

# UNITY



The newsletter of the Global Lung Cancer Coalition

Spring | Summer 2017

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## WELCOME

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.



To join us, please read our membership criteria, and download a membership application form at [www.lungcancercoalition.org](http://www.lungcancercoalition.org)



GLCC members meet in Vienna

## GLCC MEMBERS SHARE EXPERTISE IN VIENNA

**The Global Lung Cancer Coalition's annual members meeting took place in Vienna, Austria in December 2016, prior to the 17th World Conference on Lung Cancer (see page 6).**

The meeting gave members the opportunity to meet 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, on 6 December, the GLCC hosted a joint information session with the International Association for the Study of Lung Cancer (IASLC). Titled *Focus on Advocacy and Communication*, and chaired by Aoife McNamara of the Irish Cancer Society and Andreja Šajnić from the University Hospital

Centre Zagreb in Croatia, it featured the following topics and speakers:

- *A Realistic Goal? Achieving a Tobacco Free Ireland by 2025* – Donal Buggy, Head of Services and Advocacy, Irish Cancer Society
- *The Global State of Lung Cancer Research: Communicating the Messages* – Sarah Winstone, Incisive Health International, UK
- *Helpline: Adapting to Changing Needs and Evolving Science* – Jennifer King, Director of Science and Research, Lung Cancer Alliance, USA
- *How It Feels Campaign: The Impact of a Large General Public Campaign* – Kay Bayne, Director of Marketing, Lung Cancer Alliance, USA



## A CLEARER, MORE FUNCTIONAL WEBSITE

**The GLCC's new website went live in October 2016, in time for review by members at our annual conference in Vienna.**

The redesign of the site was commissioned by GLCC member organisations at our 2015 annual conference in Denver, Colorado, USA. The general view was the existing site had become too cluttered and was difficult to navigate, especially for new visitors.

Working with media partner Incisive Health, the GLCC's secretariat appointed UK-based web design agency Kariba to build a new website that delivers the following:

- accessible information about the GLCC and its members
- key facts about lung cancer and the research that's taking place on a global and national level
- easy navigation of the Global e-Atlas and other GLCC resources



- a high-quality experience for all visitors, no matter if they're using a desktop computer, tablet or phone
- a fresh and engaging look that is welcoming to visitors.

The building of the main components of the site is now complete, but further updates of current content and the addition of new content will take place throughout the year.

This will include the translation of key GLCC resources into 16 languages which were agreed by the members of the GLCC. Already, this process has begun, with the website now featuring translated versions of our immunotherapy factsheet.



**Click here to visit our new website**

## LACK OF SYMPATHY FOR PEOPLE WITH LUNG CANCER

**A report compiled by Lung Foundation Australia has revealed that Australians, in comparison to other nationals, have the least sympathy for people with lung cancer, often judging all as smokers.**

Based on the results from a GLCC survey conducted in 15 countries, the Lung Foundation Australia report showed that 29% of Australians said they had less sympathy towards people with lung cancer than those diagnosed with a different cancer. This compares to 10% in Argentina, which had the lowest percentage of 'less sympathetic' people.

Heather Allan, Chief Executive of Lung Foundation Australia, said the study's findings were nothing to be proud of. "Whatever the attitude, it is unfair – we need to have empathy, and we need to understand that anyone can get lung cancer."

Professor Suzanne Chambers of the Menzies Health Institute of Queensland said the negative attitude of Australians towards lung cancer may have a lot to do with the success of anti-smoking campaigns in Australia.

"We have de-normalised smoking, and that has been an important thing to reduce the rates of smoking to reduce cancer. The flipside of that, though, is for people who are actually diagnosed with lung cancer, they can feel like, 'Well, it is my fault'.

"I have certainly had people with lung cancer tell me they wished they had breast cancer – it is all warm pink and fuzzy and there is nothing warm pink and fuzzy about lung cancer."



