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.

The GLCC has refreshed its e-Atlas to include statistics from 2020, following the latest update to the Globocan database and national datasets.

Our interactive resource brings together data on key lung cancer indicators from countries around the world. This includes information on incidence, mortality, survival, existence of a cancer plan, existence of a cancer registry, and whether a country has implemented the WHO Framework Convention on Tobacco Control.

The e-Atlas, which was launched in 2014, can be used to:
- view and export individual country profiles
- compare and export the statistics of up to four countries
- compare incidence, mortality and survival on a world map
- examine incidence, mortality and survival in a country by sex and age range.

The look and navigation of the e-Atlas has also been improved so users can find the information they want more easily.

Overall, we hope the resource will help GLCC members and other lung cancer advocates to create compelling campaigns that improve the quality and consistency of lung cancer diagnosis, treatment and care in their country.
In February, The Health Policy Partnership (HPP) launched its Lung cancer in Europe: the way forward report, which was created with representatives from the GLCC and other lung cancer organisations. The think-piece presents a case for change to improve the lives of people affected by lung cancer in Europe and identifies four strategic priorities:

- Improve awareness, reduce stigma
- Enhance opportunities for early detection, with screening at its core
- Take targeted approaches to reduce disparities in access and outcomes
- Improve the availability of quality care

The HPP states that with the EU recently publishing its cancer plan, there’s a real opportunity to put in place what’s needed to improve lung cancer outcomes.

Please click here to read the full report.

At the start of the year, the GLCC ran its third annual global patient experience survey to understand the continuing impact of Covid-19 on lung cancer care, and to compare the experiences of patients in different countries.

We had a brilliant response to our survey, with 555 patients from 21 countries completing our questionnaire. Thank you to all the members who shared the survey through their networks and on social media, and to the survey’s steering group for their guidance and support.

As in previous years, we submitted the global findings of the patient survey to the IASLC World Conference on Lung Cancer. We also submitted three abstracts for poster or oral presentations, which have all been accepted. The abstracts focus on:

- Patient preferences for speaking to their treatment team
- Patients’ involvement in decision-making
- Patients’ willingness to attend a screening appointment or lung health check

We will present all our findings from our third global patient experience survey to GLCC members in August. Following this, we will launch a global report with key findings.

In addition, we have sent members involved in this year’s survey an infographic highlighting the main findings from their national survey. We hope the infographics will be a useful resource to support your campaigns and advocacy work on improving patient experiences.

We have also uploaded the national infographics onto the GLCC website. They are published in English and, when possible, the relevant national language.

Please click here to access all the national insights from our third global patient experience survey.
IMPACT OF COVID-19 ON LUNG CANCER TRIALS

Enrolment in lung cancer clinical trials declined by 14% during the Covid-19 pandemic, according to a report co-authored by the GLCC’s Jesme Fox, representatives from GLCC member organisations and other lung cancer experts.

Titled Impact of the coronavirus disease 2019 pandemic on global lung cancer clinical trials: Why it matters to people with lung cancer, the study behind the report focused on 294 lung cancer clinical trials from around the world. Monthly enrolment data was collected from each trial and a 64-question survey was issued to international clinical trial sites from 45 countries.

The most frequent challenges identified at the sites were fewer eligible patients (63%), a decrease in protocol compliance (56%), and the suspension of trials (54%). Patient-specific challenges included access to trial site (49%), ability to travel (54%), and willingness to visit site (59%).

Please click here to read the report, which was published in the Journal of Thoracic Oncology.

LUNG CANCER SCREENING IN SPAIN

In January, the GLCC Secretariat spoke to Dr Juan Carlos Trujillo about the launch of the CASSANDRA lung cancer screening pilot in Spain.

Dr Trujillo said he developed the concept for the project with Dr Luis M Seijo following talks with other healthcare professionals who were thinking about how the early detection of lung cancer and other respiratory diseases could be improved in Spain.

As a first step, Dr Trujillo and Dr Seijo convened a forum, including surgeons, oncologists, radiologists and respiratory physicians, to discuss a screening pilot. The forum presented the idea to professional and patient societies. After gaining their support, a protocol outlining the steps to set up and implement a screening programme was created.

