

UNITY



The newsletter of the Global Lung Cancer Coalition

Autumn | Winter 2022

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WELCOME

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 42 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.



To join us, please read our membership criteria, and download a membership application form at lungcancercoalition.org

FINDINGS FROM RESEARCH INTO SCREENING RESOURCES



In 2022, the GLCC started to identify and assess the information given to people who are invited to take part in lung cancer screening programmes around the world.

Now, the findings of our research, and some of the resources that are distributed, can be found on the **[GLCC's screening resource centre](#)**.

Key observations include:

- A person considering lung cancer screening should have the opportunity to speak with an appropriately trained professional who can help them interpret the screening information they've received.
- Tailored information should be provided to people at different points of the screening pathway to help them feel supported and make informed choices.

- Educating people about lung cancer, curative treatment and potential outcomes if you are diagnosed with the illness could encourage more people to get themselves screened.
- It's important to involve people at risk of lung cancer in the design of screening information resources and ask them to assess the resources before they are distributed.

As GLCC members continue to advocate for and establish national lung cancer screening programmes, we hope this research helps them to develop high-quality screening information resources for their country's population.

In the future, we'll continue to update the screening resource centre and add links to resources such as key journal papers, guidelines for health professionals, national policies, protocols and patient information.

GOOGLE TRANSLATE

Articles marked **Google Translate** have been translated from a non-English news story. This means you may need to paste the story into Google Translate and select your appropriate language.

IMPACT OF PANDEMIC SESSION AT WCLC

At the World Conference on Lung Cancer 2022, the GLCC and the IASLC presented a successful educational session called Covid 19: A roadblock to effective lung cancer care in 2022.

Speakers who explored the impact of the pandemic included:

Dr David Baldwin of Nottingham University Hospitals NHS Trust, UK

stated that when the Covid lockdown occurred in the UK, there was a 68% decrease in referrals and bookings relating to lung cancer, and that this drop has not been recovered yet.

Merrel Hennink, patient advocate of Longkanker Nederland (Netherlands GLCC member) spoke about the impact of Covid-19 from a patient's perspective and discussed data from the GLCC's annual global patient experience survey.

During the session, other lung cancer topics were also covered, including:

Dr Shani Shilo, founder of the Israeli Lung Cancer Foundation, and Professor Matthew Peters, chair of the GLCC and head of respiratory medicine at the Concord Hospital, Sydney, Australia spoke about going from pilots to programmes for lung cancer screening in their countries.

Lauren Pretorius, chief executive of Campaigning for Cancer (South African GLCC member) spoke about optimising virtual home health services (telehealth) for people with lung cancer.

 **Please click here for more information about the session at WCLC 2022.**

GLCC'S ANNUAL MEETING 2022


In August, members of the GLCC and supporting partners gathered in Vienna, Austria, for the GLCC's annual meeting.

The main features of the meeting included:

- An analysis of the GLCC's latest patient experience survey.
- Dr Samantha Quaife of Queen Mary University of London sharing findings on lung cancer screening resources.
- Maureen Rigney of GO2 for Lung Cancer raising questions about the language used in information materials for people affected by lung cancer.
- Jesme Fox of Roy Castle Lung Cancer Foundation outlining that the GLCC's information leaflets are under review and some have already been refreshed.
- Louise Abbott of Evoke Incisive Health explaining how the GLCC's e-Atlas has been substantially redesigned and updated.
- Win Boerckel, GLCC adviser on psychosocial interventions, demonstrating how to effectively use focus groups involving people with lung cancer and the value of doing this.



Korina Pateli-Bell of FairLife Cancer Care (Greece) and Peter Czanyo of Fundacion Pacientes Cancer de Pulmon (Argentina) at our 2022 annual meeting.

 **Please click here for more information about our annual meeting in Vienna.**

GLCC HONOURS WIN BOERCKEL

At our 2022 annual meeting in Vienna, Austria, we honoured a retiring Win Boerckel for his many years of service to the GLCC and the lung cancer community.

After Win's wife died from cancer in 1982, he became an oncology social worker and joined CancerCare in the US.

