

Annual Report 13



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We bring together key opinion leaders in respiratory medicine, physiotherapy, nursing and primary care...



Our vision is to “ensure lung health is a priority for all in Australia”...

WHO WE ARE

Lung Foundation Australia was founded almost a quarter of a century ago to provide support for patients and carers living with lung disease. We bring together key opinion leaders in respiratory medicine, physiotherapy, nursing and primary care to develop resources, training and education to help increase awareness of the importance of maintaining good lung health, help provide better management and slow disease progression.

The Lung Foundation supports all aspects of lung health from COPD to lung cancer to the rarer lung diseases such as pulmonary fibrosis. We have a proud history of community education and run a toll free patient information and support centre with a lung care nurse. We're a national organisation which supports research, develops educational resources, trains health professionals, and undertakes community awareness activities and advocacy around Australia.

STRATEGIC GOALS

- To promote lung health
- To promote early diagnosis of lung disease
- To support those with lung disease and their carers
- To promote equitable access to evidence-based care
- To promote quality research

OUR VALUES

At Lung Foundation Australia, we are:

- Community focused
- Quality focused
- Respectful of the individual
- Responsible for our work environment
- Striving for excellence

to make lung health a priority for all in Australia.



A/Prof David Serisier, Chairman



William Darbishire, CEO

The success and advances at the Lung Foundation are only possible because of the massive amount of time that both community members and clinicians generously donate.

Foreword

2013 has been another spectacular year for Lung Foundation Australia. For the second year running we have achieved average income growth of more than 25% and it is also pleasing to see the results returning to surplus once again. The Lung Foundation annual income broke through the \$5 million barrier in 2013, allowing us to provide even more services for those in the community affected by lung disease.

We started 2013 with a completely new governance model as a public company limited by guarantee.

At that time the governance of the organisation was handed over from the National Council to a new board of directors. The board met frequently during the year and approved the 2013 to 2016 strategic plan at their February meeting.

Our grateful thanks go to the Lung Foundation Australia board of directors who provided such solid strategic direction and leadership in 2013:

- Associate Professor David Serisier - Chair
- Mr Andrew Churchill – Treasurer
- Professor Peter Frith
- Mr David Hayne
- Professor Christine Jenkins
- Mr David MacIntosh AM
- Professor Martin Phillips
- Dr David Michail
- Dr Simon Bowler
- Professor John Upham

During 2013, we were sorry to see Professor Upham, Dr Bowler and Mr MacIntosh step down from the board. We are deeply grateful for the input and guidance they have provided to the Lung Foundation over the years.

We are also most grateful to the Lung Foundation National Council members who have given their support and energy so selflessly to the organisation as a key strategic advisory group. In addition to the board of directors the following served on the National Council during 2013:

- Professor Gary Anderson
- Professor Mark Holmes
- Associate Professor Peter Holmes
- Dr James Markos
- Dr Lucy Morgan
- Professor Matthew Peters
- Professor Paul Reynolds
- Mr Peter Stapleton AM
- Dr Christopher Worsnop

During 2013, Associate Professor Peter Holmes stepped down from the National Council after more than two decades of service to the Lung Foundation. Peter will be sorely missed and has been the inspiration for many of our consultative groups over his many years of service.



During the year we continued to work with our Lung Health Alliance partners and have agreed on a positive strategic direction for 2014 and beyond.

The Lung Health Alliance Partners are:

- Asthma Australia
- Australian Respiratory Council
- Cystic Fibrosis Australia
- Lung Foundation Australia
- National Asthma Council Australia
- Thoracic Society of Australia and New Zealand

The success and advances at the Lung Foundation are only possible because of the massive amount of time that both community members and clinicians generously donate. As you will see in the pages of this report, our volunteers, particularly our clinical advisors, form the backbone of all our projects. Without our volunteers we would achieve nothing.

2013 has been another momentous year for the Lung Foundation. Our thanks go to all our dedicated and talented staff members and, in particular, the executive management team who have all served "above and beyond" the call of duty in 2013:

- Glenda Colburn (Director - Lung Cancer National Program)
- Chris Emery (Director of Operations)
- Elizabeth Harper (Director - COPD National Program)

14% of all deaths in Australia are caused by lung disease, including COPD, asthma, bronchiectasis, lung cancer, influenza and pneumonia.

We continue to raise funds for important research work in the lung health field and in 2013 we passed an important benchmark of more than 150 research awards made possible by the Lung Foundation over the years, with more than \$2.5 million awarded in recent years. In 2013, we advertised 12 awards and scholarships, six of which will be presented at the Thoracic Society of Australia and New Zealand (TSANZ) 2014 Annual Scientific Meeting.

Our strategy is very clear - the Lung Foundation will continue to respond to the ever-increasing need in our community, providing support and a voice for those affected by lung disease. We will continue to ensure the sustainability of our organisation in an environment that

faces increasing competition for funding dollars. At Lung Foundation Australia we are driven by the knowledge that good lung health is crucial to an individual's overall health. Like lungs, we never rest - in our pursuit of solutions for the community we serve.

We commend the 2013 Annual Report to you.

14% of all deaths in Australia are caused by lung disease, including COPD, asthma, bronchiectasis, lung cancer, influenza and pneumonia.





Elizabeth Harper, Director

COPD National Program

KEY ACHIEVEMENTS

The COPD National Program had a very successful year under the clinical guidance of Professor Peter Frith, Professor Christine McDonald, Associate Professor Ian Yang and Dr Kerry Hancock. An enormous workload was undertaken by the COPD National Program team members with the support of a large number of dedicated volunteer clinicians and consumers.

- The launch of new training programs and resources completed a comprehensive suite of COPD resources across the primary care continuum, including:
 - COPD Pharmacy Online training and supporting resources and collateral to assist a pharmacist to implement a COPD Service in Community Pharmacy
 - Pulmonary Rehabilitation Training online to up-skill health professionals in the delivery of evidence-based, best practice pulmonary rehabilitation
 - Updated COPD Action plan
- Collaborations with Medicare Locals to improve management of COPD in primary care and reduce hospital admissions
- Formal quality accreditation and continued growth of the Lungs in Action community based exercise maintenance program
- The largest World COPD Day event to date - more than 70 community pharmacies participated in about 240 events held nationally

FOCUS POINTS

COPD Service in Community Pharmacy

In September, we launched the COPD Pharmacy Online training. Mr David Hayne led a committee of members from respiratory medicine and nursing, general practice, the Pharmaceutical Society of Australia, The Pharmacy Guild, the Australian College of Pharmacists, the Society of Hospital Pharmacists of Australia, the Australian Association of Consultant Pharmacy, community pharmacy and academic pharmacy in the development of this comprehensive program.

