# UNiTY



The newsletter of the Global Lung Cancer Coalition

Autumn | Winter 21

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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 awarenesse 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 to 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



The GLCC recently launched two new resources to help members and lung cancer screening advocates campaign for national lung cancer screening programmes in their country.

Developed by renowned medical writer Dr Susan Mayor, the two resources are called Starting the conversation: Making the case for a national lung cancer screening programme and Building the case for a national lung cancer screening programme.

Starting the conversation aims to support members or advocates who are just starting or at the early stages of their campaign to develop a national lung cancer screening programme.

Building the business case builds on Starting the conversation and is intended to support members and advocates further along the road in developing a national lung cancer screening programme.

Both resources are fully customisable, so members and advocates can adapt

the templates to meet their needs and insert the latest available figures from their country. If national or local figures are not available for certain indicators, these sections can be removed, as the templates also include global figures.

As well as creating these standard versions, we also collated data for several indicators and developed country-specific resources for 14 members who said they would like a tailored national toolkit.



Please click here to download the two new screening resources.

If you are a GLCC member and interested in having a customised national toolkit created for your country, please email glcc@roycastle.org





## **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.

## LAA PUBLISHES SCREENING REPORT

Lung Ambition Alliance, of which the GLCC is a founding member, published its *Lung cancer* screening: the cost of inaction report in July 2021.

In the report the LAA states that nearly a quarter of all lung cancer deaths could be avoided in high-risk populations through targeted lung cancer screening worldwide.

The new report also highlights that an increase in early lung cancer diagnoses could lead to a huge economic benefit for countries around the world.



Please click here to find out more and download the report.

# US NATIONAL SCREENING CAMPAIGN



GO2 Foundation for Lung Cancer was delighted to be one of the partners who launched the Screen Your Lungs national campaign in the US.

The public service advertisement for the campaign focuses on transporting people back to a time when smoking was part of everyday life, so they identify themselves as being eligible for an annual low-dose CT scan.

The advert is supported by a Screen Your Lungs website, which features information about where to get screened, a screening quiz and a range of resources for the public.



Please click here to visit the Screen Your Lungs website.

# INCREASING SCREENING AWARENESS



In November, Prevent Cancer Foundation used its Back on the Books campaign to let people in the US know they may now be eligible for lung cancer screenings that could save their life.

Earlier in June, the Foundation also broadcast a live webcast called 'Progress and challenges in cancer screening', which is still available to view on their website.



Please click here to find out more about the November campaign.



Please click here to watch the webcast on cancer screening.

# CONSIDERING A SCREENING PROGRAMME FOR SLOVENIA

GLCC member Navdih took part in a webinar in November that considered the feasibility and potential impact of a lung cancer screening programme in Slovenia.

One of the experts attending the event was Professor Marko Jakopović, who discussed the success of the national lung cancer screening programme in neighbouring Croatia. There, almost 90% of invited high-risk citizens have had a low-dose CT scan.

During the online event, experts also talked about considerations that are currently preventing a screening programme from being introduced in Slovenia. These include the criteria which will determine who is invited for a scan and how often people should attend screening appointments.



Please click here to watch the webinar about a lung cancer screening programme for Slovenia. Please note it is in Slovene.



























## LUNG CANCER SCREENING CALL FOR EUROPE



In September, the European Respiratory Society (ERS) and 55 partner organisations issued an open letter to the European Parliament's Special Committee on Beating Cancer (BECA) which encouraged it to do more to increase early lung cancer diagnosis by 20% by 2030.

In the letter, the ERS and partners urged policymakers to:

- Extend recommendations on cancer screening to additional cancers, including lung cancer, via an update to guidelines in 2022.
- Support projects that explore the barriers limiting the early detection and early diagnosis of lung cancer, such as EU4Health, EU Mission: Cancer, and other relevant programmes.
- Connect Europe's experts through cross border collaborations such as multidisciplinary centres of excellence.



Please click here for more information and to read the open letter.

## SCREENING PILOT FOR **PORTUGAL**

Pulmonale are set to propose a pilot lung cancer screening project to the government of Portugal.

Developed with lung cancer specialists, it's hoped that if the pilot leads to expected results it will be replicated on a national level.



Please click here to find out more. Google Translate

## SUPPORTING THE CASE FOR SCREENING

Aoife McNamara of the Irish Cancer Society (GLCC member) and Suzanne Wait of The Health Policy Partnership have written an in-depth blog post about lung cancer screening.