At CancerCare, Win ran a lung cancer support group from 1996 to 2021 and represented the organisation at the GLCC for more than 20 years.

We'd like to thank Win for his many contributions to the coalition and his leadership role as treasurer on the steering committee.



Win Boerckel with Maureen Rigney of GO2 for Lung Cancer.

PULMONALE PUSHES FOR NATIONAL SCREENING

Pulmonale launched a strong campaign in November to help ensure a national lung cancer screening pilot project is implemented in Portugal.

Called Agir Antes de Sentir (Act Before Feeling), the campaign aims to raise awareness of the importance of detecting lung cancer early to save more lives.

You can find out more about the campaign at agirantesdesentir.pt

You can also watch a video that supports the campaign by [clicking here](#). It features lung cancer patients and healthcare professionals speaking about the need for a national lung cancer screening programme in Portugal.




 **Google Translate**

NATIONAL SCREENING PROGRAMME FOR AUSTRALIA

Lung Foundation Australia has welcomed recommendations from the Australian government's Medical Services Advisory Committee for a national lung cancer screening programme.

The announcement comes after Lung Foundation Australia published a report called *The Next Breath: Accelerating Lung Cancer Reform in Australia 2022-25* earlier in the year.

The Foundation outlined six main recommendations to turn the tide on lung cancer. This included establishing a lung cancer screening programme.

 **Please click here to find out more.**

LUNG CANCER POLICY NETWORK LAUNCHES

In August 2022, the Lung Cancer Policy Network was launched with an inaugural report titled *Lung cancer screening: learning from implementation*.

The report showcases existing research on low-dose CT screening for lung cancer and draws four key lessons from the successful implementation of screening programmes.

In September, the Network launched an [interactive map](#) collating research on the implementation of low-dose CT screening from around the world.

The map facilitates the sharing of best practice by showcasing examples of current organised lung cancer screening programmes and the status of early detection of lung cancer in different countries. It will be updated twice a year.


The Network also published in November [an article about the EU Council's final recommendations for lung cancer screening in Europe](#). It called on the EU Council to fully reflect current evidence on screening in its recommendations and give EU member states the foundation they need to advance the implementation of lung cancer screening in their countries.

The article follows a report by the Network that states how it would [amend the EU Commission's draft recommendations on cancer screening](#).

The Lung Cancer Policy Network is an international, multidisciplinary alliance that aims to make lung cancer a policy priority worldwide.

The initiative was set up by the Lung Ambition Alliance (founded by the International Association for the Study of Lung Cancer, Global Lung Cancer Coalition, AstraZeneca and Guardant Health).



 **Please click here for further information about the Lung Cancer Policy Network.**

THE LUNG CANCER DIARIES

LungeKreft Foreningen of Norway has produced a 22-minute short film called *Lungekreftdagbøkene (The Lung Cancer Diaries)*.

It follows the lives of two lung cancer patients who were both diagnosed just before Christmas 2020.

Kay is a photographer who has his surgery filmed and talks about the treatment that follows.

Gunn has a form of cancer that can be treated with pills. She feels healthy and lives a normal life.

The film is not available with subtitles, but it still offers an informative insight into the worlds of two lung cancer patients.

[Please click here to watch The Lung Cancer Diaries.](#)
[Google Translate](#)

WALCE LAUNCHES EXERCISE PROGRAMME

WALCE (Women Against Lung Cancer in Europe) has worked with healthcare professionals to develop a free Adapted Motor Activity (AMAti) programme.

The aim of AMAti is to help lung cancer patients get active. This may result in benefits such as faster recovery after treatment, fewer side effects and late effects of treatment, improved mental health, and a reduced risk of other health problems.

AMAti activities are carried out in groups of six or seven people, twice a week for five months, and each session lasts 50 minutes.

NEW PROJECTS AND AWARDS FOR FAIRLIFE



FairLife of Greece has recently been busy with a range of new projects, and has received recognition for its efforts to improve the lives of people affected by lung cancer.

