, together with the Thoracic Society of Australia and New Zealand (TSANZ) and many other partnering research institutions, we have been vocal champions and advocated for increased government and community investment in lung research.

We acknowledge and thank the substantial number of health professionals and researchers who contribute to our lung health research program. This includes the Australasian Lung Cancer Trials Group (ALTG), the Centre of Research Excellence in Pulmonary Fibrosis, the Australasian Bronchiectasis Consortium, and the many other institutes and individual researchers that support our work more broadly.

The 2019 Research Impact Report showcases the research programs of Lung Foundation Australia and our partners, and the outcomes being achieved or advanced. We also highlight the important contributions of researchers, institutions, donors and supporters as part of our organisation's commitment to funding transparency and outcomes-based reporting.

Chairperson Professor Christine Jenkins AM and CEO Mark Brooke.

In addition to the sizeable voluntary contribution of so many health professionals and researchers, we are truly grateful for our community's support. Donations, both small and large, have driven many advances in research, launched numerous careers, and provided the seed funding necessary to allow novel research ideas to be developed and subsequently go on to attract larger government funding.

The depth of Lung Foundation Australia's and our partners' research agenda includes:

- Competitive peer-reviewed awards and grants program in partnership with TSANZ
- Industry sponsored travel grants for early-career researchers to attend and present at national and international lung health conferences
- Clinical trials groups in lung cancer and Pulmonary Fibrosis
- Disease registries in Idiopathic Pulmonary Fibrosis, Interstitial Lung Disease (ILD) and bronchiectasis
- Early- and mid-career PhD scholarships and fellowships in lung cancer and ILD
- Research capacity building programs including the ALTG Annual Scientific Meeting, the ALTG Preceptorship and the Australian Rare Lung Disease Short Course.

Sadly, research investment remains woefully low and inconsistent with the nation's burden of lung disease and lung cancer. Government and government agencies' investment in lung health research is simply not keeping pace with demand in order to address the associated social, economic and health burden. Your Lung Foundation Australia has continued to seek individual and corporate philanthropy to advance many important research endeavours and this will remain a priority.

As a starting point we have commissioned PricewaterhouseCoopers to conduct an independent analysis of lung disease and lung cancer research investment compared to both the burden of disease and other health research priority areas. This report will be presented to the Australian Government and key stakeholders in mid-2020.

Looking forward, Lung Foundation Australia will finalise the 2030 Hope Through Research Strategy to better guide our investment to focus on areas of greatest need. We are also pleased to announce the Hope Research Fund, which aims to raise $50 million over the next 10 years to create a national fund for lung disease and lung cancer research.

We sincerely thank each and every supporter including the tremendous number of consumers and carers now actively engaged in research governance, planning and priority setting. This is an important element of our work and one we see as a continuing priority.

The Board acknowledges those who have left gifts in memoriam or bequests to Lung Foundation Australia. We encourage Australia's lung health professionals and researchers to rally behind the Hope Research Fund and encourage their patients to make a gift or leave a bequest to a brighter future for all people living with lung disease and lung cancer.

We look forward to your continued support in 2020 and beyond.

Yours sincerely,

Professor Christine Jenkins AM
Chairperson

Mark Brooke
Chief Executive Officer

Collaborating to Find a Cure

Transformative change in lung health cannot be achieved without collaboration

Lung Foundation Australia fosters sustainable partnerships with the lung research community to achieve tangible and meaningful outcomes for patients and their families. Over the past 30 years, we have actively sought to grow our research partnerships across government, non-government and industry to bring together the knowledge, skills and resources necessary to advance lung health science, prevention and management.

Through our research program, we also support research leaders to secure National Health and Medical Research Council (NHMRC) and Medical Research Future Fund (MRFF) funding. In 2019, Lung Foundation Australia directly supported four investigator-led applications for NHMRC funding and five applications for MRFF grants.

We are delighted to share that two MRFF grants were successful in 2019:

- Improving outcomes of children and young adults with primary ciliary dyskinesia (PCD): a multi-centre, double-blind, double-dummy, 2x2 factorial, randomised controlled trial (RCT)
  Led by Professor Anne Chang, Menzies School of Health Research (total value = $2,375,118)
- Transforming pulmonary rehabilitation to reduce hospital admissions in COPD
  Led by Professor Anne Holland, La Trobe University (total value = $1,220,668)

Together, we're working to discover life-changing detection, treatment, support and care to improve quality of life for patients.