Titled Lung cancer screening: the time is now, the blog features a wide range of statistics and other evidence to support the case for the implementation of targeted lung cancer screening programmes.



Please click here to find out more.

## GREECE, ARE WE READY FOR SCREENING?

In mid-November, FairLife of Greece hosted an online conference called Lung cancer screening programme in Greece - Are we ready?

The main topic of the conference was the presentation of the results from the first lung cancer screening study conducted in Greece.



Please click here to find out more.

## AWARD FOR SCREENING CHAMPION



Bill Simpson with members of the Lung Health Check scheme funded by the Roy Castle Lung Cancer Foundation

Three GLCC members from the UK (Asthma UK and British Lung Foundation Partnership, Lung Cancer Nursing UK, and Roy Castle Lung Cancer Foundation) have given a Special Recognition Award from the GLCC to patient advocate Bill Simpson.

The award recognises Bill's outstanding efforts to raise awareness of the importance of early diagnosis and the need for lung cancer screening in the UK.



Please click here for more information.































The Formosa Cancer Foundation of Taiwan launched the 2021 Love Lung with Ease campaign to raise public awareness of the importance of low-dose CT scan screening.

The campaign also involved Formosa giving grants to women over 40 who are at high risk of developing lung cancer and need financial support to pay for a CT scan.



Please click here to find out more. Google Translate

## BULGARIA READY FOR NATIONAL ANTI-CANCER PLAN



APOZ of Bulgaria launched a public consultation on the development of a national anti-cancer plan for 2021 to 2030.

The conference in October was attended by medical experts, representatives from healthcare organisations and Andrey Slabakov, a member of the European parliament who sits on the Special Committee on Beating Cancer (BECA).

Areas discussed included screening, prevention, treatment and follow-up care for cancer, and experts stated their readiness to gradually introduce screening for several cancers, including lung cancer.



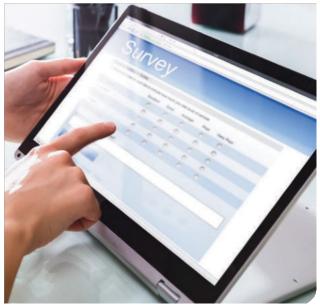
Please click here to find out more. Google Translate

## SECOND PATIENT SURVEY FINDINGS PUBLISHED

At the World Conference on Lung Cancer in September, the GLCC presented the findings of its second patient experience survey.

Focusing heavily on the impact of the Covid pandemic on lung cancer patients, the survey revealed:

- During the pandemic, lung cancer patients globally thought there was an unnecessary delay to diagnosis.
- Throughout the pandemic, lung cancer patients have mainly asked patient organisations for information on the Covid-19 vaccine and the impact of the virus on treatment now and in the future.
- Over three-quarters of the organisations who took part in the survey believe the pandemic has restricted the diagnosis, treatment and care of lung cancer in their country.
- Almost all organisations have continued to offer patients new services introduced at the start of the pandemic, including online webinars and emotional support groups.
- Only members from Australia, Canada, the UK and US said their national or regional government has offered their organisation financial support during the pandemic.





Please click here to find out more and download global and national findings from the second patient survey.

























## EDUCATING YOUNG PEOPLE IN GREECE

FairLife of Greece organised a range of activities with children and young people to highlight how smoking can have a negative impact on people's health and the environment.

14 Minutes Fairlife is a video that features 11 teenagers from nine different schools in Greece talking about the importance of a healthy lifestyle.

Fairlife's new campaign 'A world without cigarettes through the eyes of children' involved young people creating drawings to show how they perceive and experience a world with or without cigarettes.

And on the Global Day of Climate Action and World Lung Day (25 September 2021), FairLife sent out the message 'Let life take your breath away. Not lung cancer' to raise awareness of the damaging effects smoking has on human health and the environment.





Please click here for more information and to view some of the children's drawings

## **COUGH CAMPAIGN** FOR AUSTRALIA

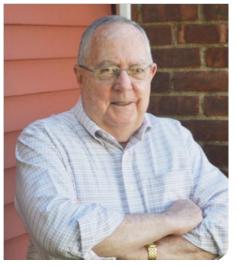
Lung Foundation Australia launched a new radio and social media campaign in September to stop Aussies from ignoring the warning signs of lung cancer.

Called 'What if your cough isn't just a cough?', the campaign aims to tackle complacency, as new research revealed that 1 in 3 Australians would not act on a new, persistent cough lasting more than three weeks.



Please click here for more information.