The forum then reached out to hospitals in all of Spain’s 17 regions to gauge interest to ensure the pilot is accessible to people across the country and its findings are representative of the healthcare needs of its population. So far, over 40 hospitals across 16 regions have agreed to participate.

The CASSANDRA project starts later this year and will run for five years. The forum will use a mix of public awareness campaigns and outreach to primary care physicians to invite people to have a CT scan. Smoking cessation services will also be a key component of the pilot.

Dr Trujillo says he expects the pilot will identify people with early lung cancers and other important respiratory conditions that need to be managed.

PULMONALE LAUNCHES POSITIVITY CAMPAIGN

Pulmonale of Portugal launched a public awareness campaign for February’s World Cancer Day that encouraged people living with cancer not to lose hope during recovery.

Titled Não Pare de Acreditar (Don’t Stop Believing), the campaign highlighted how the diagnosis and treatment of lung cancer has advanced over the past decade; that new therapies are being developed all the time to improve quality of life; and that we are increasingly moving towards cancer becoming a chronic illness.

Please click here to find out more

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Google Translate
GO2 Foundation for Lung Cancer relaunched a new and improved Lung Cancer Registry in January 2022.

The Registry now features a more user-friendly interface and intuitive design. The new and extensive caregiver section is available in English, Spanish, simplified Chinese, German and French; the site’s patient survey is currently only available in English, but this may change in the future.

It’s hoped the relaunched Lung Cancer Registry will lead to more lung cancer patients and their caregivers across the globe providing information about their experiences with diagnosis, biomarkers, treatment, side effects, quality of life and other survivorship issues.

People can also use the Registry to view anonymous patient data and compare it with their own, receive information about clinical trials and Registry studies, connect with researchers and healthcare providers, advance their understanding about lung cancer, and use the secure Registry for medical record keeping.

Please click here for more information

GLCC SPECIAL RECOGNITION AWARD

Our first post-pandemic special recognition award was presented by the Lung Health Foundation of Canada to Mary Ann Bradley for her tremendous work as a lung cancer patient advocate.

In 2006, the GLCC launched an awards scheme to recognise and celebrate journalists from around the world who help to raise awareness of lung cancer and issues that surround the disease.

Over the years, the scheme has expanded, and now, anyone who goes above and beyond to raise awareness of the world’s biggest cancer killer can receive a special recognition award from the GLCC. This includes patients like Mary Ann, carers and medical professionals.

Please click here to watch a video by The Lung Health Foundation which showcases Mary Ann’s contributions.

Please click here to learn more about the GLCC’s Journalism and Special Recognition Awards.

WALCE’S MOLECULAR TESTING PROGRAM

Women Against Lung Cancer Europe (WALCE) has launched a support program to help people who have advanced non-small cell lung cancer and live in Europe.

Called EPROPA (European Program for Routine Testing of People with Advanced Lung Cancer), the program aims to:
• increase the molecular screening of people with advanced non-small cell lung cancer (NSCLC)
• help people with NSCLC become enrolled in clinical trials that use targeted therapies
• provide financial and logistical support to help people access clinical trials outside their own country.

Please click here for more information

You can also contact Stefania Vallone of WALCE to find out more.
YOGA VIDEOS TO IMPROVE BREATHING

To help people with lung cancer regularly perform breathing exercises, Fundación Pacientes de Cancer de Pulmón (FPCP) of Argentina has made some videos with yoga instructors and published them online.

In the videos, the yoga instructors explain and perform exercises and recommend how someone can start on a journey to improve the way they breathe. So far, the videos have been very well received by patients, and FPCP is gathering feedback to help make future videos even more helpful.

Please click here to view FPCP’s yoga videos.
Google Translate

FINANCIAL IMPACT OF LUNG CANCER REPORT

Lidia Barberio, the director of Longkanker Nederland, has co-authored a report on how lung cancer is having a huge financial impact on people diagnosed with the illness in the Netherlands.