"Having dedicated funding support for lung diseases attracts more researchers to tackle these projects, and with more research comes more discoveries that have the potential to improve the health of patients living with lung diseases."

Doctor Clare Weeden, Lung Foundation Australia Deep Manchanda Early Career Fellowship in Lung Cancer recipient.

Investing in the best and brightest researchers

Building research capability and capacity offers significant opportunities to make immediate and long-term improvements to the health and wellbeing outcomes for people living with lung conditions.

In collaboration with the Thoracic Society of Australia and New Zealand (TSANZ), 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, more than $437,800 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.

Without the support of our industry partners and community supporters, through major gifts and bequest, our awards program would not be possible. Your contributions are making real and meaningful change.

"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 Idiopathic Pulmonary Fibrosis (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.

2019/20 Research Award Recipients

AWARD TITLE	VALUE & PARTNER	RECIPIENT	PROJECT TITLE
LUNG CANCER			
Lung Foundation Australia Ellen Yates Memorial Grant-in-Aid for Lung Cancer Research	$20,000 over 1 year, funded by Yates family	**Dr Afaf Abed** Fiona Stanley Hospital	Genomic HLA heterozygosity, T-cell receptor (TCR) – repertoire diversity and tumor PD-L1 expression as predictive biomarkers of response to immunotherapy in lung cancer patients
Lung Foundation Australia Deep Manchanda Lung Cancer Fellowship	$320,000 over 2 years co-funded by Manchanda family (with matched funding provided by research institution)	**Dr Venessa Chin** Garvan Institute of Medical Research	Utilising single cell sequencing to change the management of lung cancer
RARE LUNG DISEASE			
Lung Foundation Australia Diana Cox PhD Scholarship in Idiopathic Pulmonary Fibrosis (IPF) Research	$45,000 over 3 years, funded by Diana Cox	**Dr Laura Glenn** University of Sydney	Novel diagnostic techniques in Interstitial Lung Disease (ILD)
Lung Foundation Australia Brian Eaton Memorial PhD Scholarship in IPF Research	$90,000 over 3 years, co-funded by Eaton family (with matched funding provided by research institution)	**Dr Matthew Parker** University of Sydney	Novel methods to distinguish IPF from connective tissue disease-associated ILD
Lung Foundation Australia Lizotte Family Research Award for Interstitial Pulmonary Fibrosis Research	$5,000 over 1 year, funded by Lizotte family	**Dr Yet Hong Khor** Austin Health	Understanding lung function trajectories in ILD

AWARD TITLE	VALUE & PARTNER	RECIPIENT	PROJECT TITLE
Lung Foundation Australia Ludwig Engel Grant-in-Aid for Physiological Research	$5,000 over 1 year, funded by Ludwig Engel	**Dr Alexander Wong** The Children's Hospital at Westmead	Normal day-to-day variability in oscillometry in school aged children: Defining target thresholds for future intervention studies in childhood asthma
Pulmonary Fibrosis Australasian Clinical Trials Grant-in-Aid	$30,000 over 1 year, funded by CREATE	**Dr Lauren Troy** Royal Prince Alfred Hospital	Novel diagnostic techniques in ILD: extension of the COLDICE study findings
Lung Foundation Australia Ivan Cash Grant-in-Aid for IPF Research	5,000 over 1 year, funded by Ivan Cash	**Dr Paris Papagianis** RMIT University	Pathogen-induced lung remodelling during the early life period in mice
Lung Foundation Australia John Reid Prize for Physiological Research	$500 funded by Reid family	**A/Prof Graeme Zosky** University of Tasmania	Systemic inflammation modifies the regional gene response to mechanical ventilation
CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)			
Lung Foundation Australia Boehringer Ingelheim COPD Fellowship	$160,000 over 2 years, funded by Boehringer Ingelheim	**Dr Simone De Luca** RMIT University	New ways to treat vascular cognitive impairment and dementia in chronic lung disease
Lung Foundation Australia Cochrane Airways Australia Scholarship	$2,500	**Ms Kelsey Sharrad** University of South Australia	Psychological interventions for asthma in children and adolescents
Lung Foundation Australia A Menarini Travel Grant (American Thoracic Society Conference)	$3,000 funded by A Menarini Australia Pty Ltd	**Ms Zoe Lear** WA Health	Poster prize
Lung Foundation Australia A Menarini Travel Grant (American Thoracic Society Conference)	$3,000 funded by A Menarini Australia Pty Ltd	**Dr Katrina Tonga** Sydney University	Poster prize
Lung Foundation Australia A Menarini Travel Grant (Asian Pacific Society of Respirology Conference)	$3,000 funded by A Menarini Australia Pty Ltd	**Dr Khine Khine Yin Mon** Liverpool Hospital	Poster prize
Lung Foundation Australia A Menarini Travel Grant (European Respiratory Society Congress)	$3,000 funded by A Menarini Australia Pty Ltd	**Mr Karosham Reddy** Sydney University	Poster prize
Lung Foundation Australia A Menarini Travel Grant (European Respiratory Society Congress)	$3,000 funded by A Menarini Australia Pty Ltd	**Dr Sabine Zimmermann** Woolcock Institute of Medical Research	Poster prize
BRONCHIECTASIS			
Lung Foundation Australia David Serisier Memorial Award (Best Abstract)	$1,000	**Dr Su-Wei Khung** Alfred Health	The use of eucapnic voluntary hyperventilation as a bronchoprovocation technique for exercise induced bronchoconstriction in the clinical setting