**Click here to read the full article.**

## IRISH GLCC JOURNALISM AWARD

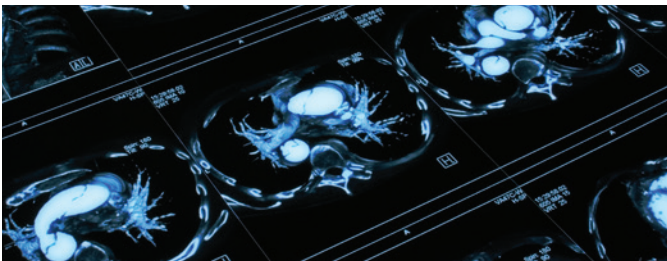
The Irish Cancer Society has awarded the first of this year's GLCC Journalism Awards to June Shannon, Clinical Editor and journalist with the *Irish Medical Times*.

June's winning article, an interview with Professor John Field of the Roy Castle Lung Cancer Research Programme, helped to drive awareness of lung cancer and how important it is to diagnose the disease early.

Further journalism award winners will be announced on the **GLCC website**.

## LUNG CANCER SCREENING PROJECT

**Roy Castle Lung Cancer Foundation has funded a lung health check and lung cancer screening project in the English town of Bulwell, near Nottingham.**



The aim of the project, which launched in January 2017, is to identify potential lung cancer patients before any symptoms appear.

This involves doctors at five medical practices in Bulwell inviting patients aged 60 to 75 who have a history of smoking to attend a lung health check appointment.

Following this assessment, any high-risk patients are offered a low dose CT scan to identify if they have any nodules on their lungs. If they do, the patient is referred to Nottingham

University Hospital's lung cancer multidisciplinary team for regular monitoring and follow-up care.

The reason why a town near Nottingham was chosen for the project is because Nottingham has a high rate of lung cancer diagnoses and lung cancer deaths compared to the average for England.

Depending on results and the funding available, the project may be extended to further boroughs and regions in the UK.



**You can find out more about Roy Castle Lung Cancer Foundation's investment in research programmes on their website.**

## LIVE CHAT WITH LUNG CANCER EXPERTS

**As part of 2016's Lung Cancer Awareness Month, Free to Breathe of the USA launched its Ask Us Anything sessions, which allow members of its online community to ask questions and get live answers about lung cancer topics.**

The first session focused on research and the future of personalized cancer medicine, and was hosted by lung cancer experts Adam Marcus, PhD and Suresh Ramalingam, MD. Then, in May 2017, a second session was hosted by Janet Freeman-Daily, a NSCLC survivor, and Jack West, MD, a thoracic oncologist, which covered tumor testing, precision medicine and clinical trials.

Overall, the first event generated nearly 350 page views. This was a record number of views in a single day for Free to Breathe's online community, which was launched by the charity and HealthUnlocked in July 2016. It offers patients, caregivers, survivors and advocates the opportunity to connect with others facing similar challenges.

Travis Garski, Social Media and Marketing Coordinator at Free to Breathe, says the community was something people affected by lung cancer in the USA needed, as many were finding it hard to meet each other face-to-face:

"We heard many patients say they struggled to find a local support group for lung cancer patients, so we decided to offer this format online as a resource to the lung cancer community"



You can visit Free to Breathe's online lung cancer community at **[freetobreathe.org/support/free-to-breathe-community](http://freetobreathe.org/support/free-to-breathe-community)**. More Ask Us Anything events focusing on specific lung cancer topics are planned for later in 2017.



## KEY ROLE FOR BULGARIAN NURSES

**GLCC member APOZ helped to organise with the Bulgarian Cancer Society and Bulgaria's Association of Healthcare Professionals the first meeting of an oncology academy for healthcare professionals.**

Held on 10 and 11 February 2017 at the Acibadem City Clinic Cancer Center, the session was attended by 80 nurses representing 28 specialized medical facilities that treat people with cancer in Bulgaria. The main focus of the inaugural meeting was lung cancer and how providing patients with information about the illness should be a key responsibility of a nurse.

This topic directly corresponds with a current project that APOZ is running with partner organisations, and which is funded by the Union for International Cancer Control (UICC). It aims to increase the authority of a nurse to present patients with information in certain clinical situations.



## A NATIONAL CANCER PLAN FOR RUSSIA?



**GLCC member Equal Right to Life helped to organise and host the 10th Forum Movement Against Cancer in Moscow, Russia, with support from the Blokhin Russian Cancer Research Center, The Association of Oncologists of Russia and Movement Against Cancer.**

Each year the Forum brings together cancer experts to discuss how cancer diagnoses and deaths can be reduced in Russia and better cancer care and support provided to its population. Currently in Russia there are approximately 500,000 new cases of cancer diagnosed each year. It's also estimated that 300,000 people die from the illness per year and 100,000 people die in the first year following a cancer diagnosis. These figures are set to get progressively worse, due to Russia's ageing population.