Titled Financial consequences of cancer: what is your experience?, the report reveals that almost 80% of lung cancer patients who answered a questionnaire said they’d experienced increased expenses and/or less income after diagnosis. However, most healthcare providers in the country, which has a well-organised healthcare system, have not considered that patients will experience this financial distress.

Please click here to read an IASLC article about the report.
Please click here to read the full report.
Google Translate

BIOMARKER TESTING RESOURCE UPDATED

Lung Cancer Research Foundation of the US has updated its biomarker testing educational resource for people diagnosed with lung cancer and their caregivers.

The free resource answers questions such as:
• What is a biomarker?
• What is biomarker testing?
• How can my biomarker information help plan my treatment?
• Where can I go to get my tumour tested?

Please click here for more information.

FREE SOCIAL WORK SERVICE

Lung Foundation Australia launched a free Lung Cancer Social Work Service in February.

The telephone service provides emotional, practical and social support to people with lung cancer and their caregivers to help them with a wide range of issues and make informed decisions about the present and future.

Mark Brooke, Chief Executive of Lung Foundation Australia, said, “Our free Social Work Service is one important step to improving the quality of life of those living with lung cancer, who face an incredibly low five-year survival rate of just 20%, but more still needs to be done.”

Please click here to find out more
FairLife of Greece held an online event in May to launch its new youth anti-smoking campaign, which has the main message “I inhale, I exhale, but I do not breathe”.

Prior to the launch, over 4,000 students from primary, secondary and high schools from Greece and abroad had taken part in FairLife’s creative writing and poster competition.

Korina Pateli Bell, President of FairLife, said about the competition and anti-smoking campaign, “Through the invitation and participation of young people in the competition, we came closer to them, the school community and their families. Through their cooperation and interaction, we spread the message about the harmful effects of smoking, and we also gained many of their creative and imaginative works.”

Kari Grønås was unanimously elected the new leader of Norway’s LungeKreft Foreningen during the organisation’s national meeting on 22 April. Kari takes over from Cecilie Bråthen, who resigned as leader after several years of fantastic efforts for LungeKreft Foreningen.

Asthma UK and the British Lung Foundation Partnership has been renamed Asthma + Lung UK and was launched in February 2022 with new branding and a new strategy.

The charity’s new logo features a pink and orange cross with white writing, representing the coming together of the two former lung charities to create one organisation.

The organisation’s new strategy is called Fighting for Breath and is focused on improving the lung health of people living in the UK.

As part of the launch, Asthma + Lung UK stated that the new strategy and brand are urgently needed because of the “shameful” state of the UK’s lung health.

Lung Cancer Canada has published its latest Faces of Lung Cancer report, which has the subtitle Reflections from Covid-19.

The report provides an overview of the current state of lung cancer in Canada and focuses on four key areas:

- How people living with lung cancer were affected by the pandemic
- The rise of virtual care
- The impact the pandemic had on healthcare providers
- Access to lung cancer treatments in Canada

The report also features testimonies from people living with lung cancer and a range of healthcare professionals, as well as a number of action points for the future.
LUNG CANCER MEDIA ROUND-UP

EUROPEAN PARLIAMENT'S REPORT ON LUNG CANCER SCREENING
The European parliament’s Report on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy is the parliament’s first official document to recognise the positive effect of targeted lung cancer screening. Published by the Special Committee on Beating Cancer in July 2022, the report calls on the wider European Commission and Council to consider including targeted lung cancer screening in their updated recommendations in 2022.

Click here to read the report

EC’S EVALUATION ON TOBACCO CONTROL
The European Commission has started an evaluation of the legal framework for tobacco control to determine to what extent it has fulfilled its goals and whether it can support a ‘tobacco-free generation’ by 2040. The evaluation will cover product regulation, advertising, promotion and sponsorship, in the broader context of related tobacco control policies.