Lung Cancer

Lung cancer is Australia's biggest cancer killer[2]. It has one of the lowest survival rates of all cancers, with an Australian family losing a loved one every hour[2], but there is hope. In recent years, advances in new treatments have seen an increase in the survival rate and quality of life for people impacted by the disease.

Together with your support, we're driving life-changing research that will revolutionise our understanding of lung cancer, improve outcomes and help bring us closer to a cure. Our research program includes an internationally-renowned lung cancer clinical trials initiative and a suite of research awards and grants that drive cutting-edge projects undertaken by the best and brightest researchers.

Spotlight on Research

Recipient: Doctor Vanessa Brunelli

Partner organisation: Queensland University of Technology

Award: Lung Foundation Australia Shine a Light on Lung Cancer Early Career Nursing Fellowship in Lung Cancer Research 2019

Award value: $200,000 over 2 years

Project: Expectations, standards and performance framework to evidence the role and practices of the Australian specialist lung cancer nurse.

Your donations in action

This fellowship was made possible through money raised by our passionate and dedicated Shine a Light on Lung Cancer community fundraisers.

The issue being addressed

In Australia, there are as few as 12 full-time equivalent specialist lung cancer nurses, compared to over 440 specialist breast cancer nurses[3]. Research shows that people who have access to a specialist nurse are 34% more likely to receive treatment than those who do not[4]. Specialist lung cancer nurses also increase timely access to treatment and anti-cancer therapy, and improve health-related quality of life for people living with lung cancer. Despite this, there is limited investment to increase this work-force capacity. The key challenge to date is the limited consistent evidence on the specialist lung cancer nurse role and practices in the Australian context.

"It's my hope that this research will allow all people living with lung cancer to receive timely, coordinated and continuous care by a dedicated specialist lung cancer nurse. People living with lung cancer deserve the same support and opportunities as those impacted by other commonly diagnosed cancers."

Doctor Vanessa Brunelli.

Purpose of the research

Doctor Brunelli's research project is a vital step towards improving access to life-changing care for Australians living with lung cancer. She is working with nurses, medical and allied health experts and consumer advocates across the nation to develop critical, consistent evidence about the role and core supportive-care practices of specialist lung cancer nurses. An expectations, standards and performance practice framework, developed and piloted by Doctor Brunelli in discrete nursing contexts, provides the digital tool to collect specialist lung cancer nurse activity across the clinical pathway. This evidence will inform future large-scale projects which will implement and evaluate the role of these nurses in the Australian healthcare system. This research will provide the evidence required for investment to increase the work-force capacity, ensuring people receive the timely, coordinated and continuous care they deserve.

Why invest in lung cancer research?

Despite the burden of disease, research dollars in lung cancer are remarkably low compared to other cancers. People living with lung cancer deserve better. Nurse-led research contributes to the evidence-base around the quality of care that patients receive which will ultimately improve outcomes. Investing in research changes the way patients are supported and will ultimately change people's lives.

"Being a lung cancer patient is not an easy journey, we come up against all kinds of difficulties. I was lucky to be given access to a nurse who made my journey so much easier. Having a nurse that I could call every day if I needed to was a lifeline. I'm hopeful that the future will be a lot brighter for lung cancer patients."

Sandy, who lives with lung cancer, has raised over $53,000 to support researchers like Doctor Brunelli through Shine a Light on Lung Cancer fundraising events.

Doctor Malinda Itchins, ALKTERNATE Clinical Lead and ALTG member.