The online training was an important part of the COPD Pharmacy Training and Support Program which included the online training, webinars and other collateral specifically developed for pharmacy.

The pharmacy training and support program was developed to complement activities recognised in the primary care continuum through the Quality Care Pharmacy Program. These activities include:

a) Health Promotion – The pharmacy setting is an ideal place to hold static displays and other health promotion activities about COPD. It is estimated a person visits a pharmacy on average 14 times per year.

- b) Risk Assessment and Screening – Pharmacist prompts to undertake risk assessment and screening were addressed through the pharmacy dispensary software (Guildcare). This incorporates the Lung Health Checklist and COPD screening using a COPD screening device. Prompts within the software are initiated whenever smoking cessation prescriptions are received. Posters and shelf wobblers were also developed to provide cues for pharmacy consumers to ask about COPD and/or request a lung health check. The Lung Health Checklist and COPD fact sheets were added to the modules on Healthpoint touchscreens which are available in more than 700 pharmacies. Lung Foundation Australia's website provides additional supporting resources.
- c) Disease State Management - Pharmacists can support people with COPD to better self-manage by checking on their inhaler device technique, undertaking a Meds Check to ensure the quality use of their medicines, conducting Home Medicine Reviews, ensuring they have the COPD Action plan and providing a copy, providing them with information about their disease, pulmonary rehabilitation and directing them toward the Lung Foundation for resources and connection to support groups.



CLINICAL SUCCESS

- Medicare Local support – The COPD National Program team met with 29 of 61 Medicare Locals in 2013 to promote the Lung Foundation’s resources for COPD and education/training for health professionals. The COPD program has provided assistance through consultation and/or more formal partnerships. This entailed presentation of resources and attendance at meetings with Medicare Locals who identified COPD as a significant issue. This interaction combined with promotions through primary care and allied health conferences and workshops resulted in a 92% increase in registrations on the COPD-X Guidelines website.
- The COPD Online training program for primary care nurses has been hugely successful with more than 800 enrolments since its launch almost two years ago. Nurses who have undertaken the training have reported increased confidence in managing patients with COPD. This program provided the base content for the new COPD Pharmacy Online training program.
- Lungs in Action – This community based exercise program for people who have completed pulmonary and/or heart failure rehabilitation continues to develop and grow. Dr Lissa Spencer provides clinical guidance to the program and has been supported by many dedicated pulmonary rehabilitation and heart failure clinicians acting as mentors to the Lungs in Action instructors. There are 48 locations nationally with a further 18 locations due to start in 2014. The Lungs in Action program was successful in obtaining quality accreditation with Healthy Living Network and as part of this process the Lung Foundation also successfully underwent a quality audit as a service provider. Healthy Living Network accreditation was established by the Department of Health and is only awarded to evidence-based exercise programs.
- Pulmonary Rehabilitation Training Online – This new online training program was launched in May 2013 and was designed for physiotherapists, exercise physiologists and nurses to provide education in the delivery of evidence-based, best practice pulmonary rehabilitation. The Pulmonary Rehabilitation Network, which now has more than 140 members, provides support to new programs.
- The dedicated COPD Evaluation Committee Chaired by Professor Michael Abramson undertook an enormous amount of work this year in continuing with the regular updates to the COPD-X Guidelines, a new version of which is due in 2014. This work was conducted concurrently with the development of the new COPD-X Concise Guide for Primary Care which was overseen by a Writing Committee Chaired by Professor Abramson and an Advisory Committee Chaired by Professor Peter Frith.

The COPD National program met with 29 out of 61 Medicare Locals in 2013 to promote the Lung Foundation’s large number of resources for COPD and education/training for health professionals...



PATIENT AND COMMUNITY SUCCESSES

COPD Patient Advocates Group – Ms Megan Rushton, began the year as Chair of the Australian COPD Patient Taskforce. The patient group changed its name to the COPD Patient Advocates Group (CPAG) after a review of its activities and what the members felt would be both achievable and rewarding. The CPAG group now acts as a consultative group for Lung Foundation Australia to provide consumer advice on resource development as well as trying to connect with the patient groups across Australia to ensure that they are providing an appropriate representation of views from consumers. The CPAG group will also provide grassroots dissemination of communication and health promotion messages within their community.

World COPD Day - In a change from previous years where these events were held mostly by patient support groups, only nine of the 240 events were patient driven. Pharmacies, GP surgeries, pulmonary rehabilitation programs, hospital and community health respiratory services, Medicare Locals, gyms and other businesses held static displays, community risk assessment and screening and/or walking events.

“Emerald says ‘Blow it’ and walks for COPD” was led by Mayor Peter Maguire and instigated by local patient, Sandie Parter. The mayor and Sandie presented on lung health at a local business breakfast and their local media covered the events. The event was supported by local health services and one of the community pharmacies.

Risk assessment and screening was conducted at Queensland Parliament House. It was a great opportunity to meet the Premier, Health Minister, Opposition Leader and other ministers and to highlight the importance of checking your lung health.

Channel 9 included a brief segment on the Lung Health Checklist during the Cricket Show with Michael Slater during the Brisbane test match at the Gabba cricket grounds.

A significant increase in media was achieved with more than 40 printed articles, three radio interviews and one television piece.

OPERATIONAL SUCCESSES

The COPD National Program team focused on collaboration during the promotion of our educational and training resources and community health messaging. Collaborations and partnerships with other organisations enabled the program to achieve much more than it could have alone.

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Glenda Colburn, Director

Lung Cancer National Program

KEY ACHIEVEMENTS

The **Lung Cancer Consultative Group** had a busy year with significant outcomes and saw the successful completion of the first year in our three year strategic plan 2013 – 2015. We launched two new patient resources 'Better Living with Lung Cancer Guide' and a Mesothelioma DVD, both of which have been distributed nationally and uptake has been positive. The Lung Cancer National Program participated in several national medical conferences throughout 2013. International collaborations have continued to grow. Glenda Colburn has taken on the position of Chair of the International Association for the Study of Lung Cancer's (IASLC) Patient Advocacy Group and continues to participate as the Australian member of the Global Lung Cancer Coalition.