New projects include:

- **BREATH**, a free, nationwide programme offering expert psychosocial support to people with lung cancer and their families and caregivers.
- A series of webinars called *The Patient's Journey*, which focus on **the early detection of lung cancer** and **personalised treatments**.
- A series of short videos called **14 Minutes of Life**, which provides simple and clear answers to questions raised by lung cancer patients and their caregivers.
- A campaign with the municipality of Vari-Voula-Vouliagmeni to clean the eastern beach of Varkiza, a suburb of Athens.
- A joint campaign with Amgen Hellas called **Find KRAS G12C**. It aims to raise awareness of early biomarker testing for the KRAS G12C mutation and the importance of getting a diagnosis that can lead to targeted treatment.

- **FairLife's second scientific conference**, which focused on early screening, new therapeutic approaches and much more.

FairLife has also recently received the following awards:

Patient Partnerships Awards 2022

- Gold award for creating Learn-Act-Hope, a digital library of lung cancer information.
- Gold award for its anti-smoking youth campaign 'The first generation without smoke, without vaping'.
- Bronze award for its initiatives on lung cancer screening and improving the quality of life of lung cancer patients and vulnerable social groups.

Healthcare Business Awards 2022

Bronze award in the 'Actions aimed at information, awareness and prevention' category.

MONEY WORRIES PREVENTS SYMPTOMS FROM BEING CHECKED IN IRELAND

Research commissioned by the Irish Cancer Society has revealed that cost is the main barrier for people not visiting their GP to get early lung cancer symptoms checked.

Out of 1,000 people surveyed, 1 in 5 people said the cost of a doctor's visit would prevent them from having worrying signs checked by a healthcare professional.

The survey also found that 1 in 2 people are not confident about spotting the early signs of lung cancer, with younger people being least aware of the signs and symptoms of this serious disease.

Throughout November 2022, the Irish Cancer Society ran a free lung health roadshow in shopping centres across Ireland.



The aim of the roadshow was to help the public identify symptoms they should not ignore and reduce the likelihood of cost as a barrier to healthcare.

The roadshow gave people the opportunity to get a free health check and have a conversation with a nurse about their lung health. A referral to a GP was also arranged when further help was needed.

ALCASE DEVELOPS ITALIAN VERSION OF GO2'S NAVIGATING LUNG CANCER

ALCASE Italia has translated into Italian GO2 for Lung Cancer's *Navigating Lung Cancer - 360° of Hope* handbook.

ALCASE states on its website that this will give every lung cancer patient and carer in Italy access to complete and up-to-date information on lung cancer, diagnosis, specialists, therapies, and clinical studies. five-year survival rate of just 20%, but more still needs to be done.

[Please click here to view the Italian version of Navigating Lung Cancer](#)

[Please click here to view the original English version of the handbook](#)

LUNG CANCER AWARENESS MONTH HIGHLIGHTS

Many members of the GLCC launched new campaigns and activities in November 2022. Please click on each member's name to find out more about what they got up to.



Fundacion Pacientes de Cancer de Pulmon
Posted videos from patients and healthcare professionals on its Facebook page.



Longkanker Nederland
Launched a white scarf campaign to raise awareness and money.



Lung Foundation Australia
Raised awareness and fundraised through its Shine a Light campaign.



APOZ
Supported a new national lung cancer awareness campaign called I Cough Like This.



Lung Cancer Canada
Hosted and participated in events to raise awareness of the challenges caused by lung cancer.



Roy Castle Lung Cancer Foundation
Launched its On the Right Path campaign to increase early diagnoses.

A MORE TREATABLE KIND OF METASTATIC CANCER?



Dr Giorgio Lo Iacono, a thoracic surgeon affiliated with GLCC member ALCASE Italia, provides an overview of oligometastatic cancer and potential treatment options for it.

It is still too often believed that metastatic cancer is always “widespread and incurable”. Fortunately, this pessimistic concept continues to change, having been presented at a congress of the American Society of Clinical Oncology (ASCO) a few years ago.

The new concept that emerged was that some metastatic tumours, whose spread is limited, can also be treated with local therapy, such as radiotherapy, in addition to systemic therapy, such as chemotherapy.

