In 2001, nine organisations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition.

Today, the GLCC is comprised of 43 non-government patient organisations from around the world.

Our aim is to increase awareness of lung cancer issues, change perceptions of lung cancer, help people with lung cancer access the information and support they need, and push governments and legislative bodies to improve treatment and care.

Already, we have achieved a lot. But we also know that much more must be done to improve the outcomes and lives of people affected by lung cancer – something we are determined to do.

A fantastic 712 patients from 14 countries took part in our fourth annual global patient experience survey, resulting in findings we hope our members, policy makers and campaigners will start to use in their work.

Key findings included:

- Most respondents said they’d undergone biomarker testing, but nearly one-fifth were unaware if they had or not. This suggests gaps in patient information and communication about these tests.

- Participants said face-to-face meetings were their preferred method of conversation in all situations, except when respondents were worried about something. In these cases, the preference was a telephone conversation.

- 91% of participants felt involved in decisions about their treatment and care when speaking to their treatment team, although only one-third of participants felt fully involved.

- People were often confused about the availability of and the process involved with lung cancer screening programmes, highlighting the need for education about these initiatives.

- The huge impact of FairLife of Greece since its foundation in November 2020.

All the findings from our 2023 patient experience survey were presented at the IASLC World Conference on Lung Cancer in September. Shortly, they will also be made available on the GLCC’s website, along with country specific infographics.

Finally, we’d like to say thank you to our survey steering group members and all the patients from Argentina, Australia, Bulgaria, Canada, Denmark, Greece, Ireland, Israel, Italy, Portugal, South Africa, Spain, UK and USA who took the time to share their experiences.
NEW MEXICAN MEMBER

We are delighted to welcome Frente Unido por el Cáncer de Pulmón (United Front for Lung Cancer) as the newest member of the GLCC.

Established two years ago in Mexico, the organisation aims to transform lung cancer care in the country so every person with the illness is treated comprehensively and with dignity.

You can find out more about Frente Unido por el Cáncer de Pulmón at frentepulmon.org

WIN BOERCKEL OBITUARY

A few of the many testimonials we received about Win from his GLCC colleagues are provided below:

“With his commitment, enthusiasm, and good humour, he has contributed so much to improving the lives of people affected by lung cancer. Even after retirement, he continued to provide support and wise counsel.”
Jesme Fox, GLCC Secretary, UK

“A thoroughly lovely gentleman who was kind and generous to me, and whose input to the GLCC was so important.”
Simon Malia, Roy Castle Lung Cancer Foundation, UK

“I had the pleasure of working with Win for many years, and his influence on the GLCC is very significant. On a personal note, Win was always very kind to me and very supportive of my professional development, always showing support and sharing a kind word. He was the essence of a good leader.”
Aoife McNamara, Irish Cancer Society, Ireland

“Win was an inspiration for all of us.”
Korina Bell, FairLife Lung Cancer Care, Greece

The GLCC community is greatly saddened by the loss of Win Boerckel, our former treasurer and member of our organisation for over 20 years.

Throughout his time working for the GLCC and CancerCare in the US, Win fought important battles to address some of the many unmet needs of people living with lung cancer.

His contributions to the GLCC were many. One of the earliest and most significant was his realisation of the significance of the expression, “No one in the world deserves lung cancer”. This became the inspiration for our early and successful efforts to address blame and stigma.

Win always set his sights on noble goals and had a brave heart and a clear vision. He is deeply missed.

COPING WITH LUNG CANCER PROJECT

We’d like to say a huge thank you to the steering group members, wider GLCC membership and people with lung cancer who have got involved with our Coping with Lung Cancer project.

In 2022, we began Coping with Lung Cancer to better understand patient experiences of emotional support. This included the conducting of a survey which received 554 responses from lung cancer patients from eight countries.

In 2023, we took the project forward by organising a small discussion group to gain qualitative insights from those who provide emotional support to patients. Areas covered included the challenges and barriers to providing emotional support and examples of best practice.

In particular, the group highlighted the importance of professional emotional support services, which are uniquely placed to help to patients, as well as the need for support to come from spiritual, familial, community and peer connections.

