The newsletter of the Global Lung Cancer Coalition

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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 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 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

GLCC AWARENESS, ATTITUDES AND SCREENING STUDY

On World Cancer Day (4 February), the GLCC published its latest international study into awareness of lung cancer symptoms, attitudes towards lung cancer, and views on lung cancer screening.

The headline global findings from the study include:

**Symptom recognition**
- 37.5% of people do not know any symptoms of lung cancer.
- Men are more likely to report not knowing any symptoms compared to women (40.49% v 34.85%).
- People aged 18 to 24 are more likely than other age groups not to know any symptoms (45.11%). The percentages for other age groups are 25–34: 33.16%, 35–44: 35.64%, 45–54: 37.12%, 55+: 38.44%.

**Attitudes towards lung cancer**
- Over 42.62% of people agreed with the statement ‘I have less sympathy for people with lung cancer than other types of cancer’.
- Men have less sympathy for people with lung cancer than women (50.38% v 35.67%).
- People who currently smoke/have previously smoked are slightly less sympathetic than people who have never smoked (43.15% v 42.33%).

**Views on lung cancer screening**
- 84.89% of people agreed there should be a national lung cancer screening programme in their country.
- Support for screening programmes grew with age, increasing from 65% of 18 to 24-year-olds to 86.01% of people aged 55 and over.
- While both largely supportive, people who currently smoke/have previously smoked are even more supportive than people who have never smoked (86.78% vs. 82.48%).

Continued on page 2
GLCC AWARENESS, ATTITUDES AND SCREENING STUDY

Continued from page 1
The study was conducted between 3 July and 6 July 2023 across the following 29 countries, with responses received from at least 1,000 adults per country:

Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Egypt, France, Germany, Great Britain, Greece, Italy, Israel, Japan, Mexico, Netherlands, Norway, Peru, Portugal, Republic of Ireland, Slovenia, South Africa, Spain, Sweden, Switzerland, Taiwan, Turkey and USA.

Thank you to every GLCC member that helped to make the study possible.

You can now click here to access the full global report and national insights for each country that participated in the study.

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

ALL PATIENT EXPERIENCE SURVEY FINDINGS NOW AVAILABLE

A reminder to members that all the findings from the GLCC’s fourth annual global patient experience survey are now available on our website.

You can download global findings in a PDF or Word document format, and you can download national infographics for the following countries:

Argentina, Australia, Bulgaria, Canada, Denmark, Greece, Ireland, Israel, Italy, Portugal, South Africa, Spain, UK and USA.

Already, we’ve heard from members about how they’ve used the findings from the survey in their own work:

FairLife of Greece used national insights from Greece in a letter to the country’s Ministry of Health and presented results in their third annual conference (see page 5).

Evgenia Aleksandrova, President of APOZ (our Bulgarian member), used findings in a seminar for journalists about lung cancer (see page 8).

The Israeli Lung Cancer Foundation used data gathered by the GLCC in an article published on Ynetnews, a leading Israeli news site.

Please contact the GLCC at glcc@roycastle.org to tell us about how you’ve been using patient experience survey findings in your work.

EARLY DETECTION STRATEGY REPORT BY THE LUNG CANCER POLICY NETWORK

As a member of the Lung Cancer Policy Network, the GLCC is pleased to have contributed to the international alliance’s latest report: Increasing the earlier detection of lung cancer: a toolbox for change.

The aim of the report is to provide national decision makers with practical and evidence-based tools to support the development and implementation of an early detection strategy for lung cancer in their countries, no matter where they are in the world.

The report explores existing and emerging approaches to early detection through case studies and expert interviews. It also draws on the expertise of the Network to propose key policy recommendations to inform strategy development.

Please click here to report about the report and download it.
THANK YOU, DR SAWA
WELCOME, PROFESSOR TAKAHAMA

By Carolyn “Bo” Aldigé, Vice-Chair of the GLCC

For two decades, the Western Japan Oncology Group (WJOG) has been well represented as a member of the GLCC by Dr Toshiyuki Sawa.

Dr Sawa brought the important perspective of a practising thoracic oncologist to our group and became a treasured friend and colleague.

I speak from personal experience when I say his focus has always been squarely on the patient.

When I spoke at patient congresses in Japan in 2005 and 2011, I saw on both occasions Dr Sawa patiently answer questions from patients and family members long after the formal programme had finished.