At this year's Forum, which was held on 2 February 2017, experts agreed that one of the main problems Russia faces is the lack of a National Cancer Control Plan. Thankfully, the first steps to create such a plan were taken in 2016, a move fully supported by Russia's Ministry of Health. Now, it's expected that a first draft of the plan will be presented at June's congress of Russian oncologists in Ufa, Bashkortostan.

In particular, experts at the 2017 Forum said they would like to see the introduction of a national screening system, primarily for tumours of the lung, gastrointestinal tract and the musculoskeletal system. Concerns were also voiced about outdated diagnostic equipment and a lack of oncologists, radiologists and treatment to control cancer and symptoms.

At the end of the Forum, attendees reaffirmed last year's call to Russian President Vladimir Putin for the full development and implementation of a National Cancer Control Plan. They also restated solutions and measures that would help to develop the plan and ultimately reduce cancer mortality in Russia.



# PROSECUTING TOBACCO COMPANIES

**Longkanker Nederland is actively supporting a mother of four's attempt to bring tobacco producers before the criminal courts – something that's not happened in the world before.**

Anne Marie van Veen, who began smoking at the age of 15 and is now 43, was diagnosed with lung cancer in 2014. With a Dutch anti-smoking foundation and COPD patient, she filed the following charges against four tobacco manufacturers in September 2016: attempted murder, manslaughter, grievous bodily harm (because of the highly addictive carcinogenic additives in tobacco) and falsification of documents.

Anne Marie says she does not want to claim any compensation. Her goal is to prevent her children, and other people's children, from falling victim to the seduction techniques of the tobacco industry.

To help Anne Marie gain public backing for her legal case, Longkanker Nederland helped her set up the *Sick of Smoking* website. It asks people to register their support for the prosecution of the tobacco companies and provides information about smoking, the targeting of children and the law case. Already, over 22,000 people have expressed their support, with more than 1,800 indicating they are also willing to start a legal procedure.



To find out more, and to register your support for Anne Marie's legal case, please visit [sickofsmoking.nl/en](http://sickofsmoking.nl/en)

## WALCE'S SMOKING CESSATION EVENTS

**To coincide with World No Tobacco Day 2017, Women Against Lung Cancer in Europe (WALCE) co-hosted two smoking cessation events in Brussels, Belgium.**

On 30 and 31 May, a giant cigarette tunnel was erected near to the front of the EU Parliament. Inside the tunnel visitors could pick up educational information, talk to pulmonologists and undergo a basic spirometry test.

In addition, on 31 May, Italian MEP Alberto Cirio held a session at the EU Parliament that focused on the

World Health Organization Framework Convention on Tobacco Control's article 14, which demands reduction measures concerning tobacco dependence and cessation. The session informed delegates on how best to advocate for the implementation of article 14 on a national level.



## SHINING A LIGHT ON LUNG CANCER

**As part of Lung Cancer Awareness Month in November 2016, ALCASE Italia held its second *Illumina Novembre* (Enlighten November) event.**

Inspired by similar initiatives in the USA, *Illumina Novembre* involved communities throughout Italy dressing buildings, landmarks and their homes with white lights, balloons and ribbons, as well as people wearing white ribbons and clothing. The aim of the event is to draw attention to lung cancer through the colour that symbolizes it; to encourage people to find out more about the illness, including signs and symptoms; and to show people affected by lung cancer that they're not alone.

ALCASE Italia said they were particularly pleased that towns and cities from both the north and south of Italy both took part in *Illumina Novembre*. The organisation believes increased participation maybe because the media is increasingly covering lung cancer issues, including recent breakthroughs in targeted agents and immunotherapy. In addition, the public are becoming more aware that lung cancer is not just an illness that affects old men and heavy smokers; it is a disease that can affect all adults, no matter their age, where they live or their social status.



Ca' Loredan and Ca' Farsetti, Venice

# ROUND-UP FROM THE WCLC

The **IALSC 17th World Conference on Lung Cancer** took place in Vienna, Austria between 4 and 7 December 2016. Here, we look at some of the main news stories from the conference.