## WIN BOERCKEL **RECOGNISED** AS A HERO



Everyone at the GLCC was delighted to see Winfield 'Win' Boerckel feature as a nominee in CURE magazine's Lung cancer heroes 2020 essay book.

Win holds the position of treasurer on the GLCC's steering group and is director of social service at CancerCare, which is a member of the GLCC from the US.



Please click here to view the Lung cancer heroes 2020 essay book. Win features on page 53.

## ALCASE TRANSLATES ASCO **INFORMATION**



Alcase recently completed the translation of lung cancer patient information published by the American Society of Clinical Oncology (ASCO) into Italian.

To help share this information to interested parties in Italy, Alcase broadcast four webinars which were hosted by its medical director. Dr Gianfranco Buccheri

Three of the webcasts focused on non-small cell lung cancer and one webcast focused on small cell lung cancer.



Please click here to find out more.











# LUNG CANCER AWARENESS MONTH COALITION IS REBOOTED

Now under the stewardship of GO2 Foundation for Lung Cancer rather than the IASLC, the Global LCAM Coalition launched with a new look in late October.

## **LCAM** Coalition



The LCAM Coalition is a global alliance of cancer and related organisations who bring their collective voices together to amplify the conversation around lung cancer, and specifically during Lung Cancer Awareness Month.

The LCAM Coalition provides members and the public with information and tools to raise awareness, including shareable infographics that are easily downloadable for use on multiple channels.



Please click here for more information and to learn how to join.

## LUNG CANCER AWARENESS MONTH HIGHLIGHTS

Please click on each member's name to find out more about their campaigns.



Lung Foundation Australia launched its 10th Shine a Light on Lung Cancer campaign. It encouraged Aussies to raise awareness and funds for lung cancer research by hosting a fundraiser or donating a virtual lantern of hope.



AEACaP launched its #SinRespiro campaign to encourage Spanish society and public organisations to make the impact of lung cancer more visible and promote the need for prevention and research.



Alcase Italia launched its seventh Illumina Novembre event. It involves people attaching white lights, ribbons, bows and balloons to properties and monuments in over 100 towns and cities in Italy.







Longkanker Nederland launched its 'Lung cancer does not wait' campaign to help increase the number of early diagnoses of lung cancer in the Netherlands.



Roy Castle Lung Cancer Foundation launched its Spot the Difference campaign to help people recognise the many different, and often subtle, symptoms of lung cancer, and to take action if they're spotted.



Pulmonale launched a campaign called 'No two lungs are alike. No two cancers are alike'. The campaign aimed to highlight the uniqueness of each lung



cancer diagnosis, including the characteristics of the patient and each disease



GO2 Foundation for Lung Cancer launched its Lung Cancer: It's Personal campaign to bring to life the stories of people affected by lung cancer and raise awareness of the illness.

Lung Cancer Research Foundation partnered with the African Methodist Episcopal Church International Health Commission to launch a campaign that targeted black Americans. It focused on raising awareness of prevalence, risks factors, the importance of screening and the prevention of lung cancer.

























## LUNG CANCER MEDIA ROUND-UP



#### **ASCO 2021 LUNG CANCER NEWS**

At the American Society of Clinical Oncology's annual meeting in June 2021, leading clinicians and researchers from around the world presented the latest in cancer research.

This included results from the Impower010 phase 3 trial, which show promise that immunotherapy could be used after surgery to lower the risk of early-stage lung cancer from returning.

A phase 2 study (CodeBreak 100) showed that a new drug called AMG 510 improved survival for people with non-small cell lung cancer who had already had treatment and whose cancer was being driven by a mutation in the KRAS gene (KRAS G12C).



Click here to explore the digital program of the 2021 ASCO annual meeting.

## INVESTIGATING THE BIOLOGY OF SHAPE-SHIFTING LUNG CANCER

In a study published in *Cancer Discovery*, Dr Triparna Sen and colleagues from the Memorial Sloan Kettering Cancer Center uncovered the molecular changes behind the transformation of lung adenocarcinoma into much more aggressive small cell lung cancer, which happens in about 15% of cases.

In a later study published in the *Journal of Hematology* and *Oncology*, Dr Sen and her team successfully focused on the switch from lung adenocarcinoma to squamous cell carcinoma. This change occurs in about 7–9% of cases.



Cancer Discovery study.



Journal of Hematology and Oncology study.

## UNMET NEEDS AND QUALITY OF LIFE

Research published in the *European Journal of Cancer Care* suggests that unmet physical and psychological needs of people with lung cancer have a significant impact on their quality of life and affect their ability to continue with everyday activities.