FOCUS POINTS

The Lung Cancer National Program consists of four main aspects and these are managed by a dedicated team within the Lung Foundation and significant support from volunteer clinicians and consumers.

- Lung Cancer Consultative Group (Chair Prof Kwun Fong)
- Australasian Lung cancer Trials Group (Chair Prof Paul Mitchell)
- Kylie Johnston Lung Cancer Network (Chair Prof Matthew Peters)
- Australia and New Zealand Lung Cancer Nurses Forum (Chair Ms Mary Duffy)

Highlights of 2013 include the Indigenous work the LCNP collaboratively developed including lung cancer symptom awareness posters, a flipchart, aboriginal patient stories including popular national singer/songwriter, Archie Roach's survival story, the 'Let's yarn about lung cancer' DVD was created to inform aboriginal people about the risks and symptoms of lung cancer. We also created an aboriginal awareness pin.

The LCNP placed a winning bid in 2008 to host the 15th World Conference on Lung Cancer (WCLC) in Sydney in 2013. After nearly six years of planning, 2013 saw the successful delivery of this international congress with the majority of delegates noting this was one of the most exciting and scientifically stimulating WCLCs. The new, more compact conference schedule featured more abstract sessions and presentations than any other in the history of WCLC, with a record number of 2,319 abstract submissions. 5,331 delegates attended representing 94 countries, and the conference finished with a higher than anticipated profit.

CLINICAL SUCCESSES

A key clinical focus was in the primary care setting working with local communities to deliver GP and Medicare Local workshops. The Lung Foundation, together with Cancer Australia, conducted workshops to raise awareness of lung cancer symptoms, early diagnosis strategies and rapid referral into an appropriate hospital, promoting the newly launched 'Investigating symptoms of lung cancer: a guide for GPs'. These workshops also provided an opportunity to promote our GP Guidelines and other resources for lung cancer and COPD. These workshops were well attended and interactive.

Australasian Lung cancer Trials Group (ALTG) – 2013 was another strong year for ALTG, with membership increasing to more than 400 members and finances in good shape. ALTG were successful in obtaining ongoing funding from Cancer Australia for 2013 – 2016. This funding supports clinical trial protocol development and group activities during the next three years. ALTG held their strategic planning meeting for the 2013 – 2016 period and identified four main focus areas: funding, clinical trials, capacity building and communications, and business planning.

In October, ALTG was awarded an NHMRC project grant to complete recruitment for the NITRO trial. More than 400 of the required 550 patients have been recruited with the remaining patients to be recruited in 2014.

At the World Conference on Lung Cancer, the ALTG organised and hosted an inaugural meeting of International Lung Trial Groups. Eighteen trial groups from around the world attended the meeting and discussed international collaborations on trials and establishing an international forum. ALTG is providing secretariat support on the establishment of this International Lung Trial Group Steering Committee to oversee future activities and collaborations.

PATIENT AND COMMUNITY SUCCESSES

November is lung cancer awareness month saw the LCNP build on the successes of our lung cancer awareness activities. Lung Foundation Australia hosted the first international 'Shine a Light on Lung Cancer' gathering in Sydney during the World Conference on Lung Cancer with more than 32 countries and local communities participating. A further three vigils (Canberra, Perth and Albury) took place during November with more than 300 participants. 2013 saw the introduction of a Shine a Light social media campaign which included Facebook and Instagram to connect people who could not attend the vigils. November social media activity increased our followers from 1,949 to 2,817, with 634 visits to our Shine a Light website page.

Lung Foundation Australia would like to gratefully acknowledge the outstanding contributions of lung cancer survivor, Sandy Sampson (pictured), who has raised almost \$35,000 for lung cancer patient support initiatives. Sandy is a passionate advocate for lung cancer awareness and has participated in media interviews, consumer activities and events as well as sharing her personal story on the Kylie Johnston Lung Cancer Network (KJLCN) website.

KJLCN continues to provide information and support to those affected by lung cancer. Due to demand, we contracted a lung cancer nurse based at the Peter MacCallum Cancer Centre in Melbourne to assist with patient services including telephone support groups, patient support, online patient forums, articles and other ad-hoc duties.

A 2013 highlight was the hosting of our first ever international consumer forum 'A focus on lung cancer' in Sydney just before WCLC. More than 140 consumers and lung cancer health professionals attended this patient centred forum that featured a panel of global leaders in lung cancer treatment, research, support and advocacy including IASLC President elect, Dr David Carbone and US patient advocate, Bonnie J Addario from the Bonnie J Addario Lung Cancer Foundation based in San Francisco.

All panellists gave presentations and participated in an interactive Q & A session. Forum presentations were filmed and are available on the Lung Foundation website.

OPERATIONAL SUCCESSES

The Lung Foundation successfully leveraged a generous bequest from Mr Neville Bantoft, a young man who passed away from lung cancer, to support lung cancer research PhD scholarships. The LCNP identified three universities to co-fund these scholarships, allowing two extra opportunities to be offered. One remaining PhD will be advertised in 2014.

ANZ-Lung Cancer Nurses Forum (ANZ-LCNF) hosted a Mesothelioma Workshop in Sydney on 26th May 2013, the program was endorsed by the Cancer Nurses Society of Australia with more than 80 attendees. Sponsorship was obtained to deliver this workshop with delegates providing positive feedback. Proceeds from this workshop allowed the ANZ-LCNF to provide six travel grants for Australian Nurses to attend the WCLC in Sydney.

Lung Foundation Australia is seeking funding for a two-year pilot program to provide Lung Cancer Nurses as part of the 2014-15 federal budget. While grateful for the steps taken by the Australian Government to support people with cancer in recent years, the Lung Foundation believes there is a vital need for more lung cancer specific nurse roles to improve outcomes and reduce the burden on the overall health bill. The recommended pilot focuses on placing Lung Cancer Nurses in hospitals which have specialist lung cancer services, leading to:

- minimised delay in referral from GPs
- timely access to diagnosis, treatment and care
- improved patient outcomes

We started a direct meeting program with federal government stakeholders to secure this funding. These meetings will continue until the 2014 budget in the hopes of a positive announcement in the May budget.





ASBESTOS-RELATED DISEASE/MALIGNANT PLEURAL MESOTHELIOMA

2013 saw the development of an Asbestos-Related Disease/Malignant Pleural Mesothelioma (ARD/MPM) Nurse Education Program supported by funding from Comcare Australia's Asbestos Innovation Fund. The one year pilot led by Judy Rafferty, clinical nurse educator, saw the creation of an online and practical educational program as well as the graduation of 10 nurses from around Australia who piloted and undertook this program. These nurses became the first members of the Malignant Pleural Mesothelioma Nurse Special Interest Group and mentors for their nursing peers.