## NEW STAGING MANUAL

A revised tumor classification, based on more than 70,000 non-small cell lung cancer patients and 6,100 small cell lung cancer patients, is now available to lung cancer specialists around the world in the form of the 8th Edition of the Tumor, Node, and Metastasis (TNM) Classification.

The new edition is published by the Union for International Cancer Control, the American Joint Committee on Cancer, and the International Association for the Study of Lung Cancer (IASLC) in their respective staging manuals.

To ensure the cancer care community has the necessary infrastructure in place to make a smooth transition to the 8th edition, it's been agreed that the implementation of the staging system should be delayed until 1 January 2018.

## ATEZOLIZUMAB RESULTS

Dr Shirish Gadgil of the Karmanos Cancer Institute at Wayne State University in Detroit, USA presented encouraging data about patients who received atezolizumab as part of the OAK Trial.

It showed that these patients experienced, on average, 4.2 months improvement in overall survival compared with patients enrolled in the docetaxel arm of the trial.

The subgroup analysis results demonstrated that atezolizumab improved overall survival regardless of histology and PD-L1 status, as measured by IHC or tumor gene expression.

## OSIMERTINIB CLINICAL TRIAL

Dr Vassiliki Papadimitrakopoulou of MD Anderson Cancer Center in Houston, USA revealed the positive results of the AURA3 trial.

He stated that people with non-small cell lung cancer who received the drug osimertinib experienced reduced disease progression by 70% compared to patients enrolled in a control group who only received chemotherapy.

## CENTER OF EXCELLENCE MODEL

Dr Raymond Osarogiagbon from Baptist Cancer Center in Memphis, USA reported the benefits of using a Center of Excellence (COE) model that focuses on underserved communities.

Osarogiagbon explained that the COE program is a patient-centric model for lung cancer that establishes a standard of care for community hospitals which often treat minority and underserved patient populations. He said the model allows doctors to diagnose lung cancer patients in those areas early and provide treatment that is on par with lung cancer care offered at academic medical centers.

"Four out of five lung cancer patients are treated in a community hospital setting and may not receive the same level of care as those treated at a leading academic center; so, if we are going to move the needle on lung cancer care, we must do it where patients receive their care."

## SMOKING BAN IN IRELAND WORKS

Dr Luke Clancy of the TobaccoFree Research Institute in Dublin reported the planning and investment in banning smoking in workplaces in Ireland in 2004, and subsequent smoking legislation, has paid off.

As well as being associated with a reduction in early mortality, studies on the effects of the ban demonstrate a 13% decrease in all-cause mortality, a 26% reduction in ischemic heart disease, a 32% reduction in stroke, and a 38% reduction in chronic obstructive pulmonary disease.

However, Dr Clancy stated that the prevalence of smoking in Ireland remains at 18.5%, compared to 29% for the whole of Europe. He said to combat this Ireland hopes to be tobacco free by 2025, but that the full implementation of the World Health Organization Framework Convention for Tobacco Control (FCTC) recommendations may not be enough to achieve this.



**From IASLC website**  
**Read the full article by clicking here**



## GLOBAL CANCER CASES AND DEATHS

**A new report on the global burden of cancer has revealed that the number of new cancer cases grew worldwide to 17.5 million in 2015 from 13.1 million in 2005.**

This 33% increase was mostly due to aging populations (12.6%) and population growth (16.4%), plus increasing age-specific incidence rates (4.1%).

In addition, the report, which was published in December 2016 on the website of the *Journal of the American Medical Association Oncology*, also stated that:

- Cancer was responsible for 8.7 million deaths in 2015, approximately 70% of which occurred in low and middle-income countries.

- The global burden of cancer will grow over the next two decades, with an estimated 22 million new cases and 13 million deaths occurring in 2032.
- Globally, the odds of developing cancer during a lifetime are 1 in 3 for men and 1 in 4 for women.
- Tracheal, bronchus and lung (TBL) cancer was the leading cause of cancer deaths for men.
- Breast cancer was the leading cause of cancer deaths in women.