Click here to find out more about the initiative

EARLY DETECTION RISE IN ENGLAND
Figures released by NHS England in April 2022 show that its Targeted Lung Health Check programme has already diagnosed 600 people with lung cancer. Positively, 77% of these cancers were caught at stage one or two. In 2018, less than a third of lung cancers were diagnosed at these early stages. The Targeted Lung Health Check involves travelling trucks visiting different areas of England to give people most at risk from lung cancer a lung MOT.

Click here to find out more

WHY DO LIFELONG SMOKERS NOT GET LUNG CANCER?
Researchers from Albert Einstein College of Medicine, New York, have used new methods to assess genetic mutations among lung cells in heavy smokers and people who did not smoke. They found that smokers had significantly more mutations in their lung cells than non-smokers. However, heavy smokers did not have more mutations than less heavy smokers. The researchers suspect that DNA repair mechanisms may be the reason behind this, but further research is needed.

Click here to find out more

AI SET TO HELP NSCLC PATIENTS
A new study led by researchers at The Royal Marsden NHS Foundation Trust in London, UK, has found that artificial intelligence could help shape the post-treatment surveillance on non-small cell lung cancer (NSCLC) patients and improve their outcomes. The OCTAPUS-AI study compared different artificial intelligence models to determine which could most accurately identify NSCLC patients at risk of recurrence following curative radiotherapy.

Click here to find out more

SOCIO-ECONOMIC DIFFERENCES IN SCLC AND NSCLC
New research suggests that people with small-cell lung cancer (SCLC) may have more socio-economic disadvantages than those with non-small cell lung cancer (NSCLC). Researchers believe these disadvantages are then likely contribute to the poor survival outcomes observed in SCLC.

Click here to find out more

ACHIEVING EQUITY IN LUNG CANCER SCREENING
Researchers have written a new commentary about improving equity in lung cancer screening for black people in the US. The researchers state that identifying a solution will require an understanding of the underlying causes of disparities, defining which disparities to eliminate, and the development of new tools to tackle the issue.

Click here to find out more

NEW CEO OF IASLC: “GLOBAL REACH A STRENGTH”
In her first commentary piece, Karen Kelly, the new CEO of the International Association for the Study of Lung Cancer, states that the unique global reach of the IASLC will be “key to conquering thoracic malignancies worldwide”.

Click here to read the commentary
In our ongoing series of How to… features, we look at how you can use social media platforms to survey your members and the wider public.

Due to their incredible popularity, social media networks such as Facebook and Twitter are the perfect place for your organisation to survey its members and the wider public about many different topics. To help you do this, we cover in this article how you can create and distribute a survey on social media; what types of survey you may want to create; and our top tips on getting the feedback and opinions you want.

Creating and distributing a survey on social media

The easiest way to survey your followers on social media and the public is to use online platforms that allow you to create surveys, quizzes and polls and then post a link to these on your social media pages.

Popular companies that offer this service include SurveyMonkey, Typeform and Jotform, but there are many to choose from. We recommend you simply carry out an online search for ‘survey platforms’ and look at what’s available to find the right tool for your organisation and the survey you want to conduct.

It’s also worth noting that most survey platforms offer free services, but their paid-for plans allow you to carry out more tailored and in-depth surveys, as well as access to a wide range of helpful tools.

As an alternative to using a survey tool, you may be able to use your preferred social media platform to create a simple poll and make this available on your organisation’s page.

For example:

- **Facebook** allows you to create a post that features a poll with two response options
- **Twitter** allows you to create a post that features a poll with up to four response options
- **Instagram** allows you to add a poll sticker to a photo or video with up to four response options
The types of surveys you could post

1. For capturing demographic information
Find out more about your followers, such as their gender, age, location, etc, and how they've been affected by lung cancer.

2. For collecting feedback
Ask your followers what they think about your organisation or one of your services, resources or events. This can help to inform improvements and future strategies.

3. For collecting market research
Ask your audience more general questions about lung cancer and its impact on their lives, for example, how well they've been supported so far, what their experience was like at diagnosis, what treatment they're receiving and how it is affecting them.

4. For measuring customer experience
Customer experience questions should focus on all the ways a beneficiary, supporter or partner interacts with your organisation. For example, your questions may ask people about their experiences with your website, newsletter, support line, members of staff, etc.