One of the highlights of the pilot program was a four day workshop for the 10 nurse participants at the Asbestos Disease Research Institute (ARDI) in Sydney at the end of July. The workshop included visits with local hospitals and centres, observing a lung multi-disciplinary team meeting and visiting a pathology and radiology department. The workshop program also included presentations from key opinion leaders on pertinent topics such as surgery, exercise for mesothelioma patients, the history of asbestos and asbestos-related disease, legal considerations, treatments, and living with mesothelioma. This provided an opportunity for the nurse participants to network, share ideas, discuss current work practices and plan for the future of the Mesothelioma Nurse Special Interest Group.

A key clinical success of this program was the development of an online and practical ARD/MPM Nurse Education program. The education program was piloted by the 10 nurse participants and will be available in 2014, following endorsement by the Australian College of Nursing.

Two key patient and community successes from the ARD/MPM Program were the development of a new Malignant Pleural Mesothelioma Education Brochure and the hosting of the inaugural Mesothelioma Morning Tea awareness

activities by the 10 pilot nurse participants within their hospital institutions. These mesothelioma morning teas and displays provided an opportunity for community members and those living with mesothelioma to learn more about the disease, collect mesothelioma education resources and speak with a nurse about asbestos-related diseases and mesothelioma. These activities gained media interest with articles in newspapers and on local television in Canberra.

The operational successes of the ARD/MPM program in 2013 were primarily completing the Comcare Australia funded project within the allotted 12 month period. Within this space of time an online educational program had to be developed and transitioned to a web platform specifically designed for the program, 10 nurses needed to be recruited (with representation of at least one nurse from each State/Territory), plan and conduct a four day workshop, develop a practical education component, prepare and print a patient education brochure, launch the MPM Nurse Special Interest Group, and seek additional funding to support the project.

The project team met all milestones within the budget and on time, providing excellent opportunities for the ARD/MPM Program to continue its growth in 2014.





Nigel McPaul,
Group Project Manager

Rare Lung Diseases and Chronic Cough

Pulmonary Interstitial Vascular Organisational Taskforce (PIVOT) and Cough in Children & Adults: Diagnosis & Assessment (CICADA).

KEY ACHIEVEMENTS

The PIVOT and CICADA Consultative Groups had a positive 2013 with a number of activities being undertaken to raise awareness of rare and interstitial lung diseases (PIVOT) and chronic cough (CICADA) within both the clinical and patient communities.

PIVOT

Focus Points

The PIVOT Consultative Group's key achievement in 2013 was the Inaugural Australian Rare Lung Disease Short Course (ARLDSC) held in Sydney in August. The joint venture between Lung Foundation Australia and the Thoracic Society of Australia and New Zealand (TSANZ) brought together more than 130 delegates from around Australia and included respiratory physicians, scientists, advanced trainees and respiratory nurses.

Clinical Successes

The Inaugural ARLDSC comprised a scientific program that brought together leading national and international experts. These experts presented information on connective tissue disease, cystic lung disease, diffuse pulmonary infiltrates, idiopathic interstitial pneumonia, and a paediatric program on the Saturday.

Feedback indicated that, overall, attendees found the event to be a positive and valuable experience with many praising the program content and selected speakers. Attendees also expressed great support for future Rare Lung Disease Short Courses.

The Australian Registry Network for Orphan Lung Disease (ARNOLD) continued to gather valuable information on the incidence and prevalence of orphan lung disease in Australia. Information gathered from ARNOLD supported further research into Orphan Lung Disease and was also a valuable resource for groups such as Rare Voices Australia.

Patient and community successes

The PIVOT Consultative Group continued to update and distribute patient education brochures on interstitial, orphan and rare lung diseases. 2013 saw the update of the sarcoidosis educational brochure and discussions at the PIVOT Consultative Group meeting at the TSANZ ASM on potential new educational brochures.

Operational successes

At the conclusion of the ARLDSC several attendees participated in a meeting to consider what assets Australia currently has in Interstitial Lung Disease (ILD) research and construct a plan for their utilisation. This meeting proved to be a valuable

opportunity for these specialists and researchers to share thoughts on current and future ILD research and collaboration with other leading ILD specialists and researchers.

Australian IPF Registry

The Australian Idiopathic Pulmonary Fibrosis (IPF) Registry gained substantial momentum in 2013, with 362 IPF patients and their respiratory physicians participating across all States and Territories. Directed by a national multidisciplinary steering committee, this initiative has created a unique research platform and will be funded into 2014.

The Registry gained recognition and interest and data was presented at national and international forums. The Registry Principal Investigators were awarded a major three-year research grant by the National Health and Medical Council (NH&MRC).

CICADA

Focus Points

The CICADA Consultative Group's key achievement in 2013 was the launch of a consumer educational resource co-badged and developed in collaboration with Asthma Australia called 'Understanding Cough, Wheezing and Noisy Breathing in your Child'.

Clinical Successes

The CICADA Consultative Group met at the TSANZ Annual Scientific Meeting (ASM) in Darwin in March and discussed a number of topics including a timeline for the scheduled update of the CICADA Chronic Cough Guidelines. It was agreed the group would wait for the USA guidelines to be launched before updating the next Australian guidelines.

Patient and community successes

2013 saw the launch of a consumer focused educational brochure providing parents with easy-to-read information on cough, wheeze and noisy breathing in children. The educational brochure developed and co-badged with Asthma Australia combined information from the CICADA Chronic Cough Guidelines, National Asthma Council and Asthma Australia resources into a small brochure available to parents of children with a cough, wheeze or noisy breathing.

Operational successes

The CICADA Consultative Group fostered a valuable relationship with Asthma Australia in the development of the co-badged consumer educational brochure which will strengthen CICADA's ability to develop and disseminate future resources.



Melissa Ram, Project Manager

Self Management and Palliative Care

KEY ACHIEVEMENTS

In 2012, Lung Foundation Australia was successful in a grant application via the Department of Health to assist those living with a lung disease better self-manage their disease. A series of 10 short evidence-based DVDs, focusing on increasing a patient's knowledge and confidence on managing their lung disease were developed, and a series of 10 regional seminars were facilitated nationally. More than 1700 sets of the series were disseminated throughout Australia to health professionals, patients and via patient support groups and seminars. The seminars attracted attendees ranging from 23 in Darwin to 147 in Port Macquarie.