**From JAMA Oncology, 3 December 2016**  
**Read the full article by clicking here.**

## STUDY SAYS CELLS SPREAD LIKE UNANCHORED TENTS



**Scientists have discovered that spreading lung cancer cells are like tents which have collapsed and are adrift in the wind.**

Writing in the *Journal of Clinical Investigation*, researchers from the University of York in the UK and the University of Texas in the USA describe how the communications centre of a cell – known as the Golgi apparatus – receives a signal from proteins which prompts the movement of membrane sacks inside it. This movement alters the shape and surface of the cancer cell, allowing it to break free from its moorings and travel to other areas of the body.

The researchers also stated that it is a protein called PAQR11 that is critical to this process, and that they now want to look at how to target the protein without damaging healthy cells, in which the protein also exists.



**From BBC News, 25 November 2016**  
**Read the full article by clicking here**

## STATINS DON'T EXTEND LUNG CANCER SURVIVAL

**Taking cholesterol-lowering statins doesn't benefit lung cancer patients when used alongside chemotherapy, according to new research funded by Cancer Research UK.**

Previous studies have said statins could play a role in preventing cancer, as well as extending survival in patients with several common cancers, including lung cancer.

But a new study, published in the *Journal of Clinical Oncology*, from Imperial College London and University College London (UCL) scientists, shows the drugs have no positive effect as a treatment for patients with small cell lung cancer.

The trial included 846 patients from 91 hospitals in the UK, who were monitored for two years, making it the largest randomised trial of statin treatment in cancer patients to date.

Professor Dean Fennell, a Cancer Research UK expert in lung cancer, commended the research and said it was proof of how hard it is to find new treatments for this type of lung cancer.

"We need further research into more targeted treatments. And using new technologies to understand the faulty genes at play in each patient's tumour, or immunotherapy, may be a more promising way to improve survival."



**From Cancer Research UK website, 3 March 2017. Read the full article by clicking here**

## IN FOCUS

INSTITUTO  
ONCOGUIA

**WORKING AS A PSYCHO-ONCOLOGIST IN BRAZIL, LUCIANA HOLTZ BECAME AWARE MANY OF HER PATIENTS FELT LOST AFTER THEIR CANCER DIAGNOSIS. HER RESPONSE WAS TO ESTABLISH AN ORGANIZATION THAT ALL CANCER PATIENTS COULD TURN TO FOR HELP.**



**A**ccording to the National Cancer Institute in Brazil, there were 28,220 new lung cancer cases in the country in 2016 – 17,330 men and 10,890 women. Latest figures from the institute also reveal that there were 24,490 lung cancer deaths in Brazil in 2013.

Currently, people diagnosed with any type of cancer in Brazil are often not receiving the treatment, care and support they need. In the country there is a lack of accessible information about cancer; not enough cancer specialists; a lack of access to high-quality treatment; health professionals need training on how they can improve the quality of life of cancer patients; and Brazilian society doesn't understand the importance of diagnosing cancer early or how leading a healthier lifestyle can reduce their risk of being diagnosed with cancer.

It's for all of these reasons, and particularly the lack of information provided to cancer patients, that Luciana Holtz, a psycho-oncologist, founded Instituto Oncoguia in 2009. Based in Sao Paulo, and with 16 employees, the non-profit organization aims to help cancer patients in

instituto  
**Oncoguia**





Instituto Oncoguia worked with Brazilian lung cancer patients to understand the issues they face.

Brazil have a better quality of life by taking action in the following four ways:

- offering quality cancer information to people with cancer and their families, and the wider public
- giving support and guidance to cancer patients and their families through one-to-one and specialist support
- providing health education to professionals such as social workers and health community workers to improve the cancer care and support they deliver
- defending and protecting the rights of patients.

“Oncoguia believes in its potential to help patients as individuals,” says Luciana. “We offer a Cancer Patient Support Program through our toll-free support line, which provides information about pathology, patients’ rights and what to expect following a cancer diagnosis.

“We also run the Oncoguia Portal, which is an informative and interactive website for cancer patients, their families and society in general. And we educate society about cancer by distributing information materials, hosting lectures, conducting thematic campaigns, and through other initiatives.”

Luciana also says that Instituto Oncoguia aims to improve the lives of large numbers of cancer patients in Brazil through its advocating initiatives. “Our Advocacy team aims to diagnose and investigate problems faced by cancer patients and caregivers; it proposes sustainable and responsible solutions to cancer issues; and through legal and ethical means, it develops strategically planned political actions to influence policymakers so they make the changes needed to improve people’s lives.”