Australasian Lung Cancer Trials Group

Clinical trials play a critical role in advancing lung health science and the evidence-base required to deliver quality diagnosis, treatment and care for people living with thoracic cancer. Through our clinical trial partnerships, we connect patients and clinicians with trials being undertaken across Australia and internationally. For people living with thoracic cancer, these opportunities can provide access to cutting-edge treatments and offer hope for a brighter future.

In 2019, the Australasian Lung Cancer Trials Group (ALTG), an initiative of Lung Foundation Australia's research program, celebrated its 15th year. Since its inception, membership has grown from 70 founding members to over 850. This represents the full range of professional disciplines involved in caring for patients with lung cancer and mesothelioma, clinical trial professionals and consumer representatives.

Collaborative development of clinical trials

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. Engaging field experts in this early and diverse review and development process enhances the success of applications for competitive funding opportunities and maximises the chances for a successful clinical trial. In late 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.

"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.

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 more responsive treatment options for advanced lung cancer. Unfortunately, some lung cancers will eventually become resistant and alternative treatments are required.

In 2019, **ALKTERNATE**, a first-of-its-kind trial opened to investigate the effectiveness of alternating treatments in ALK+ metastatic non-small cell lung cancer (NSCLC). The study protocol alternates treatment between a newer drug, lorlatinib, and one of the first drugs shown to be effective in ALK+ lung cancer, crizotinib. The **OSCILLATE** trial, utilising a similar principle of alternating drugs in EGFR+ advanced NSCLC patients, successfully completed recruitment in 2019 with analysis planned for 2020. In both of these trials, it is hoped that alternating drug cycles will delay emergence of resistance to the drugs.

"Coming together to push for greater longevity for those living with ALK+ metastatic NSCLC, both now and in to the future, is a privilege. Seeing patients with minimal treatment options available bring a willingness to contribute their cases and time to the growing body of scientific research behind drug resistance is inspiring."

Doctor Malinda Itchins, ALKTERNATE Clinical Lead and ALTG member.

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 response that would normally eliminate some of the cancerous cells. One of the core objectives of the ALTG clinical trial portfolio is to examine the effectiveness of these drugs in the 'real world' treatment setting.

In 2019, ALTG opened the clinical trial **ILLUMINATE** which seeks to use immunotherapies to release the 'brakes' and help make cancerous cells visible to the body's own immune system in EGFR+ metastatic NSCLC in patients who no longer respond to their earlier treatment. The immunotherapies are given together with chemotherapy, currently the best-available treatment for these lung cancer patients. Patients are being recruited from 10 hospitals in Australia and the trial will run simultaneously in Taiwan and China as part of ALTG's international collaboration.

The **BR.34** clinical trial, which is part of ALTG's long-standing collaboration with the Canadian Cancer Trials Group, offered the same drug combination with or without chemotherapy in newly diagnosed metastatic NSCLC patients. The aim of this trial was to determine whether the addition of chemotherapy to immunotherapy increased survival in lung cancer patients. The analysis of the study results will take place in 2021.

The **BR.31** trial, which closed to recruitment in 2019, examined the use of durvalumab after surgery in newly diagnosed Stage I-III NSCLC patients. The trial will undergo analysis in 2020 to examine whether durvalumab given post-surgery delays the re-emergence of lung cancer.

Together, these clinical trials offer hope of survival for patients with advanced lung cancer who have limited treatment options.

Improving quality of life

Distress, anxiety and depression are common in Australians living with lung cancer. The **PEARL** clinical trial is assessing the effect of early referral to palliative care on quality of life in Stage IV NSCLC and malignant pleural mesothelioma patients. Importantly, the palliative care services used in this clinical trial are already available in the healthcare system. The PEARL protocol includes an assessment of physical, psychological, social and spiritual needs of each patient, with provision of supportive care medication and referral to additional support services as required. If results of the PEARL clinical trial have a positive impact on patients' quality of life, it will provide the necessary evidence to change clinical practice and rapidly implement improvements in a readily available, but potentially underutilised, component of the healthcare system.

Educating and inspiring the next generation of researchers to collaborate for a brighter future

In partnership with the ALTG, we are working to upskill the next generation of clinicians and researchers. Together, we're addressing the critical inequity of lung cancer research and disparity in patient care.

Critical thinking in research

The ALTG's annual Preceptorship in Lung Cancer provided medical trainees, fellows, nurses and consumer advocates with a unique, intensive and active learning program designed to develop their clinical knowledge and expertise in lung cancer management. Under the mentorship of an ALTG preceptor, each attendee conducted a critical appraisal of evidence from a published paper which has contributed to current treatment standards in lung cancer. In 2019 the event focused on practice-changing clinical trials, with a discussion of the latest advances. The event was highly valued by attendees and preceptors alike.