Speaking on behalf of all GLCC members, we wish you well for the future, Dr Sawa, and you will be sorely missed at our table.

Thank you, Dr Sawa
Welcome, Professor Takahama

NICE TO MEET YOU!

On behalf of the Education and Public Relations Committee of the West Japan Oncology Group, I am glad to be a part of the GLCC.

I’m a physician who’s been specialising in treating patients with lung cancer since 2009.

I’ve always been passionate about conducting research and educational activities for Japanese physicians and patients, focusing on lung cancer biomarker testing.

Inspired by Dr Sawa’s lead at the Western Japan Organization for Cancer Research (WJOG), I’m committed to working with patients worldwide to overcome lung cancer.

WJOG is a clinical research group working to develop treatments and better supportive care. In the future, we plan to generate more data with patient input and look forward to input from the patient groups.

We would also like to work on communicating the latest data to you in an easy-to-understand manner.

Collaborating with patients and engaging in advocacy activities can make a real difference in the fight against this disease.

I was also appointed to the IASLC’s Global Multidisciplinary Treatment Standards Committee (GMPSC) beginning in 2023.

This committee aims to develop new and improve existing treatments, with input from multiple disciplines, including patients, and in collaboration with other experts.

I look forward to working with GLCC members and incorporating your feedback into our future activities!
FPCP SAYS “YOU WILL BE OKAY”

Members of Fundación Pacientes de Cáncer de Pulmón (FPCP) visited the chemotherapy rooms of two hospitals in Buenos Aires, Argentina, whilst wearing T-shirts featuring the phrase Vas a estar bien (You will be okay).

The inspiration behind the visits was a lung cancer patient called Luciano. He shared with the FPCP that something very important happened to him at diagnosis. He was told by his oncologist, “Vas a estar bien,” which helped him to be more positive about his future.

Speaking after the visits, Peter Czanyo, founder of FPCP, said, “It was a very exciting experience. It was wonderful to see how we boosted the patients’ moods when we visited them in our T-shirts and gave them matching ones.”

MEXICAN MEMBER’S NEW DOCUMENTARY

Frente Unido por el Cáncer de Pulmón of Mexico has launched a new documentary called Lung cancer: a journey of life.

It features the stories of four lung cancer patients: Magdalena, Humberto, Anastasia and Óscar. The aim of the film is to show that there are people behind every lung cancer statistic, and that these people fight every day with their loved ones and caregivers to overcome the illness.

Please click here to watch the film, which is in Spanish and runs for just over 32 minutes.

Google Translate

COMMUNICATING ABOUT COMPREHENSIVE BIOMARKER TESTING

Merel Hennink, a member of Longkanker Nederland’s patient panel since 2015, is one of the authors of a new article exploring how healthcare professionals communicate with cancer patients about comprehensive biomarker testing.

Published in the journal Cancer Medicine, the article highlights the importance of knowledgeable and confident healthcare professionals educating patients to help them make informed decisions about precision cancer treatments such as targeted therapies.

Please click here to read the full article.
ON OUR WAY TO HEALTHIER LUNGS!

Three years after its foundation, FairLife Lung Cancer Care of Greece is not slowing down in its efforts to raise awareness of lung cancer and reduce diagnoses of the illness.

In December 2023, it received a distinction at the BRAVO Sustainability Dialogue & Awards for its youth awareness initiatives on health and the environment.

In November, it hosted its third annual conference, which featured 53 speakers and commentators, and was attended by 3,140 people at the conference and online.

The charity also recently launched a new video on the importance of diagnosing lung cancer early and screening high-risk people with low-dose CT scans.

It co-hosted a walk in the northern suburbs of Athens to promote mental and physical wellbeing and FairLife's BREATH psychosocial support programme.

FairLife supporters ran the 5 km route of the 40th Authentic Athens Marathon to spread the message “Sport is health and the power of human spirit is unlimited”.

The FairLife team attended a bazaar of non-profit, independent, voluntary and activist organisations at a cultural centre in Kallithea, Athens, to inform the public about lung cancer.

Finally, the organisation promoted a new report by Lung Cancer Europe that explores the financial repercussions and difficulties experienced by people diagnosed with lung cancer (see page 9).

GO2 JOINS NATIONAL LEADERS’ CALL TO EXPAND WOMEN’S HEALTH RESEARCH AND FUNDING

GO2 for Lung Cancer united with over 300 women’s health champions by signing two letters sent to First Lady Jill Biden, who leads the White House Initiative on Women's Health Research in the US.