PATIENT AND COMMUNITY SUCCESSES

Throughout 2013 significant progress was made on the development and implementation of the self-management project 'Better Living with your Lung Disease'. This series of 10 short evidence-based DVDs, focuses on increasing a patient's knowledge and confidence on managing their lung disease, their general health, and how to be an active member in their healthcare decisions. 'Better Living with your Lung Disease' provides many practical tips ranging from improving communication between doctor and patient, tips for improving activities of daily living, and breathing exercises to reduce anxiety, panic and breathlessness.

A primary focus of the self-management project is to increase access to high quality, evidenced-based information for people living with a lung disease in regional areas of Australia. It is widely reported these populations are often disadvantaged in healthcare due to their distance from major cities. 'Better Living with your Lung Disease' funded 10 regional Patient Seminars across Australia, to deliver lung disease self-management education and skills building to the community. The 2013 seminars were a great success, with many people travelling far and wide to attend as these were the first of their kind in their area. The practical presentations were delivered by local health professionals and will be repeated in 2014 to demonstrate an increase in attendance and need.

SUPPORTIVE AND PALLIATIVE CARE

Key Achievements

Our Supportive and Palliative Care key strategies for 2013 included:

- a lung disease specific definition for Supportive and Palliative Care in both malignant and non-malignant lung disease
- a Lung Foundation Australia Position Statement outlining our stance on Supportive and Palliative Care within lung disease
- the development of a Supportive and Palliative Care Checklist (a tool to identify if consumers may benefit from accessing supportive and/or palliative care services).

Clinical Successes

Although Supportive and Palliative Care is a new area for the Lung Foundation, we have accomplished many key milestones throughout 2013. With an initial face-to-face committee meeting in February, chaired by Prof David Currow, our key strategies for 2013 were set.

The National Palliative Care Strategy is currently being reviewed by the Federal Government. The current 2012 Strategy does not include a policy for respiratory and/or lung disease. The Lung Foundation has initiated consultation with the Strategy Review Committee to ensure the 2017 Strategy includes palliative care in both malignant and non-malignant lung disease.





Juliet Brown,
Program Development Manager

Information and Support Centre

KEY ACHIEVEMENTS

It was a fantastic year for the Information and Support Centre with the largest number of enquiries to date, the launch of an electronic version of LungNet news, the re-appointment of a Lung Care Nurse and supporting the 'Better Living with Your Chronic Lung Disease' project.

FOCUS POINTS

Regional Patient Seminar, Bundaberg

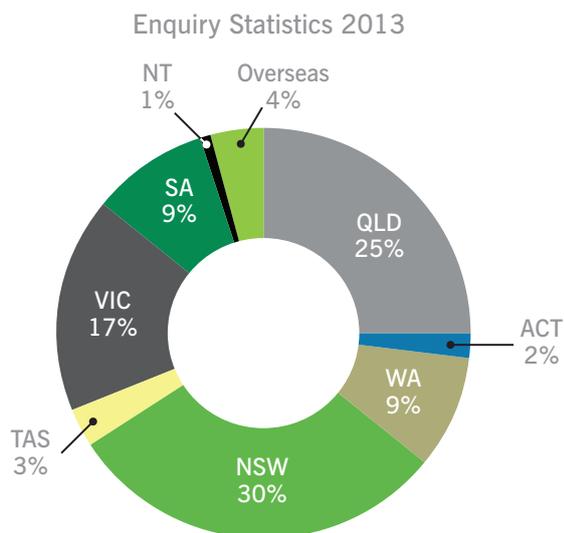
The inaugural Bundaberg Seminar was a hugely successful event coordinated in conjunction with Bundaberg Health Promotions. Lung Foundation Australia's Information and Support Centre staff members received a warm welcome from the attendees who were delighted this event was being held in their region for the first time. Almost 100 people attended to hear presentations from three guest speakers who spoke about Breathing and the Relief of Breathlessness, Energy Conservation and the Demystification of COPD.



PATIENT AND COMMUNITY SUCCESSES

Information and Support Centre Enquiry Statistics 2013

2013 proved to be an extremely busy year for the Information and Support Centre with almost 5200 enquiries received either via our free-call 1800 number or our enquiries email. A breakdown of the enquiries by state and territory and overseas is shown in the graph. 11% of our enquiries were electronic and 10% of our total enquiries came as a result of finding the Lung Foundation's website via an internet search. The most common query was about COPD (33%), followed by pulmonary rehabilitation (10%), oxygen (7%), idiopathic pulmonary fibrosis (4%), lung cancer (4%), bronchiectasis (3%). Enquiries were received from patients, carers and health professionals.



LungNet News

Our quarterly newsletter continued to be well-received in 2013 with almost 12,900 recipients at the end of the year, an increase of 200 compared with 2012. An electronic version of the newsletter was launched in August 2013 and 14.5% of readers have taken up this option, an increase of 4.5% on 2012.

Lung Care Nurse

The work of the Information and Support Centre has been augmented by the appointment of a Lung Care Nurse who provides confidential support, information and advice to telephone enquirers.

Lung Health Patient Education Days

Lung Health Patient Education Days, which provide a program of guest speakers presenting on respiratory health related subjects, took place in all States and in the ACT. More than 720 people registered to attend the 2013 program of events. The Information and Support Centre also played a pivotal role in the organisation of the series of Inaugural Regional Patient Seminars which comprised one component of the 'Better Living with Your Lung Disease' self-management project.

Patient Support Group Network

There are well over 100 self-help Patient Support Groups in our network and we were delighted by the formation of a new Support Group in Western Australia - the Northern Easy Breathers in Heathridge, a northern suburb of Perth. In Brisbane and the surrounding areas, Patient Support Group Leaders welcomed the opportunity to attend Group Leaders' meetings hosted by Lung Foundation Australia at our offices in Milton. The meeting allowed the Leaders to provide input to the planning of the National Lung Health Patient Education Day in Brisbane, including suggesting speakers and presentation topics. In addition, it was a great opportunity for them to share information about the running of their respective Support Groups.

Pulmonary Rehabilitation Programs

The Information and Support Centre continued to maintain a list of pulmonary rehabilitation programs Australia-wide, of which there are now over 300.