These limited spread tumours are called “oligometastatic” (“oligos” is Greek for “few”). The term was coined in an article published over 15 years ago in the Journal of Clinical Oncology (1995).

oligometastatic

adj. A type of metastasis in which cancer cells from the original (primary) tumour travel through the body and form a small number of new tumours (metastatic tumors) in one or two other parts of the body.

A revolutionary idea

Oligometastatic means that, at the time of diagnosis, there is a defined number of metastatic sites in addition to the primary tumour. They can be different sites in the same organ or in different organs. Initially this idea was not very welcome, especially by the more “rigid” oncologists. An oligometastatic diagnosis is not so rare.

For the four most common cancers in the United States, there are around 90,000 oligometastatic presentations each year, of which approximately 50,000 are lung cancers. The diagnosis of oligometastases has especially developed around colon cancer, where the presence of limited liver metastases has opened a surgical opportunity as a treatment option.

This subgroup of patients, who also underwent surgical removal of metastases, had better results than those patients who did not undergo surgery. This goes against our previous idea about metastatic disease. The old metastasis paradigm was that ‘once cancer spreads, there is no cure’ is no longer so certain. We have not yet identified in detail how to select these patients, but just the idea that there is such a subgroup is truly revolutionary.

Creating a standard definition

Numerous randomised clinical trials have demonstrated superior progression-free survival (PFS) in oligometastatic patients treated with ablative radiotherapy and/or surgery compared to patients receiving standard treatment, with a positive impact also on overall survival.

An ongoing challenge in this area of cancer research is agreeing on how to define the oligometastatic patient. Current definitions use different numbers and locations of tumours depending on the studies on which they are based.

In general, though, most studies agree that five or fewer disease sites are potential candidates for an oligometastatic approach. This means that, in addition to systemic therapy, local therapy is planned for each of the lesions found.

There is also quite good evidence in lung cancer, including some randomised data (Lancet Oncol. 2016; 17:1672-1682), showing that this may be beneficial for selected patients, compared to patients without treatment of metastases.

Giving new options to patients

For lung cancer, the patients most often identified are those with metastases to the brain, other parts of the lungs and the adrenal gland. Recently, bone lesions also seem to be suitable in the definition of the oligometastatic patient.

This multimodal approach needs to be carefully selected and is not suitable for everyone. In general, the best approach is that we need to have some evidence of systemic disease control before treating metastases and to manage them effectively with local therapies.

As a reflection of this research, the American Joint Committee on Cancer guidelines on NSCLC now indicate that patients with one or a small number of metastases can be offered definitive treatment modalities with the goal of becoming disease free. This offers new options to patients but requires further discussions with our multimodal teams to define the best approach. Surgery, radiotherapy, cryoablation or radiofrequency?

All of these are options for patients. Multimodal care and multimodal teams offer more choices and a better way to control cancer in our patients. It will probably benefit a small proportion of patients, but it can make a huge difference for them.

“The old metastasis paradigm was that ‘once cancer spreads, there is no cure’ is no longer so certain. We have not yet identified in detail how to select these patients, but just the idea that there is such a subgroup is truly revolutionary”.

LUNG CANCER MEDIA ROUND-UP

HIGHLIGHTS FROM THE WORLD CONFERENCE ON LUNG CANCER

Doctors and scientists from around the world convened in Vienna, Austria to share the latest news on lung cancer treatments and relevant studies.

[To view press briefings from the conference, please visit IASLC's YouTube channel.](#)

[GO2 for Lung Cancer has also compiled an excellent summary of updates from WCLC, which you can read by clicking here.](#)

TRACERX EVO – A NEW FRONTIER IN RESEARCH

Cancer Research UK announced the launch of TRACERx EVO, a new research programme that will build on the discoveries of the world's largest long-term lung cancer study, TRACERx.

[Click here for more information.](#)

LuCE LAUNCHES LUNG CANCER CHALLENGES REPORT

Lung Cancer Europe (LuCE) published its 7th report on lung cancer, which is titled *Challenges in the care pathway and preferences of people with lung cancer in Europe*.