Looking ahead, the GLCC will continue to explore the topic of emotional support to better understand how patients can be best supported along their journey.
UK MEMBERS PRESENT SPECIAL AWARDS

The GLCC presented Special Recognition awards to three remarkable women from the UK on the eve of this year’s World Lung Cancer Day.

Cathy Brokenshire passionately promotes ways to improve the early diagnosis of lung cancer and better outcomes for all. Her action is inspired by her late husband, James, who was a member of the UK’s government when he died from lung cancer in October 2021, aged just 53.

Fiona Castle was married to UK showbusiness legend Roy Castle, who died from lung cancer in September 1994. He dedicated his final weeks to raising funds for lung cancer research. Fiona continues to support the charity that now bears his name, Roy Castle Lung Cancer Foundation.

Mandee Lucas is the fourth generation of her family to be diagnosed with lung cancer. She has shared her story in the media to promote targeted lung health checks and screening.

When presenting the awards, Paula Chadwick, CEO of Roy Castle Lung Cancer Foundation, said, “Your efforts are not just for the benefit of people within the UK but for lung cancer globally. You are amazing women.”

Sarah Woolnough, CEO of Asthma + Lung UK, added that she was delighted to second Cathy, Fiona and Mandee’s nominations, and Jackie Fenemore, former chair of Lung Cancer Nursing UK, said, “We fully support this nomination in recognition of the terrific work these women have done and are still doing to help people with lung cancer.”

If you would like to nominate someone in your country for a GLCC Special Recognition award, please contact glcc@roycastle.org

FAIRLIFE LAUNCHES STIGMA CAMPAIGN

FairLife of Greece has followed in the footsteps of lung cancer organisations in Canada and Australia and launched an awareness campaign called Ask the Right Question.

The aim of the campaign is to highlight how many people diagnosed with lung cancer are viewed negatively by others and the impact this has on their lives.
LUNGFUNDATION AUSTRALIA WELCOMES VITAL FUNDING

Lung Foundation Australia greatly welcomed a significant investment in lung health initiatives as part of the Australian government's new federal budget.

This includes A$263.8 million for the implementation of a new targeted national lung cancer screening programme and A$63 million for public health campaigns that aim to reduce smoking and vaping rates.

Mark Brooke, CEO of Lung Foundation Australia, said, "From prevention to detection, diagnosis, treatment, and care, these investments in lung health, and the health system overall, will play a key role in addressing the significant unmet needs that are currently faced by Australians living with lung disease and cancer."

CANCERCARE’S VIRTUAL LUNG CANCER WORKSHOPS

CancerCare is proud to announce its first series of Coping Circle virtual workshops that focus on the topic of lung cancer.

The four educational and supportive workshops are free to patients, caregivers and professionals, and will be held on the Zoom platform.

The titles and times of the four workshops are:

Commonly asked questions: Lung cancer with LUNGevity
Thursday 5 October 2023
4.30–6 pm EST (8.30–10 pm GMT)

Commonly asked questions: Differences between chemotherapy, immunotherapy and targeted therapy with Lung Cancer Research Foundation
Thursday 19 October 2023
4.30–6 pm EST (8.30–10 pm GMT)

Commonly asked questions: Biomarkers in lung cancer with GO2 for Lung Cancer
Thursday 2 November 2023
4.30–6 pm EST (8.30–10 pm GMT)

Commonly asked questions: Survivorship and lung cancer
Thursday 8 February 2024
4.30–6 pm EST (8.30–10 pm GMT)

ROY CASTLE LUNG CANCER FOUNDATION CELEBRATES NATIONAL SCREENING PROGRAMME

Roy Castle Lung Cancer Foundation celebrated the news that the UK government will roll out targeted lung cancer screening across England.

The programme will use health records to identify people aged 55–74 with a history of smoking. These people will then be invited to an initial appointment where they’ll have their risk for lung cancer assessed. Those considered high risk will be invited for specialist scans every two years.

Professor Ray Donnelly MBE FRCS, founder of the Roy Castle Lung Cancer Foundation, said, “This is truly a memorable, momentous and wonderful day, when lung cancer screening has been announced on a national basis.