Volunteers

Our hard-working LungNet News volunteer team has been indispensable in 2013 and were joined by several new recruits. This is extremely welcome given the ever-increasing number of people receiving the newsletter. In addition to labelling and mailing all four editions of LungNet News, the volunteer team took on extra work with additional mail-outs and collating and boxing the 'Better Living with your Lung Disease' self-management DVD. Our Information and Support Centre volunteer, Eileen Perry, is in her eighth year of working with us, assisting with answering calls to the 1800 number, sending out information packages and maintaining our database of LungNet News recipients. We could not do without the invaluable support and commitment she generously provides. In addition, we acknowledge the efforts of two new volunteers, Ian Venamore who is conducting a telephone survey with the Patient Support Groups, and Fabrice Rochat who is working with the COPD National Program team.



Damon Cavalchini,
Senior Manager, Lung
Health National Program

Marketing, PR and Fundraising

KEY ACHIEVEMENTS

Tax appeal

Thanks to our supporters who donated so generously, our tax appeal raised more than \$20,000. These donations were used to help fund a lung care nurse to assist patients and their families through their diagnosis, treatment and follow up.

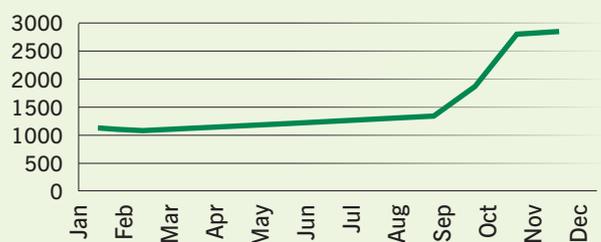
Social media

2013 has seen significant growth in our social media, particularly on Facebook with a 40% increase in people following our page.

We also started an Instagram account as a part of the Shine a Light on Lung Cancer vigils and held 'virtual vigils' which proved to be very successful, with almost 100 people posting images.

2013 has seen a significant growth in our social media, particularly on Facebook...

Facebook growth 2013



FOCUS POINT

National campaign – Increase awareness leading into campaign

In late 2012, Lung Foundation Australia signed an agreement with the Federal Government to deliver the Chronic Lung Disease Self-Management Project which launched in 2013 (see page 11) and the National Lung Health Community Awareness and Promotion Campaign which will launch in March 2014. The National Awareness campaign will involve a mix of television advertising, public relation events and general awareness activities.

The campaign aims to encourage people to “Check In with your Lungs” by doing the revised, interactive lung health checklist on the Lung Foundation Australia website.

In 2013, we began the essential process of revitalising our website with a new look and feel as well as building capacity to offer significantly improved online services.

CLINICAL SUCCESSES

Pneumonia awareness week

Pneumonia Awareness Week was held from May 6th - 12th to raise awareness about the importance of Pneumonia vaccinations. The campaign received significant support from the professional community, with representation and logo endorsement from Lung Foundation Australia, leading infectious disease specialists, respiratory physicians and GPs nationwide.

During the week, there were more than 220 stories across television, radio and print/online media.

We had a great year of media with coverage in publications such as The Australian, The Courier Mail, Women’s Day, Herald Sun, The Telegraph, The Age and many others...

PATIENT AND COMMUNITY SUCCESSES

Breath of Life

In March, we worked with Octagon on the Breath of Life Music Festival in Launceston. The event was attended by close to 10,000 people who enjoyed entertainment from a range of high-profile Australian and international acts. It was a fantastic day and enjoyed by all, raising essential funds for Idiopathic Pulmonary Fibrosis (IPF).

Media and Public Relations

We had a great year with media coverage in publications such as The Australian, The Courier Mail, Women's Day, Herald Sun, The Telegraph, The Age and many others. We also had radio coverage on ABC stations nationally and many community radio stations as well as interviews on commercial television stations.

Once again we relied on the support of our extensive clinical networks to provide expert advice and commentary on lung health related issues in the media and we are truly grateful for the expertise and support provided.

OPERATIONAL SUCCESSES

ASX Campaign

Lung Foundation Australia received close to \$32,000 from the ASX-Thomson Reuters Charity Foundation in 2013. We are pleased to report that we also made a successful application for the 2014 art union.

General activities

Our Director of Operations, Chris Emery participated in 'Tuffy's Trek' in September, an eight day event which involved trekking the Kokoda Track. To date, this fundraiser has generated more than \$45,000 for the Lung Foundation's Lung Cancer initiatives.

As part of World COPD Day, Lung Foundation Australia staff visited Queensland's Parliament House to raise awareness about COPD. It was a fantastic opportunity to meet the premier, health minister and other members of parliament to impress on them the importance of lung health programs.

Lung Foundation Australia participated in the filming of 'Breathe Easy' which is one of six episodes of ABC's new mini series titled 'Save Your Life Tonight'. Our staff performed lung health screening of the audience members using the lung health checklist and PiKo-6 devices.

2013 was a year of change in the Marketing, PR and Fundraising team with an increased focus on grants and corporate sponsorship by appointing staff to specifically look after these tasks.

This year's Christmas card sales and seals appeal raised almost \$19,000, with about \$10,000 in donations being given during the appeal. To complement the cards, Lung Foundation Australia also hosted an e-card version on our website which included links to donation options.





Chris Emery, Director

Operations

It has been an important year of change for Lung Foundation Australia with a new name and a new corporate structure commencing on 1st January 2013. It has also been a successful year as our financial results show a surplus of \$449,894, principally due to an increased level of bequests received during the year. We have continued our investment in the business development capacity of the organisation and are projecting great outcomes from this investment in 2014.

With lower interest rates during 2013, we experienced a decrease in our returns on the Lung Foundation's investments during the year. In October 2013, the board approved the appointment of a funds manager, Mr Greg Zappala – Ord Minnet (Brisbane), to oversee the management of our investment portfolio. Lung Foundation Australia management believe a more active approach to our investment portfolio will achieve greater returns.

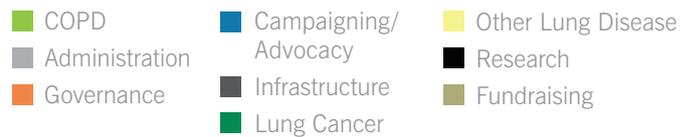
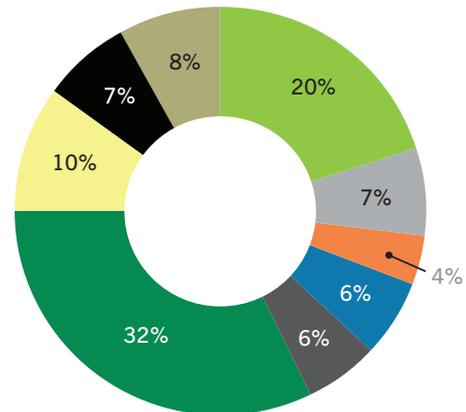
Net assets have increased to more than \$2.5 million (2012: \$2 million), an increase of more than half a million dollars providing a level of financial stability for the Lung Foundation. During 2013, we have maintained our Prudential Reserve (an initiative of the board of directors), which ensures the Lung Foundation has financial cover for at least nine months of operational expenditure.