"The main benefit I felt was hearing from the preceptors who are experts in their field talk about the trials in context and how they manage patients. That information is invaluable."
ALTG Preceptorship participant.

Uniting the lung cancer community

Consumer advocates again joined clinical delegates at the 2019 ALTG Annual Scientific Meeting (formerly the ALTG Symposium). The event united the lung cancer community to learn about the latest research and advancements in treatment, care and support for patients. Key topics included patient-focused care, survivorship and advances in treatments that are tailored to the particular tumour profile, otherwise known as precision medicine. The event was an immense success with over 95% of delegates reporting improved knowledge in the topics presented. The program highlighted that although there has been a tremendous advance in treatment of lung cancer in recent years, improved diagnostics, quality of life, treatment of rare mutations and the emergence of treatment resistance represent key challenges that would benefit from further clinical trial research.

Interstitial Lung Disease

Interstitial Lung Diseases (ILD) are a group of rare and complex lung conditions, including Pulmonary Fibrosis, which cause inflammation or fibrosis in the lung, making it difficult to breathe. Little is known about what causes these rare conditions and there are currently few treatment options available[5].

Research into these conditions in Australia has been limited, but with your support we're working to better understand how to diagnose and treat the conditions, and ultimately, find a cure. Our national registry is collecting real-world patient data which will help researchers to improve our understanding of ILD and the most effective approaches to treatment and patient care.

Australasian Interstitial Lung Disease Registry

While we understand the effects of scarring, or fibrosis, on the lungs, we're still searching to better understand what causes this. New treatments are helping to slow the progression of the scarring, and with the help of real-world patient data, we're working to better understand how to prevent and reverse these conditions.

The Australasian ILD Registry, established in 2016 with the support of Lung Foundation Australia, provides a central source of rich data to guide clinical practice and standardisation of care, and support research collaboration in Australia and internationally. At the end of 2019 there were 20 clinical sites approved for data collection with 11 sites actively entering real-time patient data. There are currently 1,352 patient participants across 13 different ILD diagnoses.

Throughout 2019, two abstracts profiling the analysis and evaluation of the first phase of the registry implementation were submitted and presented at Australian respiratory conferences. The ILD Registry Network is currently preparing a manuscript on the registry methodology with publication expected in 2020, along with additional conference presentations highlighting variation in care for ILD patients across Australia and New Zealand. The registry is now in its second phase with 13 additional sites from Australia and New Zealand to begin entering data in 2020 and beyond.

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

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

Increasing the Profile of Rare Lung Diseases

In 2019, the 4th Biennial Australian Rare Lung Disease Short Course provided over 250 researchers and health professionals with access to the most up-to-date advances in the diagnosis, treatment and management of rare lung diseases. Over 96% of participants reported that the speaker presentations improved their knowledge.

The ILD Patient Education Day, also held as part of the course, connected consumers to the latest research and provided valuable insights into the future of ILD treatment, research and management.

Through the Identifying Research Priorities for Pulmonary Fibrosis Workshop, an innovation in the 2019 program, consumers provided unique and invaluable insights. These perspectives will be fundamental to guide future patient-centric research.

Pulmonary Fibrosis

Pulmonary Fibrosis (PF) is a rare lung disease which affects each person differently. Early symptoms can be subtle, or mistaken for other conditions or signs of ageing, which often leads to significant delays in diagnosis. For some people, the cause is unknown, or idiopathic, and survival rates can be as low as some of the most devastating cancers[6].

There is no current cure for PF, however Australian-based research into this complex disease has provided advances in treatments which are helping to slow disease progression. Our research program includes a fast-growing clinical trials network and a range of research awards and grants that are driving discoveries into diagnosis and management to improve outcomes for patients.

Pulmonary Fibrosis Australasian Clinical Trials Network

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

Proudly supported by Lung Foundation Australia, the establishment of PACT was a key foundational objective of the Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) to increase engagement and involvement of patients in research decision-making. Since its establishment in 2017, PACT has grown to over 111 health professional and consumer members and opened ten clinical trials across more than 30 Australian research sites. In 2019, the network processed more than 60 patient enquiries and is set for greater growth and reach in 2020 and beyond. Thanks to research initiatives like PACT, the future for patients living with PF is brighter, compared to just years ago.

"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."

Bill Van Nierop, who lives with Idiopathic Pulmonary Fibrosis, has raised $190,000 for Lung Foundation Australia through the Long Walk for Lungs and Long Kayak for Lungs events.