“It will make such a huge difference for whom this charity exists – people with lung cancer, their families, friends and loved ones. When I first started the charity in 1990, our first and primary aim was to establish a lung cancer screening early detection programme.”

Please click here for more information.

Please click here for more information.

Click here to register for upcoming workshops or view completed workshops.
IMPROVING CARE REPORT FROM THE LUNG AMBITION ALLIANCE

The Lung Ambition Alliance, of which the GLCC is a founder member, has published a new report titled *Improving coordination of lung cancer care and patient support*.

The report considers the barriers that prevent lung cancer patients from receiving the high-quality, all-round support they need throughout their cancer journeys.

It also provides recommendations for policymakers that, if adopted, will help to improve outcomes for people with lung cancer across the world.

These recommendations focus on:
- improving access to coordinated care through a defined pathway
- improving capacity within healthcare systems
- improving access to coordinated information and psychosocial services

Please click here to read the report in full.

GLCC MEMBERS RECEIVE INNOVATIVE PROJECT GRANTS

The Lung Ambition Alliance (LAA) announced the latest 12 projects that will receive grants from Initiatives in Lung Cancer Care (ILC2), a global funding programme led by the LAA.

Among the awardees are two GLCC members: Campaigning for Cancer of South Africa and Lung Foundation Australia.

Campaigning for Cancer’s project aims to help people with lung cancer access the care they need by providing vital transport services to and from treatments.

While the Lung Foundation Australia project is focused on increasing Aboriginal and Torres Strait Islander peoples’ participation in a national targeted lung cancer screening programme.

Please click here for more information about ILC2 and all of this year’s grant recipients.

Recipients of the latest ILC2 grants

LCRF NEWS ROUND-UP

Lung Cancer Research Foundation’s philosophy is simple: scientific discoveries lead to improved outcomes for people affected by lung cancer.

To date, it has provided 409 research grants totalling over $42 million, the largest amount given by an organisation dedicated to funding lung cancer research.

LCRF continued to provide seed funding to the best and brightest investigators in 2023 by asking for submissions in several grant tracks:
- Leading Edge Research Grants
- Research Grant on Early Detection and Pre-Neoplasia in Lung Cancer
- Research Grant on Understanding Resistance in Lung Cancer
- Minority Career Development Award (CDA) for Lung Cancer

In March, LCRF announced research partnerships with AstraZeneca and Daiichi Sankyo to study antibody drug conjugates (ADCs) to improve outcomes for people with lung cancer.

And in June, LCRF and ALK Positive, a support community for ALK-positive lung cancer patients, announced a further $2 million will be invested into ALK-positive lung cancer projects over three years.

The aim of this research is to advance high-impact research focused on transforming care and improving outcomes for patients with ALK-positive non-small cell lung cancer.

See page 10 for our chat with Courtney Brandt, Director of Educational Programs at LCRF.
LUNG CANCER MEDIA ROUND-UP

2023 WCLC HIGHLIGHTS
Press briefings, press releases and podcasts from the IALSC’S World Conference on Lung Cancer in Singapore are now available to watch and listen to.

Please click here for more information.

THE BEST OF ASCO’S ANNUAL MEETING
The American Society of Clinical Oncology’s (ASCO) annual meeting featured exciting news updates and advancements in lung cancer research and treatment.

For an overview of the highlights, please take a look at Best of ASCO videos from GO2 for Lung Cancer and the Lung Cancer Research Foundation.

OSIMERTINIB REDUCES CHANCES OF DYING BY 51%
The results from a decade-long global study has shown that taking the drug osimertinib (Tagrisso) after surgery can cut the risk of dying from non-small cell lung cancer by half.

The ADAURA trial involved lung cancer patients from 26 countries who were aged between 30 and 86 and had a mutation of the EGFR gene.

Please click here for more information.

LUNG CANCER SCREENING POLICY BRIEFS
The Lung Cancer Policy Network has published a series of policy briefs that cover six key elements necessary for the effective implementation of lung cancer screening programmes.

This work builds on the Network’s framework to support the implementation of low-dose CT scan lung cancer screening, which was published in March 2023.

To download the six policy briefs and framework, please click here.