As shown in the chart, the administration expenses have been kept at a level of 7% (2012: 8%) of total expenditure. This is a favourable result when compared with other not-for-profit entities, and our donors and supporters can be confident the Lung Foundation will continue to ensure most of its income is spent on the delivery of projects and funding research.

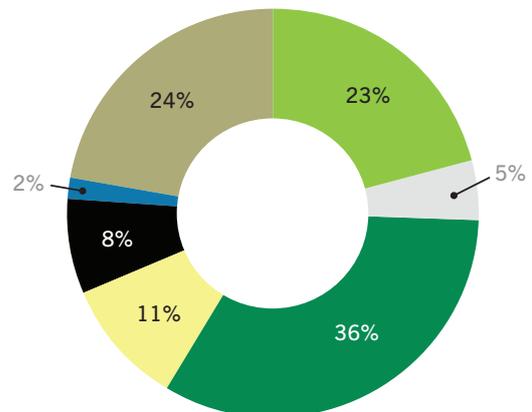
Our full-time equivalent employees increased to 20.2 FTEs (2012: 19.5 FTEs) with the growth due to the addition of business development personnel, and new staff working on the development of the Australian IPF Registry. During the year, the PiKo range of products for identifying potential COPD sufferers was incorporated into the COPD Pharmacy Online training program developed by the Lung Foundation's COPD National Program.

As always, the Lung Foundation could not have achieved its 2013 outcomes without the wonderful support of our volunteers, who continue to selflessly give of their time to the Lung Foundation, either as members of our Consultative Committees or assisting with our LungNet Program. Their continued contribution to the success of the Lung Foundation is very much appreciated.

Lung Foundation Australia 2013 Combined Expenditures



Lung Foundation Australia 2013 Combined Revenues



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Lung Foundation Australia

Summary Financial Statement

for the year ended 31 December 2013

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The unaudited summary financial statement has been prepared for presentation in the 2013 Annual Report of Lung Foundation Australia for the year ended 31 December 2013. It has been prepared on an accruals basis and is based on historical costs modified by the revaluation of financial assets and financial liabilities for which the fair value basis of accounting has been applied.

The unaudited summary financial statement has been derived from the audited financial report for the year ended 31 December 2013, 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 Corporations Act 2001, 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 2013. Members of Lung Foundation Australia are able to obtain a full financial report, directors report and auditors report by contacting Lung Foundation Australia, PO Box 1949, Milton QLD 4064.

Statement of Profit or Loss and Other Comprehensive Income

Lung Foundation Australia

For the year ended 31 December 2013

	2013 \$	2012 \$
Continuing operations		
Revenue from projects	3,513,491	3,186,255
Revenue from donations and bequests	948,362	261,800
Revenue from specifically designated funds	368,895	393,962
Other income	319,587	348,323
Total revenue from continuing operations	5,150,335	4,190,340
Project expenses	(3,513,491)	(3,186,255)
Specifically designated fund expenses	(305,250)	(139,750)
Other expenses	(967,719)	(1,006,980)
Surplus/(deficit) from continuing operations before finance income	363,875	(142,645)
Finance income	86,019	112,390
Net surplus/(deficit)	449,894	(30,255)
Other comprehensive income		
Net unrealised gains / (losses) on investments	32,292	28,034
Total comprehensive income	482,186	(2,221)
Items that may be reclassified subsequently to profit or loss:		
Fair value gains/(losses) on available-for-sale financial assets	32,292	28,034
	32,292	28,034
Net surplus/(deficit) for the year is attributable to:		
Non-controlling interest	-	-
Members	449,894	(30,255)
	449,894	(30,255)
Total comprehensive income for the year is attributable to:		
Non-controlling interest	-	-
Members	482,186	(2,221)
	482,186	(2,221)

Statement of Financial Position

Lung Foundation Australia

For the year ended 31 December 2013

	2013 \$	2012 \$
Current assets		
Cash and cash equivalents	3,747,516	2,907,694
Receivables	448,298	486,661
Inventories	15,203	3,804
Total current assets	4,211,017	3,398,159
Non-current assets		
Available for Sale Financial assets	202,607	170,315
Property, plant and equipment	207,310	206,672
Total non-current assets	409,917	376,987
Total assets	4,620,934	3,775,146
Current liabilities		
Payables	1,875,180	1,549,468
Provisions	100,373	82,206
Total current liabilities	1,975,553	(2,221)
Non-current liabilities		
Payables	66,844	71,044
Provisions	50,957	27,034
Total non-current liabilities	117,801	98,078
Total liabilities	2,093,354	1,729,752
Net assets	2,527,580	2,045,394
Equity		
Retained earnings	1,706,593	1,320,344
General reserve	300,000	300,000
Reserves for specifically designated funds	477,951	414,306
Unrealised gains / (losses) reserve	43,036	10,744
Total equity	2,527,580	2,045,394

Statement of Cash Flows

Lung Foundation Australia

For the year ended 31 December 2013

	2013 \$	2012 \$
Cash flows from operating activities		
Receipts from customers	6,269,561	4,909,455
Dividends received	13,114	12,603
Interest received	133,288	122,862
Payments to suppliers and employees	(5,531,331)	(4,923,741)
Net cash flows from operating activities	884,632	121,179
Cash flows from investing activities		
Investing in term deposits	76,224	253,484
Proceeds from sale of plant and equipment	862	
Acquisition of plant and equipment	(45,672)	(180,591)
Net cash flows used in investing activities	31,414	72,893
Net increase/(decrease) in cash and cash equivalents held	916,046	194,072
Cash and cash equivalents at the beginning of the financial year	2,831,470	2,637,398
Cash and cash equivalents at the end of the financial year	3,747,516	2,831,470

Looking ahead... plans for 2014

Lung Foundation Australia aims to ensure lung health is a priority for all in Australia. The plan to achieve this aspirational goal is captured in the opposite diagram which outlines our vision, goals, strategies and the settings across which we translate our strategies.