Click here for more information.

#### MAPPING SMALL CELL LUNG CANCER

The Human Tumor Atlas Network has constructed three-dimensional images of the dynamic cellular, morphological and molecular features of small cell lung cancer. In these images, rare stem-like cells were found with metastatic properties.



Click here for more about the small cell lung cancer atlas.



Click here for more on the Human Tumor Atlas Network.

## PREHABILITATION GUIDANCE FOR ADVANCED LUNG CANCER

Jackie Fenemore, Chair of GLCC member organisation Lung Cancer Nursing UK, and Josie Roberts, a lung cancer nurse specialist, have published two articles in the UK's *Nursing Times* about the principles and benefits of prehabilitation for advanced lung cancer.



Click here to read part 1.



Click here to read part 2.

## CLASSIFYING LUNG CANCER IN NEVER SMOKERS

A study reveals the majority of lung cancer tumours found in never smokers arise from the accumulation of mutations caused by natural processes in the body.



Click here for more information.

#### AI ACCURATELY DIAGNOSING LUNG CANCER

Research published in the journal *Radiology* found that an artificial intelligence program for lung nodule assessment using deep learning (DL) could identify specific patterns in imaging data and deliver excellent results.



Click here for more information.































More than ever, video on social media is becoming an increasingly important way for charities to engage with their followers and attract new supporters. Here, we provide some handy tips to help ensure your videos make the biggest impact.

#### 1. Find out what's out there

After deciding what type of video you want to create, a good next step is to have a look around at what other charities are doing.

You could do this by visiting YouTube, simply searching terms such as "lung cancer awareness video", or heading to the websites of other charities.

Doing this research can help to fuel your creativity; or if you're using an external production company, you can show them the videos you like to help inspire their work.

## 2. Choose your channel carefully

When creating and editing a video, think about what channels you're going to show it on, as viewers have different expectations on different channels.

For example, a person looking at Facebook may be willing to spend more time watching a video than someone who's looking at Twitter.

While on Twitter, it tends to be the case that people want more dynamic, news-focused content which they can quickly digest and respond to.

#### 3. Size does matter with video

The perfect aspect ratio for your video will vary from platform to platform. So take the time to look at the recommended specifications for your chosen platform before producing your video.

However, if you don't have time to optimise for each social media platform, a 1:1 aspect ratio is usually the way to go, as square videos continue to be popular on most channels.

























### 4. Keep your videos short

The reality with social media is that less is often more, so try hard to cut your videos back so they don't feature any surplus content that's just not needed, as it will turn viewers off.

Also think about changing the length of your videos for different social media channels. Marketing website HubSpot recommends that videos should be two minutes for YouTube, one minute for Facebook, 45 seconds for Twitter and 30 seconds for Instagram.

## 5. Say one thing and say it well

We're positive your organisation has achieved lots of amazing things and you're really proud of what you and your community do.

But the reality is that audiences don't want to have to process multiple or complicated messages when they watch your video, because it will take them time to do this.

As a result, you should really focus on the one thing you want your audience to take away from your video and make sure you communicate this message clearly and loudly.

#### 6. Grab people's attention early on

You'll often capture or lose someone's attention within the first three seconds of your video. So put your most compelling shot, interview snippet or statistic right at the top of your film to hook the viewer in.

#### 7. Give your beneficiaries a voice

More than anything, current and potential supporters want to hear how your organisation's work benefits the people you support.

The best people to tell this story is not your chief executive, director of services, or health or social care professionals. It's your beneficiaries themselves.

That's why it's vital you do your utmost to give them a voice, and especially in fundraising videos or films that are trying to raise awareness of your services.





#### 8. Have a clear call to action

Videos have one of the highest conversion rates of all content. So make sure you take the time to create a strong call to action that gets people to donate, click on a link, fill in a form, or whatever you want them to do.

Also think about creating different call to actions for different platforms. But for every one, always remember to make them personal and easy to follow.

#### 9. Optimise for mobile devices

Research shows that half of all social media videos are watched on mobile devices, and for Twitter that number is as high as 93%.

As a result, it's important you make sure your videos are mobile friendly:

- simplify graphics so it's easy for people to digest what you're communicating
- add subtitles because many social media videos are watched in public spaces with the sound off
- check whether your video will be easy to follow and understand without any audio

#### 10. Measure your success

Surprisingly, many organisations continue to put out excellent videos without actually tracking how well they're performing. Information that could help them improve their content, reuse video that's working, and identify which platforms they're best posting on.