The two letters featured specific and extensive recommendations on opportunities to advance women’s health through research, innovation and access to care. These recommendations include:

- Improving data gathering, analysis and sharing
- Creating a new focus within departments such as the Food and Drug Administration on women’s health
- GO2 looks forward to working with the White House and other stakeholders involved with the Initiative on Women’s Health Research to bring elevated attention to lung cancer.

Please click here to find out more.

GO2 President and CEO Laurie Ambrose offered specific and extensive recommendations with 303 national leaders to advance women’s health.
In November 2023, Lung Foundation Australia commended the launch of a new Australian Cancer Plan. Developed by Cancer Australia, the 10-year Australian Cancer Plan is designed to improve cancer outcomes, particularly for groups whose health outcomes are poorer, such as Aboriginal and Torres Strait Islander Australians.

Mark Brooke, CEO of Lung Foundation Australia, said, “We have advocated tirelessly to even the playing field when it comes to equitable outcomes for cancer diagnoses and treatments in our country, and the release of the Australian Cancer Plan today is a momentous step in that journey.”

Mr Brooke also welcomed news in November 2023 that the Australian government has committed to invest a further A$166 million ($103 million) into the country’s cancer services, including 100 new cancer generalist nurses.

He added, “We know the more investment in vital services like cancer nurses, the greater the benefits and savings on the healthcare system in the long run.”

Please click here for the national cancer plan story and here for the investment in cancer services story.

The countries with the highest five-year survival rates for less survivable cancers are Korea, Belgium, USA, Australia and China.

Please click here for more information.

Please click here to visit the website of the Less Survivable Cancers Taskforce.
Terry joined CLA in January 2015 as Senior Vice-President, Federation Development and Partnerships, following 13 years with the Heart and Stroke Foundation of Canada as Director, National Programs.

Terry was promoted to CEO in 2017. In this role, Terry recruited a strong team, and together, they accomplished much in the areas of public affairs, national research and health information.

Terry also led the development of a new fund development plan and was the senior staff lead on the recent development of a new governance model for the organisation.

"Under Terry’s leadership, CLA has achieved remarkable milestones, and we express our deepest gratitude for his tireless efforts in advancing our mission," says Nora Lacey, Chair of the CLA Board of Directors.

"We will certainly miss him, but know that this retirement is much deserved after years of unwavering commitment to CLA and the lung health of Canadians."

Taking over leadership of the organisation is Sarah Butson, CLA’s new Chief Executive Officer. Along with extensive experience and a genuine commitment to the cause, Sarah brings a fresh perspective that will empower CLA to make significant contributions to the lung health community, locally, nationally and globally.

Sarah is a dedicated advocate for healthy public policy. She worked for over 15 years in the field of health promotion and chronic disease prevention, 10 of which have been within the lung association family.

Most recently, as Senior Director, Public Affairs, she has led CLA’s work on important files such as air quality, youth vaping and tobacco control. Prior to this, Sarah oversaw tobacco control educational programmes and awareness campaigns as Director of Health Promotion at the provincial level.

Sarah also has a background in corporate facilitation, having supported organisations in strategic planning, team leadership and effective meeting design. During her time at CLA, she has demonstrated an ability to inspire teams, forge meaningful partnerships, and leverage resources effectively.

"I’m thrilled to be taking on this role at such a unique and exciting time for CLA, as we redefine ourselves as a standalone, national entity," says new CEO Sarah Butson.

"For over 120 years, we’ve been a leading voice on lung health in this country. But there is more to be done. As we look to the future, we must continue to protect the air that we breathe, provide new ways of supporting those impacted by lung disease and continue to invest in critical research."

"I’m thrilled to be taking on this role at such a unique and exciting time for CLA.”

New CEO Sarah Butson.
LUNG CANCER AWARENESS MONTH HIGHLIGHTS

As always, many members of the GLCC launched new campaigns and activities to tie in with November’s Lung Cancer Awareness Month. Here are just some of the highlights.

Invisible people
Asociación Española De Afectados De Cancer De Pulmón (AEACaP), Spain

In front of Spain’s Ministry of Health in Madrid, AEACaP organised the gathering of a group of invisible people.

The aim of the stunt was to highlight that the 30,000 people in Spain who are diagnosed with lung cancer every year often feel invisible.

