In 2001, nine organizations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition. Today, the GLCC is comprised of 36 non-government patient organizations 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.

In November 2017, the GLCC published the findings of a multi-national study to understand attitudes towards lung cancer and symptom awareness.

The study involved at least 1,000 adults in the following 25 countries answering an online survey: Argentina, Australia, Brazil, Bulgaria, Canada, Denmark, Egypt, France, Germany, Great Britain, Republic of Ireland, Israel, Italy, Japan, Mexico, Netherlands, Norway, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, Turkey and the USA.

Respondents were told that: “Lung cancer is mainly caused by smoking cigarettes and other tobacco products”, and then asked to what extent they agreed with the statement: “I have less sympathy for people with lung cancer than for other types of cancer.” They were also asked to name as many lung cancer symptoms they could think of.

Continues on page 2
Our Annual Meeting

The GLCC’s annual members meeting took place in Tokyo, Japan in October 2017, prior to the 18th World Conference on Lung Cancer in nearby Yokohama.

The meeting gave members the opportunity to meet with each other and share their experiences of increasing awareness of lung cancer issues, improving care and support, and securing more funding for research.

Following the meeting, the GLCC hosted a joint information session at the 18th WCLC with the International Association for the Study of Lung Cancer; this was entitled Current Issues in Lung Cancer Advocacy and chaired by Natasha B Leighl and Maureen Rigney.

The session featured the following topics and speakers:

- Lung Cancer Advocacy Tools for Everyone – The Use of GLCC Data
  Jesme Fox (UK)

- Lung Cancer Advocates and Measuring Value in Healthcare
  Carolyn Aldige (USA)

- Accessing New Lung Cancer Therapies – Challenges & Experience in Latin America
  Patricia Mondragon (Mexico)

- Patient Advocacy – Making a Difference for Lung Cancer Patients in Japan
  Toshiyuki Sawa (Japan)

- Lung Cancer Patients and Stopping Smoking – What Advocates Need to Know
  Aoife McNamara (Ireland)

Please see page 10 for further findings from the GLCC global study. You can also access the full overview of the global study by clicking here. And you can view the findings for each of the 25 participating countries by visiting lungcancercoalition.org/global-polling

BIENVENIDO, ESPERANTRA!

The GLCC offers a big welcome to its newest member: Esperantra.

Based in Lima, Peru, Esperantra is a not-for-profit organization which aims to improve the quality of life of patients and advocates for equal access to quality treatments and innovative care.

Karla Ruiz de Castilla, Esperantra’s executive director, said, “It is an honor to be part of the GLCC. We’re sure that our work together will help improve the lives of people with lung cancer in Peru and around the world.”

For more information, please visit www.esperantra.org
You can also read an interview with Karla Ruiz de Castilla on page 8.
A FANTASTIC LUNG CANCER AWARENESS MONTH

Last November, Lung Cancer Alliance’s work in the following key areas helped it achieve its most impactful Lung Cancer Awareness Month:

Creating a central platform
Lung Cancer Alliance (LCA) created a specific Lung Cancer Awareness Month (LCAM) webpage that answered key questions such as: “What is LCAM?”, “Why is it important?”, and “How can I make a difference?” The site also directed participants to suitable activities they could get involved in, from hosting a city gala, to raising funds for lung cancer research, to learning more about lung cancer.

Keeping it fresh
To keep its community engaged throughout the entire month, LCA provided a weekly schedule of LCAM activities. Each day of the week had a different theme, and each week featured different involvement opportunities, like downloading animated emojis to express feelings about cancer.

Getting the word out
LCA promoted its LCAM webpage and activities on the homepage of its main website, via its weekly e-newsletter, and through its social media networks. It also developed a Facebook profile picture frame for people to promote LCAM, and it created one specifically for lung cancer survivors.

Overall, LCA’s campaign for LCAM, resulted in:
• 346 million people reached through advocates talking about their lung cancer stories in local newspapers
• more than 500,000 people reached by LCA’s online community sharing their personal stories and LCA infographics
• 8,000 people participating in Shine a Light on Lung Cancer awareness events at 167 hospitals across the USA.

FREE TO BREATHE MERGER

On 30 September 2017, GLCC member Free to Breathe merged with the Lung Cancer Research Foundation in the USA. They will retain the name Lung Cancer Research Foundation, as it best reflects the combined organization’s shared mission: to improve lung cancer outcomes by funding research for the prevention, diagnosis, treatment and cure of lung cancer. The Lung Cancer Research Foundation is also now an official member of the GLCC.