Professor Dan Chambers, Chair of PACT (left), Associate Professor Peter Hopkins, PACT Committee Member (middle), and lab assistant (right).

Lung Foundation Australia
Pulmonary Fibrosis Clinical Trials

"I think we can make big in-roads 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, PACT Network Chair.

Improving diagnosis through new techniques

Often patients with Interstitial Lung Disease (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. This impacts on treatment decisions and health and wellbeing outcomes. A safer, reliable way to make a diagnosis is needed.

The **COLDICE** study is comparing cryobiopsy, a new technique for taking small samples of lung tissues through the airways, with traditional surgical lung biopsy for ILD diagnosis. The study is investigating the accuracy and reliability of the much smaller samples taken through cryobiopsy.

Preliminary results show that, in ILD patients requiring a biopsy, bronchoscopic cryobiopsy is consistent with the more invasive surgical lung biopsy. Lead investigator, and recipient of the inaugural PACT Grant-in-Aid for Investigator Led Pulmonary Fibrosis Clinical Research, Doctor Lauren Troy presented these results at the European Respiratory Society (ERS) congress in Madrid.

Oxygen therapy key to improving quality of life

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 crippling 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 need 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, with recruitment taking place in 2019. Professor Holland hopes the trial will provide a clear answer on the benefits and the costs of portable oxygen concentrators for people with PF.

Centre of Research Excellence in Pulmonary Fibrosis

The Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) is building research capacity to discover more effective and personalised approaches to diagnose and manage fibrotic lung diseases. Established in 2017, the CRE-PF provides a nationally-coordinated clinically-focused research program as well as education for consumers and training for future generations of researchers.

Through our partnership with the CRE-PF, Lung Foundation Australia supports the translation of evidence into patient-centred resources and programs. Throughout 2019, we collaborated to develop resources and support services, including growing our peer support programs and delivering education to patients and health professionals through a three-part webinar series.

Together with the CRE-PF, Lung Foundation Australia recognises the importance of nurturing the development of the next generation of the research workforce capable of developing and translating knowledge from bench-to-bedside.

The CRE-Advanced Training Environment (CREATE) program supports advanced trainees to hone their research skills to support the next generation of multiskilled clinicians. In 2019, 20 CREATE fellows participated in the program and were invited to attend the Australian Rare Lung Disease Short Course as part of their development. CREATE fellow Alan Teoh was awarded best clinical or scientific abstract from a member of the CREATE training program for his abstract entitled *Blood Monocyte Count As A Prognostic Marker In Idiopathic Pulmonary Fibrosis: An Australian IPF Registry Analysis. His research demonstrates that elevated monocyte count is a predictor of poorer survival in patients with IPF; thus establishing predictive biomarkers as an important target for future research.*

Australian Idiopathic Pulmonary Fibrosis Registry

Our Australian Idiopathic Pulmonary Fibrosis (IPF) Registry, a foundational pillar and project within the Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF), is a unique research platform which systematically collects data on more than 845 patients to better understand this rare and complex disease. To improve our understanding, participants generously contribute health and wellbeing outcome data regularly so it may be used to undertake a wide range of research projects. The registry is like no other in the world, providing a central source of rich data used in both national and international studies to better understand the incidence and prevalence of IPF, and drive advancements in disease diagnosis and treatment.

Identifying signals to improve outcomes

In 2019, work continued on the study of molecular phenotyping of IPF to improve patient outcomes. This project aims to identify and investigate specific blood and other biomarkers that reliably indicate lung disease, which in the future could potentially be used to help doctors diagnose IPF or predict the progression of this disease. The Australian IPF Registry Steering Committee members are undertaking this important work thanks to funding received from the National Health and Medical Research Council.

Associate Professor Peter Hopkins, IPF Registry Steering Committee Member.

Understanding the role of genetics

The Australian-first Genetic Research in IPF (GRIPF) study began recruiting families thanks to funding from a philanthopic family that will support a collaborative five-year research study with the Menzies Institute for Medical Research. This study aims to look at familial IPF, where multiple members of a family have fibrotic lung disease. It's an early step towards determining the role of genetics in IPF and aims to identify underlying genetic drivers which may improve our understanding and better inform the approach to improved detection, treatment and prevention of this devastating disease.