AEACaP also denounced the geographical inequality that exists in Spain in terms of access to innovative diagnostic and treatment procedures.

Lung cancer seminar
APOZ, Bulgaria

On 15 November, Evgenia Aleksandrova, President of APOZ, was one of the speakers at a seminar about lung cancer for Bulgarian journalists.

In her talk, Evgenia presented findings from the GLCC’s fourth annual global patient experience survey that focused on patients’ experiences of treatment and care in Bulgaria.

White scarves
Longkanker Nederlands, Netherlands

Longkanker Nederlands posted new interviews with lung cancer patients, caregivers and health professionals to help raise awareness of lung cancer signs and symptoms, as well as the need for a national screening programme and more investment into lung cancer research.

Each of the people who gave an interview wore a white scarf in their publicity photographs, which represents the white ribbon that is the symbol for lung cancer.

Be Unforgettable campaign
Roy Castle Lung Cancer Foundation, UK

Roy Castle Lung Cancer Foundation launched a new campaign called Be Unforgettable.

It aims to tackle dangerous misconceptions that may prevent someone from being diagnosed early with lung cancer.

Using the tagline ‘Forget everything you think you know about lung cancer’, the campaign highlights through personal stories that lung cancer is not an instant death sentence; you can be affected by lung cancer, no matter your age, occupation or smoking history; and that there are many lung cancer symptoms, and not everyone will have a cough.

Eva was only 22 when she learned she had lung cancer.

Please click on a member’s name to find out more about their LCAM activities.
WHO PREDICTS HUGE CANCER RISE
World Health Organization’s International Agency for Research on Cancer (IARC) released new figures in February that predict global cancer cases will rise by more than 75% by 2050.

The IARC predicts there will be more than 35 million new cancer cases by 2050, an increase of 77% from 2022 levels, and that deaths will have nearly doubled since 2012 to more than 18 million.

Please click here for more information.

GLOBAL STUDY ON LUNG CANCER SUBTYPES
A new study was published in The Lancet: Oncology in October 2023 that focuses on global variations in lung cancer incidence by histological subtype: adenocarcinoma, squamous cell carcinoma, small-cell carcinoma, and large-cell carcinoma.

Please click here to read the study.

Click here to read about the lessons and opportunities presented by the study.

LuCE LAUNCHES NEW FINANCIAL REPORT

The report is a descriptive research analysis that explores the economic burden of lung cancer, as reported by people diagnosed with the disease and those in a caregiving capacity.

Please click here for more information.

ESMO CONGRESS HAS STRONG LUNG CANCER FOCUS
The European Society of Medical Oncology’s (ESMO) annual congress was held in Madrid, Spain, in October 2023.

Presentations about advances in the treatment of lung cancer were particularly prominent.

Please click here for more information and to access resources.

SCREENING UPDATE FROM THE AMERICAN CANCER SOCIETY
The American Cancer Society has updated its lung cancer screening guideline to help reduce the number of people dying from the illness due to smoking history.

The new guideline recommends yearly screening for lung cancer for people aged 50 to 80 years old who smoke or formerly smoked and have a 20-year or greater pack-year history.

Please click here for more information.

HIGH RATES OF LUNG CANCER IN US WOMEN
New research published in JAMA Oncology in October 2023 found that US women aged 35 to 54 are being diagnosed with lung cancer at a higher rate than men from the same age group.

In the media, it is reported that scientists are struggling to fully understand the reasons behind the trend, which the lung cancer community hope will lead to more funding for female-focused research.

Please click here for more information.

CANCER RISK FOLLOWING SMOKING CESSION IN KOREA
A Korean study of 2.9 million people has revealed that quitting smoking before 50 reduces lung cancer risk by 57% compared to stopping later in life.

Researchers looked at Korean people aged 30 and older who had two or more consecutive health checks under the country’s National Health Insurance Service in 2002 and were followed until 2019.

Please click here for more information.

SCLC TREATMENT UPDATE FROM ASCO
In their updated guidelines for patients with small cell lung cancer (SCLC), the American Society of Clinical Oncology (ASCO) has recommended the CDK4/6 inhibitor trilaciclib (Cosela) as a myeloid supportive agent for patients with untreated or previously treated extensive-stage SCLC who are receiving chemotherapy or chemoimmunotherapy.

Please click here for more information.
Artificial intelligence (AI) and automation are increasingly transforming the way we all work.