You can read the full press release about the merger here, and you can find out more about the organization at lungcancerresearchfoundation.org

KISS AND WINK CAMPAIGNS

As part of Lung Cancer Awareness Month in November 2017, the Lung Cancer Research Foundation (LCRF) launched two campaigns: Blow a Kiss, and Wink and LASH OUT at Lung Cancer.

The campaigns were created to promote awareness of lung cancer in women. They encouraged participants to post a photo on social media of themselves blowing a kiss to a loved one or winking and lashing out at lung cancer. Photos were posted using the hashtags #BlowaKiss and #WinkandLashOut, and selected photos were featured on LCRF’s website and social media platforms.

To support the campaign, Kiss and Wink webpages were created that feature statistics about women and lung cancer. LCRF also developed and promoted Blow a Kiss and Lash Out videos, to encourage people to participate in each of the campaigns.

Speaking about the two campaigns, Joan H Schiller, MD, Chair of LCRF’s Scientific Steering Committee, said, “Most people don’t know that lung cancer is the leading cause of cancer death in the world, and it receives far less research funding than other cancers. We hope that the Wink and Kiss campaign will bring light to these staggering statistics. As people all over the world participate in the Wink and Kiss campaign, we anticipate it will highlight the importance of research and how lung cancer is affecting women.”

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Held over two days in November 2017, ALCASE’s third national meeting in Rome, Italy, was a hugely successful event that inspired everyone who attended.

On the first day, the meeting opened with a warm speech from Daniela Fazzolari, an Italian TV and film actor and ALCASE supporter. Following many stories of “hope and heroism” from lung cancer patients and their carers, ALCASE awarded its GLCC Excellence in Lung Cancer Journalism Award to Paola Staccioli and Serena Ranieri for their blog about living with cancer, which features on the website of Italy’s most popular newspaper, La Repubblica.

After this presentation, attendees then discussed a number of key topics, including the lack of a national lung cancer screening program, the stigma that still surrounds lung cancer, and the need to mobilize more people to increase lung cancer research and improve support for people affected by the illness.

Following this busy first day, the second day was handed over to lung cancer doctors and researchers from some of Italy’s top medical centers. They talked about some of the latest developments in mutational therapies and immunotherapy. The meeting then concluded with a presentation from Dr Paolo Macrì, a specialist in thoracic surgery who focused on screening and micro-invasive surgery.

The Oncoguia Institute has become one of the first organizations in Brazil to receive a leading certification for the transparency of its online information.

The 40 organizations that received the ‘Doar Seal – Transparent NGO’ went through an extensive process which evaluated their main website and all the other digital platforms they communicate through, for example, Facebook. This was to determine how easy it is for visitors to access core information about an organization, its mission, and how it aims to achieve its goals.

Last November, the Oncoguia Institute held a successful event in São Paulo which focused on public awareness of lung cancer and the prevention, diagnosis and treatment of the illness.

Attended by lung cancer specialists, journalists and members of the public, the event provided the perfect platform to discuss these important topics, as well as the findings from the GLCC’s global research into attitudes towards lung cancer and symptom awareness. In addition, the event offered an excellent opportunity to promote the new lung cancer guidelines produced by the Brazilian Society of Clinical Oncology (SBOC).
The UK’s Roy Castle Lung Cancer Foundation launched a new campaign called #HeadHigh as part of its activities for last November’s Lung Cancer Awareness Month.

#HeadHigh aims to challenge the stigma of lung cancer, increase awareness of the issues people with lung cancer face, and push members of parliament (MPs) to do more to improve lung cancer survival rates. Central to the campaign are 13 people who have been diagnosed with cancer, as well as their family and friends.

Throughout Lung Cancer Awareness Month, the stories of these 13 people featured in local media and were promoted by the Roy Castle Lung Cancer Foundation on its website and via social media. In addition, all 13 of them took part in a photo shoot for a 2018 #HeadHigh calendar. This calendar was then sent to key health MPs to highlight the wide range of people that lung cancer affects, and to make them look into the eyes of the people they are failing, given the lack of investment into lung cancer research and support services.