FITNESS AT A YOUNG AGE REDUCES CANCER RISK
The results from a large Swedish study spanning over 30 years has found that men with good cardiorespiratory fitness at a young age are less likely to develop lung, bowel, kidney, liver and pancreatic cancer.

Researchers from the University of Gothenburg analysed data on more than one million men who underwent a range of tests when conscripted to the military between the ages of 16 and 25.

The biggest reduction was seen in lung cancer, with high fitness levels leading to a 42% lowered risk.

Please click here for more information.

NEW INSIGHTS INTO SMALL CELL LUNG CANCER

The key findings of lead researcher Balazs Döme and his team team at MedUni Vienna primarily consist of new insights into the biology and heterogeneity of small cell lung cancer.

Click here for more information.

PROTEIN TIED TO DRUG RESISTANCE IN PATIENTS
Researchers at the Mass General Cancer Center in the US have uncovered how non-small cell lung cancer tumours may develop drug resistance over time and identified the APOBEC3A protein as a potential target for novel cancer therapeutics.

The findings point to potential solutions for treating tumours that have become resistant to standard cancer therapies.

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Click here for more information.
IGNACIO ZERVINHO FROM FUNDACIÓN PACIENTES DE CANCER DE PULMON IN ARGENTINA PROVIDES RAPID ANSWERS TO OUR QUICK QUESTIONS.

WHAT IS YOUR POSITION AT FPCP?
Coordinator for our advocacy work and improving access to treatment.

WHEN DID YOU JOIN FPCP?
2017

WHY WAS YOUR ORGANISATION ESTABLISHED?
Because Peter Czanyo wanted to help other people diagnosed with and affected by lung cancer.

WHERE IS FPCP BASED?
Hospital Tornú in Buenos Aires.

HOW MANY PEOPLE WORK FOR FPCP?
Four people.

WHAT CARE AND SUPPORT DOES FPCP PROVIDE?
We focus on three areas: emotional support, helping people navigate the health system, and advocacy.

WHAT IS FPCP’S MAIN PLAN FOR THE NEXT 12 MONTHS?
To increase the number of people we reach in Argentina. Virtual tools are helping us to do this. We’re also determined to improve our national lung cancer screening programme.

WHAT HAS BEEN YOUR ORGANISATION’S BIGGEST SUCCESS SO FAR?
With day-to-day issues, improving the quality and quantity of support provided to lung cancer patients.

In the advocacy area, we had an important role defining lung cancer priorities to candidates of the presidential election in 2019.

WHAT IS FPCP’S ULTIMATE AMBITION?
To make sure every lung cancer patient in Argentina has access to the treatment and support they need.

DOES FPCP HAVE ANY CURRENT LUNG CANCER MEDIA CAMPAIGNS?
Yes, we’ve worked with other organisations on a campaign about the importance of screening for lung cancer. You can watch the video on YouTube.

WHEN DID FPCP JOIN THE GLCC?
2006.

HAS FPCP GAINED KNOWLEDGE FROM ANOTHER GLCC MEMBER THAT HAS BENEFITED ITS WORK?
Yes, we’ve learned a lot from Patricia Mondragon at Respirando con Valor in Mexico about how to maintain contact with the patients and their families.

WHAT MESSAGE WOULD YOU LIKE TO SEND TO YOUR FELLOW GLCC MEMBERS?
We must be more aggressive and stronger against tobacco. And lung cancer screening programmes need to learn from previous screening programmes (breast, colon, cervix) about the way they engage and interact with the medical community and wider society.
FAIRLIFE LUNG CANCER CARE WAS FOUNDED IN NOVEMBER 2020 BY KORINA PATELI BELL, FOLLOWING THE LOSS OF HER HUSBAND, SIMON BELL, TO LUNG CANCER.

Since that time, FairLife has carried out many activities to raise awareness of lung cancer in Greece and ensure people affected by the illness receive the holistic support they need from diagnosis.

In this article, we take a look at some of FairLife’s highlights since November 2020. We hope these activities inspire the work of other GLCC members.

FAIRLIFE HIGHLIGHTS

December 2020
Lung Health, a free screening programme developed by the Metropolitan Hospital in Pireas, is launched with support from FairLife.