### Understanding lung cancer issues

Asked what recent lung cancer initiatives Instituto Oncoguia has carried out, Luciana says the organisation has been working hard to gain a better understanding of the problems lung cancer patients face. “We’ve just developed a focus group with people with lung cancer and family members to help us understand who they are and the main problems and barriers they face. We also conducted an online survey, which was answered by more than 230 people. The information provided by the focus group and the survey will help to clarify what are

priorities for this patient group and family members, and help to direct our actions.”

Luciana also says that with partner organizations Instituto Oncoguia launched an awareness campaign in 2016 that focused on the prevention of lung cancer and early diagnosis of the illness. “The campaign has a special website ([valeapenavivermais.org.br](http://valeapenavivermais.org.br)), which features lots of helpful content, including videos from specialists such as a pneumologist, oncologists, a thoracic surgeon, a psychologist and a nutritionist. Also, for the campaign, we developed booklets: one with tips for people who want to quit smoking and another one focused on prevention and risk factors. There were also some interactive spaces inviting the public to share posts and videos on social media.”

Looking to the immediate future, Luciana says the main aim for Instituto Oncoguia is to expand its work across Brazil. To do this, the organization has launched an *Agentes Oncoguia* (Oncoguia Agents) project. This involves people with cancer from different regions of Brazil helping to publicize Instituto Oncoguia’s work so it can reach and support even more patients.

In addition, Luciana is looking forward to working with other GLCC members. “Each country has its peculiarities and difficulties with the disease, but we have some issues that are similar. We believe it is very important to be part of an international coalition, where we can share experiences, knowledge and also work together with on strategic subjects, which will help us gain strength to change the reality of lung cancer in Brazil.

“It is a pleasure to be part of this coalition of organizations that are doing an amazing job in their countries. It is our first year as a member and we hope that we can learn and share experiences and knowledge to overcome the main barriers faced by lung cancer patients.”



For further information about Instituto Oncoguia and its work, please visit [www.oncoguia.org.br](http://www.oncoguia.org.br)



**IN OUR REGULAR SERIES OF QUESTION AND ANSWER ARTICLES, WE SPEAK TO MARY F HENNINGFIELD, DIRECTOR OF SCIENTIFIC EDUCATION AND RESEARCH AT FREE TO BREATHE.**

**Q. When was Free to Breathe established?**

**A.** It was founded in 2001 by Dr Joan Schiller, in Madison, Wisconsin, in the USA. Dr. Schiller wanted to start a movement to defeat lung cancer. She believes that through a movement fueled and sustained by countless people, we can work together to create real change for everyone affected by this disease.

**Q. What care, support and services does your organization provide?**

**A.** Free to Breathe funds lung cancer research, supports patients and caregivers, and works to build the lung cancer community. We offer print and downloadable education materials, a Support Line and an online community.

We also host a *Lung Cancer Leadership Conference* to bring together patients, survivors, caregivers, advocates and researchers, who are working towards a common goal. Each year, we bring thousands of people together through Free to Breathe events, fundraisers and opportunities for advocacy.

**Q. How does your organization's support make a difference to the lives of people with lung cancer?**

**A.** We really want people to know that they are not alone as they face lung cancer. Our Support Line is staffed by a registered nurse, which allows patients and caregivers to receive one-on-one support and be connected to resources.

Our online community provides a supportive and safe online forum in which peer-to-peer connections are made. Patients are able to share their stories and learn about the experiences of others.

We distribute materials to help educate patients and caregivers about lung cancer, testing and treatment options. Having access to educational resources can help ease the distress and anxiety that is common at the time of diagnosis.

Our event series offers opportunities for meaningful engagement with others who are committed to the cause.

**Q. Does your organization have any current lung cancer media campaigns?**

**A.** We are currently planning media campaigns around our *Ask Us Anything* sessions with our online community (see page 3). Experts are available to answer questions from participants during these online events. Our most recent topics were tumor testing, precision medicine and clinical trials. We are also planning further sessions on specific topics throughout 2017.

**Q. What are your organization’s main plans for the immediate future?**

**A.** Our current focus is to fund research with the greatest potential to save lives and improve clinical trial enrollment. Our grant program includes the Metastasis Research grants, which focus on stopping or preventing metastasis. A key component of the funded projects is to translate the work to clinical trials by the end of the award period.