To find out more about the #HeadHigh campaign, which includes a video from the people who feature in the calendar, please click here.
ROUND-UP FROM THE WCLC

The IALSC 18th World Conference on Lung Cancer (WCLC) took place in Yokohama, Japan, between 15 and 18 October 2017. Here, we look at some of the main news stories from the conference.

COMMUNITY INTERVENTION

Dr Lovoria Williams of Augusta University in the USA presented findings from a study which suggests community engagement interventions could reduce disparities in lung cancer outcomes among minorities.

Researchers used an intervention which involved developing a curriculum that focuses on the attitudes and beliefs of individuals, and training community health workers to lead educational sessions. Additionally, a community advisory board was established, and interviews and forums were held with community health workers unassociated with the project to ensure the study design and curriculum addressed community priorities and concerns.

The participants who took part were mainly African-American, had an average age of 58.3 years, and 16% were tobacco smokers. The intervention was effective in increasing their cancer knowledge and confidence to get screened for lung cancer. However, there was no change among participants in their perceived susceptibility to cancer. This is probably because participants were aware of personal risks factors prior to the intervention.

GUIDE TO EGFR TESTING

The International Association for the Study of Lung Cancer (IALSC) launched its Atlas of EGFR Testing in Lung Cancer at the WCLC. It provides pathologists, clinicians and other healthcare professionals with comprehensive information on a variety of EGFR testing topics, from tumor sample best practices to reporting and quality assurance. The sharing of the Atlas is intended to progress the quality of care for lung cancer patients across the globe, leading to improved and longer lives.

David Carbone, Fred Hirsch and Tony Mok, the editors of the guide, said, “Because the use of EGFR testing is growing rapidly, this Atlas is a critical tool to ensure best practices worldwide.”

To download the Atlas of EGFR Testing in Lung Cancer, please click here.

IMMUNOTHERAPY GUIDELINES

Guidelines on how to deal with immunotherapy adverse effects were launched at the WCLC. The new resource was developed over the past year, after the IASLC Nursing and Allied Health Committee identified at the previous WCLC a need for educational support for professionals who care for lung cancer patients receiving immunotherapy.

The new guidelines are set to be an invaluable resource for nurses and other healthcare professionals, as they cover life-threatening adverse effects patients may experience during immunotherapy. These side effects include gastrointestinal, dermatologic, endocrine, ocular, hepatic, neurological and pulmonary toxicities.

Anne Fraser, an oncology nurse practitioner from New Zealand and co-author of the guidelines, said, “As immunotherapy treatment continues to be utilized more frequently, the guidelines will be essential to helping nurses understand and mitigate the potential side effects.”

Click here for all highlights from WCLC.

EXERCISE AND QUALITY OF LIFE

Dr Morten Quist of the University of Copenhagen in Denmark presented findings from a study which aimed to determine whether exercise interventions for people with advanced lung cancer could lead to increased functional capacity and improved quality of life.

Researchers randomized 218 eligible adult patients who were undergoing chemotherapy into two groups. The control group received standard care, and the intervention group underwent a 12-week physical and psycho-social intervention, which included cardiovascular and strength training.

At the conclusion of the intervention, the exercise group was found to have improved functional capacity. Additionally, the control group experienced no change in quality of life, while the intervention group reported a significant improvement in quality of life, which may be linked to the improved functionality.
THE DANGER OF THIRD-HAND SMOKE

Third-hand smoke may lead to a higher risk of developing lung cancer, especially among babies, according to a new study.

Third-hand smoke is defined as the pollutants that remain in dust and on indoor surfaces after someone has smoked. People are exposed to it through inhalation, ingestion and absorption through the skin. The new study was conducted by a team of researchers at the US Department of Energy’s Lawrence Berkeley National Laboratory. It placed mice in an environment that was the equivalent of what a human toddler is exposed to if they live in a home with smokers. Forty weeks after their last exposure to third-hand smoke, the mice were found to have an increased incidence of lung cancer, larger tumors and a greater number of tumors compared to 19 control mice.

According to Bo Hang, one of the researchers, young children are most susceptible to third-hand smoke because they crawl and place objects in their mouth, increasing their chances of coming into contact with surfaces contaminated with third-hand smoke.

From Tech Times, 12 March 2018

LIGHTING UP CANCER CELLS

Doctors at the Hospital of the University of Pennsylvania in the USA are using dyes that glow in the dark to help find and treat cancer.