5. For engaging with followers
Simply posting the occasional survey can be a quick and effective way of keeping your social media followers engaged with your organisation. One-question polls are great for this, because they take so little time to create.

Our top tips to get the responses you want

1. Identify the best social media platform – if you have followers on a number of social media channels, post the same test survey on all your channels and see which survey gets the most responses.

2. Be transparent, clear and specific – as soon as possible, tell people why you’re conducting your survey. Also, make your questions clear so potential respondents fully understand what you’re asking them.

3. Create the right length of survey – to do this, consider how much time respondents may have to respond and how invested they may be in the subject you’re covering. Also, remember that attention spans are short, and especially on social media.

4. Make the most of your followers – to extend the reach of your survey, ask your followers to like and share your survey with their networks.

5. Ask if you can follow up – at the end of your survey ask ‘Are you happy for us to contact you to discuss your answers?’: This gives you the opportunity to get more detailed responses from your audience.

6. Incentivise your followers – to encourage people to respond to your survey, offer them a reward for completing it, for example, a free ticket to your charity’s raffle.

7. Thank respondents – always remember to thank people for completing your survey. It may encourage them to take part in future ones.

8. Add an image to your survey post – this will help your post to stand out.

9. Listen to your followers – monitor topics of interest to your social community and think about posting surveys related to these topics.

10. Use one-question polls – these are a great way to get quick responses and keep your followers engaged with your work.

11. Ask your followers for ideas on survey topics

12. Share your survey results with your followers – encourage your followers to share results with their networks.
Please tell us about Na-Vdih.
Na-Vdih, which means Inspire in English, was established in 2008. Our headquarters is in Maribor and our activities are aimed at reducing the burden of lung cancer in Slovenia, drawing attention to key risk factors and striving to improve the early detection of lung cancer.

Our ultimate ambition is to have a tobacco-free society and a widely implemented national lung cancer screening program in line with the latest scientific knowledge.

How many people are affected by lung cancer in Slovenia?
While the curve of lung cancer incidence for males became stable at around 90 new cases per 100,000 inhabitants at the beginning of the 1990s, the incidence rate in the Slovenian female population continues to rise.

With a 4.9% annual percentage growth, lung cancer is now the fourth most common cancer in Slovenian women. This alarming increase is largely due to smoking trends in the past. In the period between 1976 and 2014, the prevalence of smoking among adult women in Slovenia increased from 15.6% to 21.3%, while in the same period the prevalence of smoking among adult men decreased from 48.0% to 28.3%.

Answering our questions in this edition of Unity is Samo Pitamic, Director at Slovenia’s Na-Vdih.
In your opinion, do people with lung cancer generally receive the support and care they need in your country?

In terms of medical support, the situation in Slovenia is comparable to EU standards. We have early access to all crucial oncological drugs and the targeted treatment is guided according to current guidelines. However, improvements in interdisciplinary communication could greatly benefit cancer patients. After leaving the specialist oncology facility, there is a great potential to improve support provided to a patient at a primary care level. There is still room for improvement in the field of integrated care.

What are your organisation's main plans for the next five years?

We want to take advantage of the new government’s current ambitions to actively digitise our society. In the context of digitisation plans in medicine, we intend to launch a national lung cancer screening program, focusing on the potential of low-dose CT (LDCT) chest screening.

This would provide useful additional clinical data and improve therapeutic potential for specific respiratory and cardiovascular diseases. In this regard, the optimal digital cooperation between different medical fields is crucial.

Why does Slovenia need a lung cancer screening program?

Non-specific disease symptoms and factors, such as smoking stigma and fear of a positive diagnosis, contribute greatly to late diagnoses of lung cancer.

A study published in 2010 found in Slovenia that as many as four months elapse between the appearance of the first signs of the disease and the diagnosis of lung cancer. Unfortunately, the condition is not improving, as shown by data from the latest cancer registry, indicating a very high proportion of lung tumours in diffuse stage IV.