To make sure you don't make this mistake, consider using some of the many social media analytics tools that are out there. They're often free and typically don't take too long to set up.



Take a look at Hootsuite's article on social media analytics tools.



## Can you please give us an overview of the Lung Health Foundation?

The Lung Health Foundation is dedicated to ending gaps in the prevention, diagnosis and care of lung disease in Canada. Established in 1900, and formerly known as the Ontario Lung Association, we've spent many years building the deserved reputation as a firm leader, strong voice and primary resource in lung health.

Where is the Lung Health Foundation based? Our headquarters are in Toronto, Ontario, and we have 40 members of staff across Canada.

## How many people are affected by lung cancer in Canada?

An estimated 1 in 15 Canadians (7%) is expected to be diagnosed with lung cancer in their lifetime, and an estimated 29,600 people are expected to be diagnosed with lung cancer in 2021.

Lung cancer is also the leading cause of cancer death, responsible for more cancer deaths among Canadians than the other three major cancer types (colorectal, breast and prostate) combined.







Lung Health Foundation's Stop Asking the Wrong Question about Lung Cancer campaign features videos from people talking about their lung cancer diagnosis.

In your opinion, do people with lung cancer generally receive the support and care they need in Canada?

Patients face many barriers to accessing care, treatment and support in Canada. This is, in part, due to the stigma associated with lung cancer, because it's still seen as a 'smoker's disease'.

We see that stigma transcend into various aspects of lung cancer research, awareness and care. For instance, a recent study on cancer funding disparities noted the blame culture of lung cancer has led to the underfunding of potentially life-saving research.

It's particularly worrisome that lung cancer is by far the largest cancer killer in Canada yet it's the least funded.

How is the Lung Health Foundation trying to improve the situation for people with lung cancer and their families in Canada? We engage in lung cancer advocacy at national and provincial levels in Canada. A few of our priorities include improving access to lung cancer screening, diagnostic assessment programs, and affordable and innovative treatment options.

We also engage in public education and healthcare provider education, invest in groundbreaking research, and give patients and their families the support they need throughout their entire cancer journey.

## Can you tell us about any of your current lung cancer media campaigns?

Our 'Stop Asking the Wrong Question about Lung Cancer' campaign is a national campaign urging Canadians to stop asking if people with lung cancer smoked and start asking the right questions.

For example, 'Why is lung cancer by far the largest cancer killer yet receives the least research funding?' or 'Why have lung cancer survival rates barely improved in decades?'.

What are the Lung Health Foundation's main aims for the next five years?

Our lung cancer goal for the next five years is to give people with lung cancer a fighting chance by eliminating the barrier of stigma and increasing lung cancer survivorship by 5%.

We'll do this through an integrated approach which includes supporting patients and caregivers, research investments, policy change, public education, and healthcare practice change.

Have you gained any knowledge from another GLCC member that's benefited your organisation?

We're very fortunate to have worked with Lung Foundation Australia on developing our Stop Asking the Wrong Question campaign. Their leadership and creativity inspired us to adapt the campaign to be applicable within the Canadian context.

How do you think working with GLCC members in the future will benefit your organisation? I'm certain that collaboration between GLCC members will allow us to make greater progress in improving outcomes for patients with lung cancer.

Learning from each organisation about their own initiatives and what has been effective in their respective jurisdictions can serve as inspiration to other members.

In addition, sharing best practices that have been implemented in different countries can aid organisations in developing policy recommendations for government.

An estimated 1 in 15 Canadians (7%) is expected to be diagnosed with lung cancer in their lifetime.



For further information about the Lung Health Foundation and its work, please visit lunghealth.ca



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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.lungcancercanada.ca

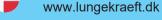
The Lung Health Foundation: lunghealth.ca



OnkoMaják www.onkomajak.cz



Patientforeningen Lungekraeft:





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



Slovenia-NAVDIH (INSPIRE): www.na-vdih.si



Campaigning for Cancer campaign4cancer.co.za



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.pembehanim.com.tr



Asthma UK and the British Lung Foundation Partnership: www.blf.org.uk

Lung Cancer Nursing UK: www.lcnuk.org

Roy Castle Lung Cancer Foundation: www.roycastle.org



CancerCare: www.cancercare.org

GO<sub>2</sub> Foundation for Lung Cancer: www.go2foundation.org

Lung Cancer Research Foundation: www.lungcancerresearchfoundation.org

Prevent Cancer Foundation: www.preventcancer.org

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