June 2021
Information and support line launched, which has received more than 1,500 calls, up to September 2023.

February 2022
Learn-Act-Hope, a digital library on lung cancer, is launched. The library features interviews, talks and audiovisual materials.

June 2022
The patient’s journey, a webinar about prevention, diagnosis, biomarkers, personalised treatments, is broadcast online.

September 2022
BREATHE, a psychosocial support programme, is offered nationwide, free of charge, to lung cancer patients, their family and caregivers, in collaboration with qualified mental health professionals.

October 2022
14 Minutes of Life, a series of short videos, is launched. The videos feature simple, clear answers to questions often raised by people with lung cancer and their caregivers.

“Our biggest reward is the love and support of patients, caregivers, family members and the public. The positive feedback we receive is the best guide for our future actions.”

Korina Pateli Bell, Founder of FairLife

FAIRLIFE IN NUMBERS

6 prizes received for contribution to society
40 congresses and conferences participated in
4 European and international surveys participated in
Collaborated with 20 scientific institutions
70 health professionals
100+ volunteers
20,500 social media followers
1.55 million views of FairLife videos on Facebook and YouTube
90,000 website visits
1,950 publications
YOUNG PEOPLE AND WELLNESS

November 2021

FairLife raises public awareness of prevention, screening and early diagnosis at Asklepieia en drasi – The cultural heritage of health, a new institution that links ancient healing temples with physical exercise, a healthy lifestyle and nutrition.

October 2021–March 2022

Middle and high school students take part in a creative writing, poster and slogan competition organised by FairLife that’s titled The first tobacco/vape free generation.

November 2021

FairLife hosts a scientific online conference that focuses on the prevention and early diagnosis of cancer. During the conference, FairLife promotes a study by the Health Policy Institute that shows the clear benefits of lung cancer screening with a low-dose CT scan. The study was supervised by Professor Kyriakos Souliotis and Dr Evi Hatziadreou, public health expert and Vice President of FairLife.

November 2021 and November 2022

In Greece, FairLife promotes the Get Checked and Get Diagnosed campaigns developed by Lung Cancer Europe (LuCE), of which FairLife is a member.

January 2022

New ambassadors from the world of sport are recruited to promote exercise and a healthy lifestyle in the fight against lung cancer. The ambassadors include Olympic water polo champion Ioannis Fountoulis, Olympic sailing champion Byron Kokkalanis, and Greek cycling champion Zisis Soulios.

RAISING AWARENESS AND TAKING ACTION

November 2021

FairLife hosts a creative writing, poster and slogan competition that’s titled The first tobacco/vape free generation.

May 2022

Inhale...exhale...Or BREATHE?, a new anti-smoking campaign is launched with the help of 4,000 children from 140 schools in Greece and abroad.

November 2022 and March 2023

FairLife promotes messages about resilience and optimism in the fight against lung cancer at the Authentic Marathon of Athens and the 11th Athens Half Marathon.

May 2022

FairLife promotes and coordinates the GLCC’s Patients’ experiences of lung cancer during Covid-19 survey in Greece.

November 2022

FairLife hosts an in-person conference that’s attended by over 50 representatives from the scientific and research community in Greece and abroad. The conference focuses on prevention, early diagnosis and the latest scientific developments regarding the treatment and management of lung cancer.

May 2023

Ask the Right Question, a campaign about the stigma that surrounds lung cancer, is launched for the first time in Europe. As part of the campaign, FairLife publishes an action plan to tackle the most pressing challenges in the fight against lung cancer in Greece.

June 2023


November 2021 and November 2022

FairLife promotes the results of surveys conducted by Lung Cancer Europe (LuCE). The 2021 report is titled Experiences and quality of life of people impacted by lung cancer in Europe, and the 2022 report, Challenges in the care pathway and preferences of people with lung cancer.

Korina Pateli Bell with her late husband, Simon
Please tell us about LCRF.
The organisation was established in 2005 and our headquarters are on 7th Avenue in New York. In total, 17 people work for LCRF, and the organisation’s overall mission is to improve lung cancer outcomes by funding research for the prevention, diagnosis, treatment and cure of lung cancer.