One such dye is called TumorGlow, which is being tested on lung, brain and other kinds of tumors. Dr Sunil Singhal, who is the driving force behind TumorGlow, says he discovered that when large amounts of the dye are put into the blood of a patient before surgery it collects in cancer cells. When the cells are exposed to infrared light, they glow.

Dr Singhal is also testing another dye which binds to a kind of a protein that is common in cancer cells. It is being tested on lung cancer and ovarian cancer and has already produced some encouraging results. In one study the dye showed 56 of 59 lung cancers that had been detected before surgery. The dye also showed nine additional cancers that were not found before surgery.

Potential benefits of using the glow in the dark dye include the removal of less healthy tissue during surgery and clearly identifying when cancer has spread.

From Omaha World Herald, 15 March 2018

In February 2018, the BBC broadcast a news story about the lack of funding for lung cancer research in the UK and the growing number of people diagnosed with the illness who have never smoked.

Presenting the story was the BBC’s legal correspondent, Clive Coleman, who lost his sister, a young mother of two, to lung cancer. Clive worked with the Roy Castle Lung Cancer Foundation to create the content for the video. It includes an interview with lung cancer patient Joanna Marshall, who talks about the limitations of her current treatment. Joanna is also one of the 13 people who was central to the charity’s recent #HeadHigh campaign (see page 5).

To watch the full news story on YouTube, please click here.
Q. When was Esperantra established?
A. It was established in 2005.

Q. Where are your organization’s headquarters?
We’re based in Lima, the capital of Peru.

Q. How many people work for your organization?
A. We currently have eight members of staff, but our projects and activities are carried out thanks to their work and the support of our volunteers, which include health professionals, patients, relatives and students.

Q. Why was Esperantra established?
A. It was founded as a non-profit organization to help reduce the number of deaths caused by non-communicable diseases such as cancer. We also aim to improve the quality of life of patients and their families by providing them with information, training and support; and we inform, educate and guide the people of Peru to prevent disease in the first place.

Q. What care, support and services does your organization provide?
A. We run a number of support programs, with the main ones being:

Training and information to help the patient gain a good knowledge of the illness that’s affecting them and issues related to it. This involves us holding two monthly talks in which patients and their families can ask questions and get answers. Similarly, we host two forums per year for the general public, which are focused on preventing illness and the importance of a healthy life.

Esperantra also offers patients the opportunity to sign up to our University of the Patient program. This allows them to attend specialized talks on topics related to cancer, leadership training, self-esteem and strategic planning. The University of the Patient and the work of patient associations linked to Esperantra stimulates the emergence of leaders who can represent patients with cancer and their needs.
Emotional support to show people they are not alone, and to help them cope with a wide range of emotions. Patients and relatives can schedule a consultation with our professional psychologist. The psychologist can help people identify the support they need, provide them with help, and give them the tools to manage stress, depression, anxiety and disbelief, as they face their own mortality.

Legal support to help solve the problems patients and relatives often face with social security.

Advocacy to place the topic of cancer on the public agenda, to protect and raise awareness of the rights of cancer patients, to influence the search for solutions for a wide range of issues, and to share knowledge and experiences with similar organizations in other Latin American countries. We also carry out marches, demonstrations and relays to highlight and hopefully eradicate problems in our health system.

Information center to provide patients, their families and the general public with the latest information on different types of cancer, treatment, prevention and timely detection, as well as tips for leading a healthy life. The center has books and leaflets on cancer, treatment, side effects, emotional issues and other health-related problems, as well as health magazines, videos and online access to databases and websites of interest.

Recreation activities to give patients and their family members, including children, adolescents and adults, the space they need to feel relaxed, have fun and share experiences with others.

Physical rehabilitation to help improve the physical function of patients, restore their independence, and help them have a better quality of life.

Q. How many people has Esperantra supported?
A. Over the past year, we estimate we reached approximately 10,450,000 people with our messaging about adopting healthy habits to live a healthy life and prevent illness. We provided training to 26,431 patients and relatives about the illness affecting them, and training to 12,263 patients and relatives about their rights. We also provided emotional support to 8,160 patients.

Q. How does your organization’s support make a difference to the lives of people with lung cancer?
A. We educate the public about healthy habits which can help prevent lung cancer, and raise awareness of signs and symptoms of lung cancer to help make sure that it’s diagnosed early. We also want to change the stigma that surrounds lung cancer, and cancer in general, because when it’s detected early and treated properly it can often be managed and cured in many cases.