We also fund the Accelerate Clinical Trials grant, which focuses on ways to improve clinical trial enrollment. Our goal is to fund pilot research projects that will investigate novel strategies to improve accrual of patients with lung cancer to therapeutic clinical trials by at least 50% within a defined healthcare facility, system or community.

**Q. What is your organization’s ultimate ambition?**

**A.** Our mission is to ensure surviving lung cancer is the expectation, not the exception. Our vision is to double lung cancer survival by 2022.

**Q. What has been your organization’s biggest success so far?**

**A.** We have been able to provide more than \$5 million in funding for lung cancer research. This funding supported 51 investigators at 35 institutions throughout the United States. The research we funded directly resulted in 83 publications. Investigators we funded were able to secure more than \$20 million in additional research funding.

**Q. Why did your organization join the GLCC?**

**A.** The former executive director of Free to Breathe, Regina Vidaver, joined GLCC to share in the mission to improve the outcomes of patients with lung cancer worldwide.

**Q. Do you think GLCC members can benefit from each other?**

**A.** Yes, most definitely. By sharing our experiences and knowledge, we can help each other achieve our goals of supporting patients and caregivers. Each organization may have different objectives and goals, but we all share the common mission of improving outcomes for people diagnosed with lung cancer.

**Q. Have you gained any knowledge from another GLCC member that has benefited your organization?**

**A.** Yes, the opportunity to interact with other GLCC members has helped in many ways. This past *World Conference on Lung Cancer* was the first time I attended the GLCC meetings, and learning about research and different approaches to campaigns, patient education, healthcare policy and other programs was extremely valuable.

**Q. Can you think of a media campaign by a GLCC member organization that you thought worked particularly well?**

**A.** At the 2016 *World Conference on Lung Cancer*, Esraa Elsayed from CanSurvive in Cairo, Egypt presented the results of a campaign for a fashion show featuring survivors. This fashion show was the finale of the *Cancer from Patients’ Perspective Summit*. Having survivors model garments created for them by Egyptian designers was a novel and effective way to challenge the stigma of lung cancer.

The book created as a result of the fashion show and the media campaign to promote it helped spread the message about the challenges patients with lung cancer face and defied perceptions about people living with lung cancer. Telling survivors’ stories through fashion was a very powerful tool with an important impact.

**Q. What message would you like to send to your fellow GLCC members?**

**A.** I would like fellow GLCC members to know that Free to Breathe is so proud to be a member of this organization. Thank you for all you do to advocate for patients with lung cancer worldwide. Please reach out to us if there is ever anything we can do to help your organization in your important mission. We hope that by working together, we can continue to make a difference in the lives of people dealing with this deadly disease. I look forward to meeting more members in person.



free to breathe  
a partnership for lung cancer survival



For further information about Free to Breathe and its work, please visit [www.freetobreathe.org](http://www.freetobreathe.org)





**Cancer Advocacy Coalition of Canada:**  
www.canceradvocacy.ca

**Lung Cancer Canada:**  
[www.lungcancercanada.ca](http://www.lungcancercanada.ca)



**Cittadinanzattiva:** [www.cittadinanzattiva.it](http://www.cittadinanzattiva.it)



**West Japan Oncology Group (WJOG):**  
www.wjog.org



**Movement Against Cancer:**  
[www.rakpobedim.ru](http://www.rakpobedim.ru)



**La Asociación Española Contra el  
Cáncer:** [www.aecc.es](http://www.aecc.es)



**National Lung Cancer Forum for Nurses:**  
[www.nlcfn.org.uk](http://www.nlcfn.org.uk)

**Roy Castle Lung Cancer Foundation:**  
www.roycastle.org



**Free to Breathe:** [www.freetobreathe.org](http://www.freetobreathe.org)

**Lung Cancer Alliance:**  
[www.lungcanceralliance.org](http://www.lungcanceralliance.org)

**Prevent Cancer Foundation:**  
[www.preventcancer.org](http://www.preventcancer.org)

In 2016, the GLCC acknowledges the support of its sustaining partners: **AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Eli Lilly, GlaxoSmithKline, Novartis, Pfizer, Roche.**

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