In your opinion, do people with lung cancer generally receive the support and care they need in the US?
Unfortunately, the current screening guidelines in the US are based on tobacco use history for people aged 50 and up. At least 20% of lung cancer cases are not caused by smoking, and more young people are receiving a lung cancer diagnosis.

Because lung cancers typically do not exhibit symptoms until the disease has progressed, many people are not diagnosed early enough to increase survival rates significantly.

In addition, many people are faced with stigma associated with lung cancer because of the connection to tobacco use, and many feel that they are to blame for their illness. Sometimes this results in delayed care, when speed to detection and treatment is quite literally what dictates survival rate.
Knowledge of the many risk factors, signs and symptoms of lung cancer, coupled with advocating for early detection screening and combatting stigma, will go a long way to improving outcomes for people with lung cancer.

**What do you think could be the biggest breakthrough to help people with lung cancer?**

Our philosophy is simple: scientific discoveries lead to improved outcomes. LCRF provides critical seed funding to the best and brightest investigators, helping establish proof-of-concept evidence to pave the way for follow-on funding.

To date, LCRF has provided 409 research grants totalling over $42 million, the largest amount provided by an organisation dedicated to funding lung cancer research.

**What care, support and services does LCRF provide?**

We provide up-to-date and credible sources of information on diagnosis, treatment, and what to expect from treatment, through our free educational materials and in-person and virtual educational events.

We also have tools to help facilitate discussions with one’s healthcare team, so you can play an active role in treatment decisions. Our materials are available in both digital download and print format.

We also have a Lung Cancer Support Line, which is available for free to anyone affected by lung cancer. Our support line is equipped with extensive and up-to-date resource guides to help you navigate the various uncertainties that come with living with lung cancer. We can help you find financial assistance, transportation or lodging to and from your medical appointments, support groups or peers, and much more.

**How does LCRF’s work make a difference to the lives of people with lung cancer?**

Despite being the leading cause of cancer mortality, lung cancer receives far less research funding than any other cancer. That’s why funding from non-governmental organisations is so critical.

The Lung Cancer Research Foundation (LCRF) plays a pivotal role in this funding landscape, supporting early-career investigators who, if not for our funding, may not receive funding at all.

When it comes to research, we can accomplish more together than we can alone. Research is a team sport, and our investigators are conducting innovative studies that are leading to lung cancer research discoveries.

We have made unprecedented progress in the field of lung cancer research, changing what it means to face a lung cancer diagnosis. The pace of FDA Food and Drug Administration approvals for lung cancer treatments has been accelerating in recent decades.

Today, there are more treatment options than ever before. In the past few years, we’ve seen an exponential increase in treatment approvals and expect this trend to continue.

**Does the LCRF have any current lung cancer media campaigns?**

LCRF is committed to improving awareness of lung cancer risk, symptoms, early detection and treatment in historically excluded communities.


This year, LCRF is also creating an extension of this programme for the Hispanic/Latino American community to provide its resources in Spanish and English, a video documentary featuring a leading oncologist and two of her patients, and PSAs featuring a well-known Spanish-speaking celebrity. We anticipate the programme will launch in September 2023.

**Do you think GLCC members can benefit from each other?**

Yes! I think it would be great to learn the mission and priorities of other GLCC members, so we can benefit from the information and services that each other provides. For example, members from Spanish-speaking countries might benefit from knowing the LCRF has several educational materials available in Spanish-language, and recently hosted a webinar completely in Spanish in September.

**What message would you like to send to your fellow GLCC members?**

We are proud to be members of the GLCC and look forward to continuing to build our relationship with the coalition and its members. We would be delighted to connect with anyone on the work that LCRF does, particularly around our mission to fund the most impactful research to help advance the treatment and cure for lung cancer.

You can learn more about the work of the Lung Cancer Research Foundation at lungcancerresearchfoundation.org
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In 2023, the GLCC acknowledges the support of its sustaining partners: Amgen, AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Daiichi Sankyo, Eli Lilly, Gilead, Merck, Novartis, Novocure, Regeneron, Roche, Sanofi and Takeda, as well as Pfizer for part funding specific projects.

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