Q. What needs to change in Peru to improve the situation for people with lung cancer and their families?
A. Changes need to be made to the two main health systems which operate in the country. Currently, 30% of Peru’s population are covered by a social security system that allows them to access support regarding any health issue, but they may have to wait six months or more to access treatments for lung cancer. In addition, 50% of the population are covered by a subsidiary health system, but it does not offer treatment for lung cancer patients.

Q. What has been Esperantra’s biggest success so far?
A. We promoted the creation of a national cancer plan for the most vulnerable people in Peru, which currently benefits 50% of the population. Esperantra also helped to establish regulation for high-cost diseases, and we continue to monitor public health policies and make sure they are patient centered.

Q. What message would you like to send to your fellow GLCC members?
A. It is an honor to be part of this working group. We’re sure that our work together will help improve the lives of people with lung cancer in Peru and around the world.
GLCC’S FINDINGS ON SYMPTOM AWARENESS AND ATTITUDES TO LUNG CANCER

On pages 1 and 2 of this edition of Unity, we presented key findings from the GLCC’s multi-national study into symptom awareness and attitudes towards lung cancer. In this feature, we look at some of those findings in greater detail.

Symptom awareness

Raising awareness of lung cancer symptoms is vital because treatment is more likely to be successful if lung cancer is diagnosed early. But, on average, respondents to our survey could only name one or two symptoms of lung cancer, with women being able to name an average of 1.57 symptoms and men 1.22 symptoms. In addition, 42% of all respondents could not name one symptom, which is particularly worrying.

The GLCC’s study also revealed that respondents from different countries could name a varying number of lung cancer symptoms. At the top were people in Mexico, who identified an average of 2.3 symptoms, while at the bottom were people in Japan, who named an average of 0.7 symptoms.

Most commonly named lung cancer symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough</td>
<td>38%</td>
<td>33%</td>
<td>3%</td>
</tr>
<tr>
<td>Shortness of breath!!</td>
<td>35%</td>
<td>31%</td>
<td>39%</td>
</tr>
<tr>
<td>Coughing up more spit or phlegm</td>
<td>15%</td>
<td>14%</td>
<td>17%</td>
</tr>
<tr>
<td>Tiredness!</td>
<td>11%</td>
<td>9%</td>
<td>2%</td>
</tr>
<tr>
<td>Chest pain</td>
<td>10%</td>
<td>9%</td>
<td>1%</td>
</tr>
<tr>
<td>Weight loss/ loss of appetite</td>
<td>7%</td>
<td>5%</td>
<td>8%</td>
</tr>
<tr>
<td>Loss of voice without a sore throat</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Repeated chest infections</td>
<td>2%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>18%</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Don’t know / not aware of any symptoms</td>
<td>42%</td>
<td>46%</td>
<td>37%</td>
</tr>
</tbody>
</table>

Comparative data

The GLCC commissioned Ipsos Mori to carry out a multi-national study on perceptions of lung cancer in 2010, and another multi-national study on symptom awareness in 2013. You can access the findings from these studies by heading to lungcancercoalition.org/global-polling
Attitudes to lung cancer

To understand the magnitude of the stigma that surrounds lung cancer, the GLCC told people responding to its survey that: “Lung cancer is mainly caused by smoking cigarettes and other tobacco products”. We then asked them if they had less sympathy for people with lung cancer than other types of cancer.

Overall, 21% of people agreed they have less sympathy for people with lung cancer than other forms of cancer, although this figure did vary between countries. See chart below.

The GLCC’s study also revealed that respondents from different countries could name a varying number of lung cancer symptoms. At the top were people in Mexico, who identified an average of 2.3 symptoms, while at the bottom were people in Japan, who named an average of 0.7 symptoms.

Number of cigarettes smoked versus sympathy for people with lung cancer

The GLCC’s study also revealed that respondents from different countries could name a varying number of lung cancer symptoms. At the top were people in Mexico, who identified an average of 2.3 symptoms, while at the bottom were people in Japan, who named an average of 0.7 symptoms.
MEMBERS OF THE GLCC

In 2018, the GLCC acknowledges the support of its sustaining partners: AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Eli Lilly, Merck, Novartis, Pfizer, Roche, Takeda.