In 2014, to augment the important work we already do to support patients with lung disease, we will increase our focus on health promotion of early diagnosis through symptom recognition, primary prevention through risk reduction and secondary prevention through self-management.

In March, we will launch our Check In with Your Lungs campaign – our first national advertising and public relations campaign funded by the Department of Health. It will highlight the importance of lung health and promote awareness of symptoms of lung disease.

We will also be working with key stakeholders to advocate for better access to evidence-based programs, including: lung cancer nurses, increased access to pulmonary rehabilitation and an increased MBS rebate for spirometry testing.

Other work for the year includes the following:

Promote lung health

- Initiate a new lung health promotion/respiratory infectious diseases group to oversee our work in primary prevention and risk reduction
- Through our 2014 awareness campaign, encourage Australians to “Check In with Your Lungs” by taking the Lung Foundation Lung Health Checklist
- Reach out to ATSI communities and other migrant communities through translation of materials
- Reach out to younger audiences through social media platforms

Promote early diagnosis of lung disease

- Continue to develop and promote training and educational materials for use in primary care settings – in particular develop a concise COPD guideline and guide to diagnosing lung cancer in primary care
- By the end of 2014, we hope to have made contact with 15 more Medicare Locals taking our total to 44 of the 61 across Australia

Support those with lung disease and their carers

- Explore new models of patient support: online, web-based
- Explore online education to support patient self-management
- Promote the importance of exercise in those with lung disease through Lungs in Action
- Build on palliative and supportive care program
- Widen patient support seminars to include more rural and remote venues

Promote equitable access to evidence-based care

- Support the development of pulmonary rehabilitation guidelines
- Through our work with state and federal politicians advocate for wider access to lung cancer nurses, spirometry testing and pulmonary rehabilitation

Support quality research

- Initiate work to set up a registry of Australian patients diagnosed with bronchiectasis
- Continue to raise money to support important research
- Complete recruitment of 600 patients with IPF to our IPF registry to support collaborative research nationally and internationally

Governance

- Explore the feasibility of a higher profile physical presence in Sydney and Melbourne

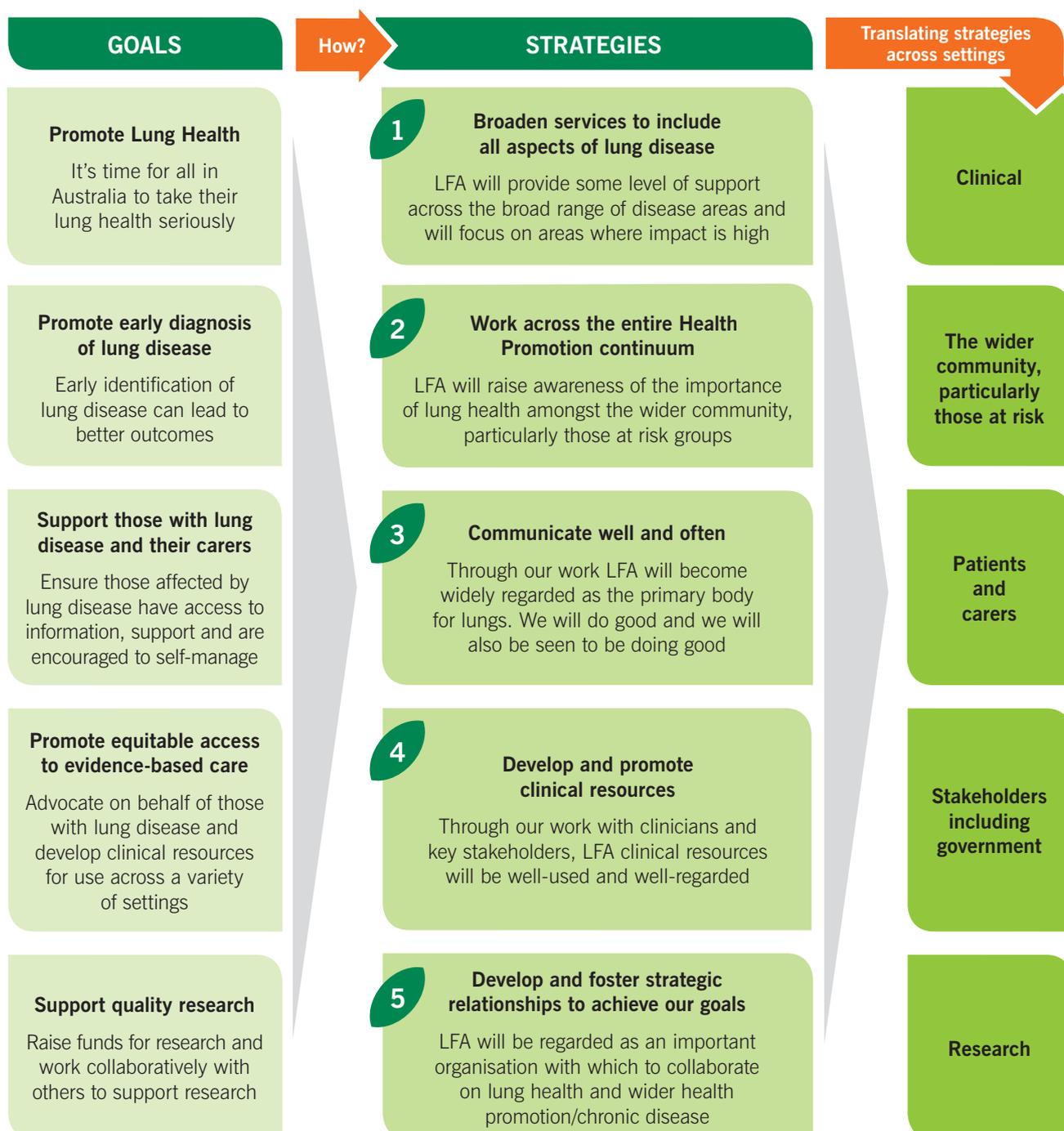
We have a big year ahead and we can't do it without your support.

Become a member – If you would like to become a Lung Foundation Australia member, please contact us on 1800 654 301 or visit www.lungfoundation.com.au

Donate – You can help the Lung Foundation provide support, resources to and advocacy on behalf of the millions of Australians affected by lung disease.



Ensure lung health is a priority for all in Australia



Lung Foundation Australia

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