In Slovenia, such tumors are detected in 54% of patients in the latest time period, and their fatality is evidenced by the fact that only 3% survive the five-year period after diagnosis. The fact that the majority of lung cancer cases are already symptomatic at diagnosis reminds us that we urgently need to start screening the at-risk population.

How will you incorporate a lung cancer screening program into Slovenia's current healthcare system?

In order to promote a LDCT national screening program, Na-Vdih organised an online event with the journal Medicine Today, in November 2021. We talked about potential concerns regarding the introduction of a national screening program in Slovenia with pulmonologist Aleš Rozman, PhD, radiologist Igor Požek, MSc, and Professor Marko Jakopović, PhD.

Professor Jakopović discussed the success of the national lung cancer screening program in neighbouring Croatia. Despite the Covid-19 pandemic and the earthquake that hit Zagreb and some other areas of Croatia in 2020, almost 90% of invited high-risk citizens had a low-dose CT scan. Their example could be a good incentive for Slovenia.

However, there are some concerns which currently represent an obstacle for an LDCT lung cancer screening program in Slovenia. There have been a few concerns raised by our medical society, such as how to select the population at risk and identify the optimal screening intervals. They should be addressed first and then the optimal way to include the screening program into the current healthcare system should be defined.

According to Dr Aleš Rozman, screening could be successfully implemented at extended general medicine clinics, which have been opened all over Slovenia. They aim to improve access to preventive medicine and the management of patients with chronic diseases. A team, extended by a specialised medical nurse, could largely support the identification of people with an increased risk for lung cancer and help with the screening journey of each individual person at risk.

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<td><a href="http://www.pulmonaile.pt">www.pulmonaile.pt</a></td>
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<tr>
<td>Equal Right to Life</td>
<td><a href="http://www.ravnoepravo.ru">www.ravnoepravo.ru</a></td>
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<tr>
<td>Movement Against Cancer</td>
<td><a href="http://www.rakpobedim.ru">www.rakpobedim.ru</a></td>
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<tr>
<td>Na-Vdih (Inspire)</td>
<td><a href="http://www.na-vdih.si">www.na-vdih.si</a></td>
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<tr>
<td>Campaigning for Cancer</td>
<td>campaign4cancer.co.za</td>
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<tr>
<td>Asociación Española De Afectados De Cancer De Pulmón</td>
<td><a href="http://www.affectedoscancerdepulmon.com">www.affectedoscancerdepulmon.com</a></td>
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<td>La Asociación Española Contra el Cáncer</td>
<td><a href="http://www.aecc.es">www.aecc.es</a></td>
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<td>Lungcancerforeningen</td>
<td><a href="http://www.lungcancerforeningen.se">www.lungcancerforeningen.se</a></td>
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<td>Forum Lungenkrebs</td>
<td><a href="http://www.facebook.com">www.facebook.com</a></td>
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<td>Formosa Cancer Foundation</td>
<td>canceraway.org.tw</td>
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<td>Pembe Hanim</td>
<td><a href="http://www.pembehanim.com.tr">www.pembehanim.com.tr</a></td>
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<td>Asthma + Lung UK</td>
<td><a href="http://www.asthmaandlung.org.uk">www.asthmaandlung.org.uk</a></td>
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<td>Lung Cancer Nursing UK</td>
<td><a href="http://www.lcnuk.org">www.lcnuk.org</a></td>
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<td>Roy Castle Lung Cancer Foundation</td>
<td><a href="http://www.roycastle.org">www.roycastle.org</a></td>
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<td>CancerCare</td>
<td><a href="http://www.cancercare.org">www.cancercare.org</a></td>
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<tr>
<td>GO₂ Foundation for Lung Cancer</td>
<td><a href="http://www.go2foundation.org">www.go2foundation.org</a></td>
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<td>Lung Cancer Research Foundation</td>
<td><a href="http://www.lungcancerresearchfoundation.org">www.lungcancerresearchfoundation.org</a></td>
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<tr>
<td>Prevent Cancer Foundation</td>
<td><a href="http://www.preventcancer.org">www.preventcancer.org</a></td>
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