The LuCE Report is an annual initiative led by lung cancer patient organisations, with the purpose of raising awareness regarding the main challenges faced by people impacted by this disease across Europe.

[Click here to view the report in English and executive summaries in many different languages.](#)

ECONOMIC BENEFITS OF WOMEN-FOCUSED RESEARCH

A report produced by Women's Health Access Matters (WHAM) has revealed that doubling the funding for research on women and lung cancer will lead to enormous economic benefits for families in the US and the country as a whole.

[Click here to read the report.](#)

THE VITAL ROLE OF LUNG CANCER CLINICAL NURSE SPECIALISTS

The UK Lung Cancer Coalition has published a report which states that more lung cancer nurses and improved data collection is required to address inequalities in lung cancer care in the UK.

[Click here to read the report.](#)

MORE BLACK PEOPLE ELIGIBLE FOR SCREENING

A report published in JAMA Network Open reveals that updated lung cancer guidelines in the US have made more black people eligible for lung cancer screening.

[Click here to read the report.](#)

SCREENING DRAMATICALLY INCREASES LONG-TERM SURVIVAL

A large-scale, 20-year international study has concluded that diagnosing early-stage lung cancer with low-dose CT screening drastically improves the long-term survival rate of cancer patients.

[Click here for more information.](#)

ADDRESSING EUROPE'S CANCER RESEARCH CHALLENGES

The Lancet Oncology commissioned a report from a wide range of experts that brings together detailed new data on cancer research activity across Europe during the past 12 years. The aim of the report is to inform Europe's Beating Cancer Plan and the EU Cancer Mission, and to set out an evidence-driven, patient-centred cancer research roadmap for Europe

[Click here for more information.](#)

HOW AIR POLLUTION MAY CAUSE LUNG CANCER

Scientists at the Francis Crick Institute and University College London in the UK have revealed how air pollution may cause lung cancer in people who have never smoked.

[Click here for more information.](#)

HOW TO... CREATE A STRONG BRAND CAMPAIGN

In our ongoing series of How to... features, we look at what brand marketing is and how you can create a campaign that raises awareness of your organisation's brand and engages target audiences with it.

What is a brand?

A brand is much more than a pleasing name and attractive logo. Essentially, it's who an organisation is and how it behaves. It's their personality, visual identity and what sets them apart.

What is brand marketing?

Brand marketing is the process of establishing and growing a relationship between a brand and its target audience.

Rather than highlighting an individual product or service, brand marketing promotes the entirety of the brand. The goal of brand marketing is to build a brand's value – and the organisation's value as a result.

“Brand is what people say about you when you've left the room.”

Jeff Bezos, founder of Amazon



EIGHT STEPS TO CREATING A BRAND MARKETING CAMPAIGN

1. Establish your brand strategy

To create and maintain long-term brand equity and trust, every brand campaign should be influenced by a brand strategy that answers these three questions:

- Why does our organisation exist?
- How do we want people to feel about our organisation?
- How will we help people?

2. Identify your target audience

For a brand marketing campaign to be successful, it's important to establish a target audience you want to communicate with.

You could do this by using existing data about who interacts with your organisation. Or you could carry out or commission research to create in-depth audience personas.

3. Determine where you can reach your target audience

People are more likely to be engaged by your brand marketing campaign if they are exposed to it across different types of media (e.g. print, digital, social media, radio, TV).

This means it's important to establish where you can best reach your target audience. For example, are more of your target audience likely to see your advertising on social media than at health clinics?

4. Set clear metrics for success

It's important to establish detailed metrics for your campaign and how your organisation will monitor and measure short-term and long-term brand success.

Tracking the overall impact of your brand campaign is important because it will help you optimise your message and the media channels you use in the future.

“The most powerful and enduring brands are built from the heart.”

Howard Schultz, CEO of Starbucks



5. Make your messaging simple

Your audience will struggle to take away multiple messages from one advertisement. Successful brand campaigns make it very easy for people to understand one primary message or call to action.