If you and your organisation feel a little overwhelmed by the pace of change, this feature article is here to help.

In it, we outline three key steps to consider to help you make the right decisions about AI for your organisation and the people you serve.

1. **Learn and understand what generative AI is**
   Generative AI tools are complex algorithmic systems capable of producing content such as copy, audio, images, and videos.

   Before you start to use generative AI tools such as ChatGPT, Copilot or Gemini, it’s important to understand what they are, how they work (at least at a basic level) and what they can and can’t do.

   A good way to build up this knowledge is through watching reputable videos on YouTube that focus on AI.

2. **Explore how can you use AI in your work**
   For members of the GLCC, the main way you’re likely to use AI is to create content. For example, you may use generative AI to create time-saving first drafts of presentations, blogs, campaign emails, bid applications or grant reports.

   The best way to discover how AI can help your organisation is to experiment with AI generative tools. However, it’s important to recognise that applications like ChatGPT create text by using a vast data set to predict the most likely word to come next.

   The results it produces can be impressive (see the poem on page 11) but don’t expect perfection. When it comes to content creation, AI is a tool best used to support your work, not replace it.
3. **Research to understand the risks to your organisation**

Because of the way AI tools are built, function and continue to learn, they come with risks that need to be considered.

Below are some of these risks, but this is not an exhaustive list. Your organisation will need to give careful thought to the specific risks it will face if it decides to use AI.

**Data security** – tools like ChatGPT and Bard learn from the data that’s inputted into them. How they do this and how much data from users is used to train generative AI is still unclear.

As a result, you can’t be sure that data or details you provide to an AI tool will not be included in a response given to another user.

**Misinformation** – AI tools lie, and they lie extremely well. This means it’s important that users don’t believe what an AI tool such as ChatGPT tells them without cross-checking it.

In addition, the information they provide is only as up-to-date as the data they were trained on.

**Bias** – AI tools are trained on huge datasets, including a vast amount of data from the internet.

Unfortunately, the internet reflects the biases and prejudices that exist in our society. As a result, AI tools can reflect these biases back to us in their responses.

**Legal and regulatory risks** – this an evolving area, so it’s important to keep up to date with national and international guidance and regulation.

In addition, you may want to contact your insurance provider and check that your organisation’s policy covers it using AI tools.

**Copyright and plagiarism** – if you decide to publish content generated by an AI tool, this content will have been created from huge amounts of data. What this means in terms of intellectual property and plagiarism is still unclear.

As a result, it’s important to be transparent about your use of AI-generated content, as this will help to reduce risk to your reputation.

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**Your next steps**

After taking the above steps, you may decide that it’s okay for your organisation to use generative AI tools. If this is the case, it may prove helpful to:

1. Develop an AI policy and guidelines for your organisation. This could involve input from your staff members and any AI experts you have access to.
2. Update your employees and the people you support about how your organisation will use AI in the future.

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**A poem about the GLCC by ChatGPT**

We asked ChatGPT to write a poem about the GLCC in less than 100 words.

We believe the poem it created highlights the many positives and failings of generative AI.

In realms where shadows silently loom,  
A coalition rises to disperse the gloom.  
Global Lung Cancer Coalition, its name,  
Championing hope in the face of the same.  
Through research, support, and shared devotion,  
They battle against this relentless ocean.  
Uniting hearts, minds, and innovation’s fire,  
Their mission: to lift souls ever higher.  
In every breath, a whisper of their call,  
For a world where lung cancer shall fall.
In 2024, the GLCC acknowledges the support of its sustaining partners: Amgen, AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Daiichi Sankyo, Eli Lilly, Gilead, Merck, Novartis, Novocure, Pfizer, Regeneron, Roche, Sanofi and Takeda.

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### Members of the GLCC

- **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**: www.lunghhealth.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
- **Frente Unido por el Cáncer de Pulmón**: frentepulmon.org
- **Respirando Con Valor A.C.**: www.respirandoconvalor.org
- **Longkanker Nederland**: www.longkankernederland.nl
- **LungeKreft Foreningen**: www.lungekreftrforeningen.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-Vdh (Inspire)**: www.na-vdh.si
- **Campaigning for Cancer**: campaign4cancer.co.za/wp
- **Asociación Española De Afectados De Cancer De Pulmón**: www.affectedoscancerdepulmon.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 + Lung UK**: www.asthaaandlung.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