The community perspective

In 2019, registry participants, their families and carers were involved in a CRE-PF project that identified and ranked research priorities that are important to people who live with IPF. Participants throughout Australia took part in a combination of questionnaires and workshops. The results of this important study will be especially valuable to Lung Foundation Australia as we implement our newly developed Consumer Engagement Strategy and further strengthen our focus on improving consumer outcomes.

"The outstanding experts involved with the published and ongoing research with the Australian IPF Registry database is quite remarkable. The genetic and biomarkers studies are absolutely outstanding and the ongoing plan to evaluate other Interstitial Lung Diseases is also very valuable to the scientific community, given the limited data published so far."

Leticia Orsatti, Boehringer Ingelheim International GmbH, Australian IPF Registry Partner.

Chronic Obstructive Pulmonary Disease

In Australia, 1 in 7 people over the age of 40 has Chronic Obstructive Pulmonary Disease (COPD)[7].

Research in COPD has provided insight into the optimal treatment and management of COPD, including the importance of exercise and pulmonary rehabilitation in managing symptoms. Through our research awards program, Lung Foundation Australia continues to invest substantially in much-needed research of this highly prevalent chronic condition.

The Lung Foundation Australia Boehringer Ingelheim COPD Research Fellowship, established in 1999, funds early- and mid-career researchers and senior leaders in research to undertake research into the diagnosis, treatment and management of COPD.

Spotlight on Research

Recipient: Doctor Christian Osadnik

Partner organisation: Boehringer Ingelheim

Award: Lung Foundation Australia Boehringer Ingelheim COPD Research Fellowship

Duration: 2017/2018

Award value: $160,000

Project: Towards tailored rehabilitation for COPD exacerbation phenotypes: looking back for the future.

The issue addressed

COPD is the most common cause of potentially preventable hospitalisations in Australia. Exacerbations, or flare-ups, in people with COPD do long-term damage and can increase risk of death. They can be overwhelming and debilitating and often recovering physically from an exacerbation can take some time.

This project sought to better understand the detectable factors that contribute to recovery after discharge to focus attention towards the correct treatment for the individual. Treatments like pulmonary rehabilitation are excellent options to facilitate recovery, but alternative models of care may also need to be developed to better support people with frailty.

"This research would simply not have occurred without the joint support of Lung Foundation Australia and Boehringer Ingelheim. I have a passion for clinical respiratory research, but the reality is that this can only occur in fine balance with concurrent full-time employment. Obtaining a fellowship salary was the only way I could backfill my other academic duties to dedicate the requisite time to undertake the research, and I am so grateful for that opportunity."

Doctor Christian Osadnik.

Outcomes

This study found that frailty was associated with considerably poorer function at the time of discharge and a heightened risk (almost 4-times) for hospital readmission within 90-days. This suggests it is a very important trait to detect during the time of hospitalisation, yet it is not common within current models of Australian respiratory healthcare. The good news is that a large proportion of people who have frailty during the time of hospitalisation will see this spontaneously resolve. It is hoped findings from the study will lead to an improved ability to appropriately triage individuals with high rehabilitation needs.

This could lead to more tailored approaches for patients, improved recovery from exacerbations and better quality of life.

The seed funding provided by the *Lung Foundation Australia Boehringer Ingelheim COPD Research Fellowship* has enabled Doctor Osadnik to go on and obtain additional research funding, to the total value of over $2.5 million.

"Research is essential to improving quality of life for people like me who are impacted by COPD. Funding is crucial to finding the answers to the many questions we have about the disease. Finding tailored treatment and management techniques provide hope for a brighter future."

Russell Winwood, who lives with COPD, has raised over $7,000 for Lung Foundation Australia through his participation in running and triathlon events.

Bronchiectasis

Bronchiectasis is a common lung disease caused by chronic infection that damages the lungs. The prevalence of bronchiectasis continues to increase worldwide, however little is understood about the incidence, diagnosis and mortality in Australia[8].

With data collected through our Australian Bronchiectasis Registry, Lung Foundation Australia is working to create a clearer picture by supporting ground-breaking research projects to improve outcomes and quality of life for those living with bronchiectasis.

Australian Bronchiectasis Registry

As the reported prevalence of bronchiectasis increases worldwide, the need to better understand how to diagnose and treat the disease is more pertinent that ever.

Lung Foundation Australia's Australian Bronchiectasis Registry (ABR) systematically collects data on patients diagnosed with bronchiectasis to provide researchers around the world a critical source of rich data to fuel their studies. Registry participation continued to grow in 2019 with over 1,380 adult and paediatric patients to-date, across 27 sites.