Work out the one message you want people to remember from your advertising and deliver this message across your campaign.

6. Maintain brand consistency

Throughout your brand campaign, it's critical that you adopt consistent messaging, visuals and tone of voice.

Doing this will help your brand to become more recognisable and earn and maintain trust from your target audience.

7. Establish an emotional connection with your audience

To gain trust from your target audience and establish a strong brand reputation, it's vital that you deliver excellent customer service – and especially so during your brand marketing campaign.

You can do this by responding promptly to your audience's calls to your organisation and the questions and messages they send you via email and social media.

People remain devoutly loyal to brands if they feel listened to and appreciated.

8. Evaluate and readjust your campaign

Your brand marketing campaign is very unlikely to be perfect the first time you implement it. So it's important that you evaluate the metrics you set for your campaign and ask for feedback from your target audience and internal teams about the campaign.

Gaining this knowledge will help you to understand how you need to adjust your next brand marketing campaign so it meets your audience's needs and performs even better.

Further information

This article is very much an overview of what a brand marketing campaign is and how you can create a successful one to help your organisation increase awareness of its brand and reach its target audience.

For further information, you may find it helpful to look at the [Brand section of the UK's CharityComms'](#) website or the website of an equivalent organisation in your own country.

“Let excellence be your brand. When you're excellent, you become unforgettable.”

Oprah Winfrey





Fundación Pacientes de Cáncer de Pulmón: www.fundacionpcp.org



LungFoundation Australia:
www.lungfoundation.com.au



Oncoguia Institute: www.oncoguia.org.br



Bulgarian Anti-Cancer Patient Association (APOZ): www.oncobg.info



Canadian Lung Association:
www.lung.ca

Lung Cancer Canada:
www.lungcancer canada.ca

The Lung Health Foundation:
www.lunghealth.ca



OnkoMaják
www.onkomajak.cz



Patientforeningen Lungekraeft:
www.lungekraeft.dk



CanSurvive: www.facebook.com/CanSurvive



La Ligue Contre le Cancer:
www.ligue-cancer.net



Deutsche Krebsgesellschaft E.V:
www.krebsgesellschaft.de



FairLife Lung Cancer Care
fairlifelcc.com



Irish Cancer Society: www.cancer.ie



The Israeli Lung Cancer Foundation:
www.ilcf.org.il



ALCASE Italia: www.alcase.eu

Cittadinanzattiva: www.cittadinanzattiva.it



Women Against Lung Cancer in Europe:
www.womenagainstlungcancer.eu



Cancer Net Japan: www.cancernet.jp

West Japan Oncology Group (WJOG):
www.wjog.jp



Respirando Con Valor A.C:
www.respirandoconvalor.org



Longkanker Nederland:
www.longkankernederland.nl



LungeKreft Foreningen:
www.lungekreftforeningen.no



Esperantra: www.esperantra.org



Associação Portuguesa de Luta Contra o Cancro do Pulmão:
www.pulmonale.pt



Equal Right to Life: www.ravnoepravo.ru

Movement Against Cancer:
www.rakpobedim.ru



Na-Vdih (Inspire):
www.na-vdih.si



Campaigning for Cancer
campaign4cancer.co.za/wp



Asociación Española De Afectados De Cancer De Pulmón:
www.afectadoscancerdepulmon.com

La Asociación Española Contra el Cáncer: www.aecc.es



Lungcancerforeningen:
www.lungcancerforeningen.se



Forum Lungenkrebs:
www.facebook.com



Formosa Cancer Foundation
canceraway.org.tw



Pembe Hanim: www.pembehanım.com.tr



Asthma + Lung UK:
www.asthmaandlung.org.uk

Lung Cancer Nursing UK:
www.lcnuk.org

Roy Castle Lung Cancer Foundation:
www.roycastle.org



CancerCare: www.cancercare.org

GO2 for Lung Cancer:
www.go2.org

Lung Cancer Research Foundation:
www.lungcancerresearchfoundation.org

Prevent Cancer Foundation:
www.preventcancer.org

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GLOBAL LUNG CANCER
COALITION