Through the ABR, Lung Foundation Australia collaborates closely with key European and North American researchers to build on the existing evidence base for treatment and explore novel approaches through state-of-the-art methodology. In 2019, we were proud to join forces with clinicians, patients and researchers in New Zealand to support and develop their national registry which will correspond with patient data collected in Australia. These partnerships open the door for further collaborations and set the foundation for attracting international industry sponsored trials to Australasia.

The consumer voice

2019 saw a renewed focus on integrating the consumer voice in the design and development of clinical trials, with the first consumer members joining the Scientific Review Subcommittee. Integrating consumer feedback into research is integral to ensure our research questions and priorities align to the needs of patients. Consumer engagement in bronchiectasis research is not only ensuring that research is responsive to societal changes and public expectations, but also aids patient recruitment and trial participation. This year, the consumer perspective also drove the development of the Bronchiectasis Action Plan and Bronchiectasis Stepwise Management Plan which will be published in 2020.

"Every year, we see the hard work of researchers from the recent past come to fruition in the clinic room and bedside. It gives us hope that similar breakthrough therapies might be just around the corner for all our patients."

Associate Professor Lucy Morgan, Australian Bronchiectasis Registry Chair.

Baseline adult data fuels research

In 2019, the ABR achieved its first publication entitled *Australian adults with bronchiectasis: The first report from the Australian Bronchiectasis Registry*. This paper describes the baseline characteristics of adult ABR participants and assesses the impact of disease severity and exacerbation phenotype on quality of life. This important step to understanding the unique patient profile has helped renew interest in a condition that has been historically neglected in research and has fuelled collaborations with the University of Newcastle and the Hunter Medical Research Institute. It has also contributed to the development of business cases for future investment in research to discover more effective prevention, diagnosis and management approaches.

Turning the spotlight to paediatrics

The ABR is the only registry in the world to include paediatric data. In 2019, the quality and integrity of this data set was integral to the successful application for a Medical Research Future Fund grant to initiate a world-first trial recruiting both children and adults with primary ciliary dyskinesia, a rare cause of bronchiectasis. This trial, commencing in 2020, is an interdisciplinary collaboration including paediatric and adult clinicians, physiotherapists and lung specialists all coming together to improve outcomes for both children and adults.

"I hope that with more research, we can find treatments that will help children and adults with this disease to live the best life they can and that hopefully one day we can find a cure."

Lauren Bennett, mother to 6-year-old Ethan who lives with bronchiectasis.

Corporate Partners and Supporters

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
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Community Champions

Your donations in action

Lung Foundation Australia thanks each individual who supported us throughout the year, no matter how big or small. Your contribution and support are helping to change the future for people living with lung disease and lung cancer. Here is a snapshot of the current research projects made possible through the generosity of our community.

Brian Eaton

In 2016, five years after diagnosis, Brian lost his fight with Idiopathic Pulmonary Fibrosis (IPF). In his memory and thanks to the generosity of the Eaton family, the *Lung Foundation Australia Brian Eaton Memorial PhD Scholarship in IPF* was founded and will support Doctor Matthew Parker's research investigating novel methods to distinguish IPF from connective tissue disease-associated Interstitial Lung Disease.

"I know the question that plagued Brian during his illness was what was the initial cause of this disease and I hope that in the near future we will have that answer." **Bernadette Eaton, Brian's wife.**

Ellen Yates

Elizabeth Yates, with the support of her family and friends, hosted two gala balls in memory of her mother Ellen Yates, collectively raising $37,000. In 2019, the *Lung Foundation Australia Ellen Yates Lung Cancer Grant-in-Aid* was founded and will support Doctor Afaf Abed's research investigating predictive biomarkers of response to immunotherapy in lung cancer.

"All patients with lung cancer should get the same treatment and importantly support offered to them as any patient with cancer would." **Elizabeth Yates, daughter to Ellen Yates.**

Diana Cox

In 2019, through Diana's generous support, the *Lung Foundation Australia Diana Cox PhD Scholarship in IPF Research* was founded. This award is supporting PhD student Doctor Laura Glenn in her research to increase diagnostic accuracy in Interstitial Lung Diseases (ILD). This research is using new technologies to gain a greater understanding of the diseases and overcome the current barriers to accurate ILD diagnosis.

"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, lives with IPF.**

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Lung Foundation Australia recognises the tremendous and voluntary contribution of committee members.

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How You Can Support Us

Invest in the future

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.

Help find a cure

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.

Get involved

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.

Philanthropy and partnerships

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 up-to-date on progress. This is our promise.

Community fundraising

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.

Lung Foundation Australia

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